Family management of asthma triggers in the home: a grounded theory

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Intellectual property and publication statements

The candidate confirms that the work submitted is her own, except where work which has formed part of jointly authored publications has been included. The contribution of the candidate and the other authors to this work has been explicitly indicated below. The candidate confirms that appropriate credit has been given within the thesis where reference has been made to the work of others. The work in chapter two of the thesis is available online (in protocol form) and in a publication as follows, respectively: Lewis, G., Milnes, L., Adams, A., Schwarze, J., Duff, A. 2020. 'What determines whether families reduce indoor environmental asthma trigger exposures for children and young people with asthma? A scoping review protocol.' Open Science Framework. [online]. Available at: https://osf.io/ykztb and, Lewis, G., Milnes., L., Adams, A., Schwarze, J., Duff, A. 2022. 'Influences on indoor environmental trigger remediation uptake for children and young people with asthma: A scoping review.' *Health Expectations*. 26; 87-97 Available from: DOI: 10.1111/hex.13670 or https://eprints.whiterose.ac.uk/193724/

The candidate was responsible for development and writing of the protocol, development of the search strategy, completion of study selection, data extraction, quality appraisal, data mapping, narrative synthesis, and drafting of the paper. The contribution of the other authors was to review the work at every stage. Co-authors also independently checked study selection, data extraction and quality appraisal, as part of a systematic and rigorous approach to conducting the review. Co-authors reviewed the manuscript and approved the final version of the paper submitted for publication.

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About the author

My career in health and related research began as a graduate Orthoptist. During my orthoptic role, I worked predominantly with young children in outpatient settings, to diagnose and manage conditions involving the visual system. I was seconded to a research role within Ophthalmology, which gave me my first research experience outside of an undergraduate academic visual laboratory setting.

During a career break, initially taken to be at home with my young family, I later studied for a master's in public health. I chose this as it appealed to my broader health and research interests. I also selected the research project dissertation route in favour of additional modules. This afforded me the opportunity to join a qualitative research project in which I aimed to explore parents' experiences of using community issued nicotine replacement therapy to promote smoking abstinence in homes of children exposed to second-hand smoke. This project provided my first experience with qualitative research and allowed an opportunity to be a first author and co-author on associated publications. This experience influenced my decision to pursue a PhD, and particularly this PhD project since it relates to family experiences of managing the indoor environment to maximise respiratory health.

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Abstract

Background

Family management of children and young people's (CYP) asthma is complex and multi-faceted. Asthma triggers and indoor aeroallergen exposures contribute to reduced asthma control and risk of attacks. Maximising asthma control includes trigger and aeroallergen exposure reductions alongside health provider supported medicinal management and monitoring.

CYP with severe or uncontrolled asthma and co-existing allergic sensitisation would likely benefit from interventions to increase trigger and allergen avoidance uptake. Current evidence suggests that avoidance strategy uptake is often low, variable, or partial.

A systematic scoping review identified a paucity of literature explaining the current behaviours and behavioural influences on indoor aeroallergen avoidance uptake in the homes of CYP with asthma.

Aims

Develop an explanation of beliefs, processes, and behaviours involved in asthma trigger/allergen avoidance decision-making, in homes of CYP with sub-optimally controlled asthma and allergic sensitisation.

Design

A grounded theory approach was adopted for data collection, analyses, and theory development. In-depth qualitative interviews with CYP and mothers explored behaviours regarding avoidance uptake and influences in families of CYP with severe, uncontrolled asthma and allergic sensitivity to pets and house dust mite.

Findings

21 individuals participated (ten CYP aged 11-15 years and 11 mothers). Dyadic and individual interviews were conducted online and by telephone. During analysis, two categories were developed with interconnecting sub-categories, which were integrated into a theory explaining families learned about asthma triggers over time, through experience. Through learning, families developed acceptable levels of certainty about the role of allergens and triggers. This certainty affected uptake of

remediation advice and was responsive to shifts in certainty occurring due to contextual changes: the core category being ‘responding to shifting certainties.’

Conclusion

The theory of responding to shifting certainties explains a range of asthma family-management behaviours. The fluidity of family decision-making suggests there are opportunities to intervene and facilitate greater remediation uptake.

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Abbreviations used

BCT	Behaviour change theory
BTS/SIGN	British Thoracic Society/Scottish Intercollegiate Network
CYP	Children and young people
ENDs	Electronic Nicotine delivery systems
ETS	Environmental tobacco smoke
FDA	Food and Drug Administration (USA)
GDPR	General data protection regulation
GP	General practitioner
GT	Grounded theory
HSIB	Healthcare Safety Investigation Branch
HDM	House dust mite
HEPA	High-efficiency particulate absorbing
HRQOL	Health related quality of life
IgE	Immunoglobulin E
JBI	Joanna Briggs Institute
MDT	Multi-disciplinary team
MRC	Medical Research Council
NHS	National Health Service
NIHR	National Institute for Health Research
NICE	National Institute for Clinical Excellence
NRAD	National review of asthma deaths
PAQLQ	Paediatric asthma quality of life questionnaire
PPI	Patient and public involvement
PRISMA	Preferred reporting items for systematic reviews and meta-analyses
QOL	Quality of life
RCPCH	Royal College of Paediatrics and Child Health
RCT	Randomised controlled trial
SABA	Short acting beta-agonist
SEG	Socio-economic group

SES	Socio-economic status
SI	Symbolic interactionism
UK	United Kingdom
USA	United States of America

Explanation of thesis terminology

Asthma attack terminology:

The term asthma attack is used throughout the thesis to describe worsening symptoms that may include cough, breathlessness, wheeze and a tight-chest, and signs such as a lower peak flow score than usual, requiring additional treatment (NHS, 2021).

Common terms include asthma attack and/or exacerbation. These are often used interchangeably, and their similarities are shown in the Global Initiative for Asthma (GINA) definition of exacerbations: *"Exacerbations of asthma are episodes characterized by a progressive increase in symptoms of shortness of breath, cough, wheezing or chest tightness and progressive decrease in lung function, i.e., they represent a change from the patient's usual status that is sufficient to require a change in treatment. Exacerbations may occur in patients with a pre-existing diagnosis of asthma or, occasionally, as the first presentation of asthma"* (GINA, 2022, pp.125). The British Thoracic Society-Scottish Intercollegiate Network (BTS/SIGN 2019) documents often refer to both attacks and exacerbations in their guidance and recommended further work was needed to develop an internationally recognised definition of an asthma exacerbation.

The decision to use the term asthma attack instead of exacerbation in this thesis was taken to reflect the language often used by people with asthma and repeatedly used by participants in the study this thesis will outline. It is argued that the term exacerbation, whilst sometimes used in medical settings, is not likely to represent the potential severity of an attack to the general public. As such, the authors of a Lancet commission recommended use of the term asthma attack, stating the use of terms such as exacerbations or flare-ups *"fostered the assumption that these attacks are mildly inconvenient and readily reversible, rather than being a marker of a high risk of future attacks and even death*" (Pavord *et al.*, 2018, pp.380).

Participant terminology:

Throughout the thesis, reference is made to participants as CYP, parents, mothers and/or families. This interchangeability reflects the inclusion of CYP and mothers (parents) as participants, but also that some family units only consisted of a mother and C/YP. In larger families, the mother and/or CYP discussed the role of other family

members in asthma management, therefore some discussion focuses on family management through the perspectives of the participants.

Chapter 1 Background

Chapter 1 will present evidence that children and young people (CYP) with asthma and co-existing allergic sensitisation are at greater risk of poorer asthma control and outcomes, particularly when they are frequently exposed to indoor environmental asthma triggers. This chapter will describe asthma, allergic sensitisation, their epidemiology, and indoor airborne environmental asthma triggers that contribute to sub-optimal asthma control. The current clinical guidelines and interventions to manage environmental asthma triggers are discussed. These issues are presented because whilst some interventions have been trialled, only trigger avoidance has been recommended by national and international clinical guidance. In this chapter, background literature is presented to show the need for the subsequent scoping review (Chapter 2) and primary qualitative study undertaken and outlined in Chapter 3, Chapter 4, and Chapter 5.

1.1 Problem statement

The promotion of trigger avoidance is challenging for health professionals to encourage and challenging for families to implement and adhere to (Portnoy *et al.,* 2012), alongside an already complex supported self-management routine (BTS/SIGN, 2019). Further interventions to encourage behavioural changes are necessary to reduce trigger exposures and improve asthma outcomes. The opening chapters (Chapter 1 and Chapter 2) were guided by the tasks that precede intervention design and development. These are, understanding the problem using the available literature, collecting new data to understand the influences on behaviour, describing current behaviour, and examining whether existing theory is relevant and appropriate to use in new intervention design (Bartholomew *et al.,* 1998; Craig *et al.,* 2008; Kok *et al.,* 2017).

1.2 Background

1.2.1 Asthma overview

Asthma is a complex and variable chronic condition of the airways that affects over 1.1 million CYP in the UK (Asthma UK, 2019a). Asthma has increasingly become recognised

as an umbrella term for a complex set of heterogeneous airway conditions with different phenotypes, underlying aetiologies and prognoses (Pavord *et al.*, 2018). Asthma is characterised by inflammation, intermittent airway obstruction and hyperreaction to triggers (BTS/SIGN, 2019). These lead to airway oedema, excessive mucous production and symptoms (Trivedi and Denton 2019). Symptoms frequently include wheeze, cough, shortness of breath and chest tightness (Turner, 2012). Subsequent long-term airway changes and reduced lung function can irreversibly extend into adulthood, and this has been noted for CYP with severe, therapy-resistant asthma (Bossley *et al.*, 2012).

1.2.2 Supported self-management of asthma

Since there is no cure for asthma (Pavord, *et al.,* 2018), supported self-management is implemented for periods where asthma can be controlled by CYP and their families. Management aims include optimum symptom control and minimisation of asthma attacks with minimal treatment side-effects (NICE, 2021). Broadly, management includes medicating, monitoring, and management of asthma triggers (BTS/SIGN, 2019). However, self-management is complex and requires iterative assessment, decision making and responses. These are further influenced by the environment they occur in and family and individual personal goals for management (Mammen *et al.*, 2018).

1.2.3 Asthma epidemiology and impact

A multinational cross-sectional survey including 97 countries revealed that the UK has the highest prevalence (over 7.5%) of severe asthma in 13–14-year-olds. In western Europe, the prevalence of wheeze within the preceding twelve months was 14.3%. Severe asthma prevalence was reported at 6.2% in 13-14 year olds in western Europe (severe asthma was defined as four or more episodes of wheeze, or one or more night's sleep disturbed due to wheeze during the preceding twelve months) (Lai *et al.*, 2009). However, difficulty in quantifying bias in epidemiological studies persists (Eder *et al*., 2006) since there are challenges in comparing prevalence estimates internationally, due to differences in diagnosing, categorising, and recording asthma diagnoses.

In 2014, the National Review of Asthma Deaths (NRAD), highlighted that UK asthma mortality remains unacceptably high and that many deaths were avoidable (Levy *et al.*, 2014). English asthma mortality rates improved in 0–24-year-olds between 2001 and 2017 (Shaw *et al.*, 2019). However, accuracy in comparing published data is challenging, due to the variability across studies in how ages are grouped and reported. More recent figures from the Office of National Statistics suggest a re-increase in asthma mortality amongst 0–14-year-olds in England between 2017 and 2018 (RCPCH, 2020), and overall in England and Wales 2008-18 (Iacobucci, 2019).

A comparison by region in England showed high asthma prevalence in Yorkshire and Humberside. The region also had the second highest asthma mortality rate across all ages (Gupta *et al.*, 2018). Amongst European countries, the UK had the highest mortality rate for 10–24-year-olds and second highest for 15–19-year-olds. Moreover, the UK mortality rates were twice that of the European countries with the second highest rates for all ages (Shah *et al*., 2019).

1.2.4 Socio-economic status and asthma

Gupta *et al*., (2018) investigated regional asthma outcome variations by socio-economic status (SES) using national datasets. An unanticipated inverse association was reported; asthma mortality was lower for younger ages amongst lower SES groups and unexpectedly higher mortality in higher SES groups was found. However, the younger age bracket spanned child and adult populations (5-44 years of age), due to lower numbers at lower ages limiting analyses of younger ages in isolation) making conclusions for CYP unclear. Suggested explanations for the inverse association were elevated prevalence of allergy and atopy in those with higher SES and “brittle” difficult to control asthma, or a combination (Gupta *et al*., 2018, pp712).

Prevalence of emergency hospital admissions due to asthma was associated with 5–44-year-olds living in areas of social deprivation in a stepwise correlation; that is, the higher the multiple index of deprivation, the higher the admission rate for asthma (Gupta *et al*., 2018).

A large systematic review of the relationship between asthma, SES and allergic conditions including 183 studies, showed lower SES was associated with higher asthma prevalence in 63% of included studies. Allergic conditions (rhino conjunctivitis, atopic

dermatitis) however, were associated with higher SES in 63% of included studies (Uphoff *et al.*, 2015). These findings are in line with those of Gupta *et al.,* (2018). This has been seen globally, since higher income countries have higher asthma prevalence (Hedlund *et al*., 2006). This was supported in child epidemiological studies, although it was also noted that prevalence of severe asthma tended to be greater in low-middle income countries (Lai *et al.,* 2009). Some question the accuracy of asthma prevalence estimations since they depend upon how asthma is defined, monitored, treated and on how data is recorded (Dharmage *et al*., 2019). This, in turn, will depend upon access to healthcare, (particularly in low- and middle-income countries) and under/over diagnosis of asthma internationally . However, trends reflect the complexity present where asthma and atopy co-exist when examining the role of SES.

1.2.5 Socioeconomic costs and disease burden

The socio-economic costs of asthma are high. A systematic review of 68 studies (including 38 from the UK), examining the economic costs of paediatric and adult asthma, reported that the greater asthma severity is, the greater the economic burden. The greatest direct costs were attributable to hospitalisation and indirect costs were attributed to lost work/school days (Bahadori *et al.*, 2009). Although, studies encompassing asthma co- morbidities including allergies were excluded. The financial costs of asthma have been estimated across all ages to be at least 1.1 billion pounds sterling in the UK. Schooldays lost to asthma are estimated at 2.8 million annually for CYP in the UK (Mukherjee *et al.*, 2016). This also impacts work absenteeism for carers/parents who stay home to care for CYP when they are unable to attend school.

1.2.6 Asthma health related quality of life

Health related quality of life (HR(QOL) can be reduced for CYP with asthma. Poorer QOL in CYP with asthma has been associated with poorer asthma control (Petsios *et al.*, 2013; Chipps *et al*., 2018). Although many factors contribute to asthma control, one longitudinal study reported the association between poorer control and lower QOL was due to poor quality sleep associated with asthma symptoms, amongst 229 children in the United States of America (USA) (Li, *et al*, 2016).

A Canadian study of 287 CYP (in school grades 2-5) explored QOL perceived by both CYP with asthma and their parents' perception of their child's QOL (Mandhane, *et al.*, 2010). Parents rated CYP's asthma related QOL as higher than the CYP did. Furthermore, a positive association between parents' QOL assessment (for their child) and their management of asthma, measured by use of short acting beta-agonist (SABA) within the previous two weeks and schooldays missed, was reported. Findings were reported as part of a single-blinded intervention study examining asthma-related QOL (using the Pediatric Asthma QOL Questionnaire: PAQLQ), pre and post school-based educational intervention (for parents, teachers, and children). The intervention group reported a reduction in parents' assessment of the child's QOL and an associated decrease in SABA use, suggesting parents' perceived QOL is associated with medication decisions. Furthermore, the authors suggested the parental intervention group's QOL being more in-line with the children's QOL report and being associated with a reduction in SABA use may indicate previous over-reliance on SABA (Mandhane *et al.*, 2010). However, there was no such association between children's QOL and medication use pre-intervention (Mandhane *et al.*, 2010). Although participants were asked about trigger avoidance as part of baseline measures, the relationship between trigger avoidance and QOL was not examined. Yet, only 28.9% of the intervention group reported trigger avoidance at baseline (pre-intervention) compared with 37.1% in the control group (Mandhane *et al.*, 2010). Post-intervention trigger avoidance was not reported.

Others have investigated the relationship between QOL and asthma triggers. Luskin *et al.,* (2014), evaluated the impact of asthma triggers and attacks on QOL in CYP (n=2679) aged ≥13 years, with severe or difficult-to-treat asthma. The presence of a greater number of triggers was associated with greater severity and frequency of attacks and poorer QOL. Additionally, three triggers were predictive of QOL. These were, emotional distress, exposure to animals and damp/mould.

A similar study in the USA investigated the relationship between triggers and QOL in 438 younger children (aged 6-12 years). Exposure to a greater number of triggers was associated with lower QOL. Exposure to more triggers was also associated with increased severity of and an increased number of attacks (Chipps *et al.*, 2018). In

contrast with Luskin *et al's*., (2014) findings for older CYP, Chipps *et al*., (2018) reported that only animal exposure was heavily associated with poorer QOL.

These QOL studies relied on parental recall of triggers and atopy presence. This may affect the accuracy of the study measures. However, both studied CYP with severe asthma, and as such all were under specialised hospital care and were arguably more likely to have experienced allergy testing and discussion.

Association alone cannot be used to infer causation (Lucas and McMichael, 2005; Turner *et al.*, 2020), and factors contributing to QOL are complex and often include socio-economic and cultural factors. However, the suggestion that this association together with biologically plausible explanations for exposure to increased numbers of triggers being causally linked to sub-optimal control and increased acute attacks provides support for improved interventions (Chipps *et al.*, 2018), to reduce trigger exposures in CYP with asthma.

1.3 Asthma triggers

Many factors affect asthma control and contribute to the presence or absence of symptoms. Extensive work has reported challenges with medication and monitoring adherence, which contributes to asthma outcomes across all ages (Lycett *et al.*, 2018). Asthma triggers are also multiple and complex. Triggers can be broadly grouped in the following ways:

- outdoor environmental triggers: including, airborne irritants or pollutants; weather/climatic; outdoor allergens, e.g., pollens (it is noteworthy that pollens can be carried on clothes, skin, and hair into indoor environments)
- Exercise/physical exertion
- Psychological/emotional heightening: known to occur cyclically, since attacks lead to anxiety and can be worsened by anxiety but anxiety can also trigger an acute attack (Pateraki *et al*, 2018)
- medical (viral/bacterial infection, or co-existing conditions)
- Adverse medical interactions, e.g., with aspirin or non-steroidal anti-inflammatory drugs such as ibuprofen (Levy *et al.*, 2014)
- Oral allergens: foods such as, nuts, fish, eggs, and milk (Levy *et al.*, 2014)

- Indoor environmental: including, irritants and pollutants such as environmental tobacco smoke (ETS), vapours from electronic cigarettes and similar devices, dust, domestic combustion (e.g., gas/solid, candles); paints, strong smells e.g., perfumes/cleaning sprays; dampness/humidity. Indoor environmental allergens, including mould spores, pests, pet/animal dander, fur, feathers, and house-dust mite (HDM) are the most common (Asthma UK, 2019a; BTS/SIGN, 2019; Vernon *et al.*, 2012). Indoor occupational exposures can also apply to older teenagers (Gabe, *et al*., 2002).

Triggers are complex and their effects can be difficult to separate, since the sources of exposure may contain multiple allergens, irritants and toxins (Gold, 2000): for example, many CYP with asthma (and their parents) cite dust as a trigger (Cabana *et al.*, 2004). Household dust may contain pet dander and HDM or other allergens and dust itself can act as an irritant when disturbed, and may also contain household toxins such as phthalates, which are also associated with allergy presence (Bornehag *et al.*, 2004). Furthermore, CYP's exposure to phthalates has been associated with increased airway inflammation and worsened pulmonary function in those with asthma (Kim *et al.*, 2018). Another example is ETS. ETS is a well-known trigger in isolation but there is evidence that ETS is associated with higher risk of other acute respiratory conditions in exposed CYP, which also trigger asthma attacks (Royal College of Physicians, 2010).

These examples illustrate the complexity of triggers and how they are often inter-linked or may act in synergy. The UK NRAD reported that allergic factors were second only to respiratory infections in triggering fatal asthma attacks across age groups. The NRAD report also highlighted that of asthma deaths reviewed, only 49% had a record of asthma triggers in personal asthma action plans and the report recommended the need for greater reflection on asthma triggers for patients and those involved in supporting asthma care (Levy *et al.*, 2014). However, a more recent systematic review showed the use of asthma action plans is variable and the evidence that outcomes improve with use is also conflicting. The review also concluded that improved individualised plans for trigger and symptom recognition, alongside attack recognition and medication plans are needed (Miles *et al.*, 2017).

Other environmental factors effect aeroallergen presence and load. Indoor temperature, humidity and ventilation can all contribute. HDM and fungi/moulds

thrive in humid conditions. Recommendations suggest that relative humidity be maintained at 35-50% to reduce HDM prevalence (Portnoy *et al.*, 2016). It has been reported that home-based cat and dog allergen concentrations are less affected than HDM by humidity. However, higher concentrations of cat and dog allergen have been detected in homes with poorer ventilation and in rooms with carpet and high humidity. Moreover, prior cat presence in the home (up to 5 years prior) has been associated with long-term presence of cat allergen, therefore, elimination of cat allergen is likely to require deep cleaning and carpet removal (Munir *et al.*, 1994). Humidity (Singh and Jaiswal, 2013), cold and damp also contribute to mould and fungi growth, both known to contribute to asthma symptoms and outcomes (Williamson *et al.*, 1997). A qualitative exploration of lower-income families at risk of fuel poverty and with a child/children with asthma, in south Yorkshire, reported that many had limited knowledge of asthma triggers or safe temperatures for health. Families experienced complex decision-making regarding home-heating and ventilation, under limited budgets and fear of falling behind with household payments. This was coupled with conflicting professional advice; for example housing professionals advising opening of windows to ventilate and reduce mould versus health professional advice to close windows where outdoor allergens were also an issue for children (Tod *et al.*, 2016).

1.3.1 Evidence of association between triggers and asthma attacks

A retrospective case-control study of children admitted to an American intensive care unit reported a statistically significant association between having an irritant trigger or allergic trigger induced attack and admission, in the 188 CYP admitted during the one year study period (Sala *et al.*, 2011).

A systematic review examining associations between environmental exposures, asthma control, and attacks for children with a mean age of 9 years or younger, reported findings based on inclusion of 27 studies. Exposure to ETS, allergens and unflued heaters increased the odds of asthma attacks 2-3 fold (Dick *et al.*, 2014). Furthermore, a case-control study of 3-17 year olds admitted to hospital following acute attack (during a 12 month period), reported that acute attacks were significantly associated with the presence of allergen sensitisation (outlined in 1.4), allergen exposure and viral infection (Murray *et al.*, 2006).

Although triggers can be broadly grouped as outlined earlier in this section, there are complex trigger interactions that limit the ability to fully separate their impact upon asthma control.

1.4 Allergic sensitisation

The term allergic sensitisation is used to describe the cellular processes that occur as a person develops sensitivity to an allergen(s). The level of sensitivity varies from person to person with allergic sensitivity and although not everyone with sensitivity will go on to develop severe allergic reactions upon exposure to allergens, allergic sensitisation occurs as a pre-requisite in the development of severe allergy (British Society for Immunology, undated). As such, not everyone with allergic sensitisation is aware of its presence before clinical test results are given. CYP attending specialist asthma clinics in an NHS hospital setting usually undergo skin prick testing and/or blood tests (for Immunoglobulin E, IgE) to confirm presence of any sensitisation. Skin prick test results are given immediately to patients and parents/carers.

Although CYP and parents may provide suggestion of suspected allergic sensitisation on giving their history to clinicians, research has shown that whilst CYP who believe they may have sensitisation to dog, cat, pollen, or dust often are shown to be sensitised by clinical tests, CYP who believed they were not sensitised to allergens were shown to be sensitised in some cases. A study of 253 children reported that 63% perceived aero-allergic sensitisation but that testing revealed 80% were sensitised. Agreement in sensitisation perception and testing was greatest for cats and dust (rather than HDM). However, between 5% and 30% of CYP who believed they were not sensitised, were shown to be sensitised, particularly to cockroach allergen, which is more prevalent in the USA, where the study was conducted (Pham, *et al.*, 2019). Differences in patient awareness of sensitisation have been attributed to the size of the particle carrying an allergen; pet allergen particles are approximately half the size of HDM particles, which may explain why sensitisation to pets is often more readily recognised by patients since greater amounts of allergen will be inhaled, than would be the case for HDM (Custovic *et al.,* 2019).

Prevalence of allergic sensitisation is rising amongst CYP in many parts of the world, including western Europe (Leth-Møller *et al.*, 2020). Co-existence of other atopic conditions such as eczema, food allergy and hay fever is common with asthma: one

cross-sectional study of 703 children aged 4-12 years, reported 79% had co-existing asthma and atopy (Arabkhazaeli *et al.*, 2015).

It has been increasingly recognised that CYP with severe, sub-optimally controlled asthma frequently have co-existing allergic sensitisation. A cross-sectional study of 5-16 year olds with severe, therapy-resistant asthma, revealed that 89% had co-existing allergic sensitisation (Frith *et al.*, 2011). However, the exact weight of the role of allergic sensitisation in the causal pathway leading to asthma attack is unclear (Custovic *et al*., 2010) and understanding of the mechanisms involved is evolving (Belgrave *et al.*, 2017).

1.4.1 Commonly reported UK indoor airborne asthma triggers

CYP with asthma may be sensitised to one or multiple allergens. For this reason, the following sub-sections will outline what is known about the prevalence and impact of co-existing asthma and allergic sensitisation to indoor (airborne) environmental allergens and triggers commonly found in the UK. These include HDM, pet/animal dander, mould, and ETS.

1.4.1.1 House-dust mite (HDM)

HDM (particularly one variety: Dermatophagoids pteronyssinus), are abundant in UK households and live in soft furnishings, particularly mattresses, pillows, bedding, and carpets. This abundance leads to high levels of sensitisation. Co-existing sensitisation, asthma and continued exposure to HDM is known to trigger bronchial hyperactivity (Platts-Mills *et al.*, 1982). There is debate over whether HDM should be considered an airborne allergen, since airborne particles are usually only detectable once dust reservoirs containing the HDM allergen are disturbed by movement (Gold, 2000). Portnoy *et al.,* (2016) explain that the low density of HDM faecal matter (the allergen) results in their being airborne and inhaled when disturbed, with a re-settling time of 20-30 minutes. Since this is believed to be the mode for triggering asthma symptoms in those sensitised to HDM, this thesis will refer to HDM as an airborne/aeroallergen. UK studies have shown that 65% of children (3-17 years old) with asthma were also sensitised to HDM (Murray *et al.*, 2006; Murray *et al.*, 2017). Furthermore, one English study showed HDM allergen exposure in addition to viral infection was associated with an increased risk of hospitalisation for CYP with asthma (Murray *et al.*, 2006).

1.4.1.2 Pet allergens

Sensitisation to animal dander has been associated with severe asthma for CYP (Konradsen *et al.*, 2014). Yet, UK prevalence of sensitisation to household pet allergens is not well documented and the number of homes with a CYP with asthma and a pet to whom they are sensitised is also unknown. There is evidence to suggest that families continue to keep pets against the advice of asthma and allergy specialists. Svanes *et al.*, (2006) studied pet-keeping habits in adults and CYP with asthma and allergic sensitisation who had participated in surveys nine years apart. Only 4.7% of those advised to re-home pets did so, despite knowledge of asthma and allergy status. However due to retrospective recall, accuracy of findings may have been biased. A Norwegian longitudinal cohort study of children with asthma reported that pet avoidance was associated with allergic rhinitis but not asthma. After the ten-year study period, 70% of families reported never owning pets, 8% re-homed pets and 22% avoided specific animal-types. A diagnosis of asthma did not deter new pet acquisition. However, 24% inaccurately recalled pet presence in the first year of the child's life, suggesting recall bias may have affected accuracy of the study results (Bertelsen *et al.*, 2010). Whilst these studies showed asthma presence was not significantly associated with pet removal decisions, the reasons underlying pet-keeping decisions were not explored and may include multi-factorial considerations. Since the articles are over ten years old and the more recent study was conducted in Norway, they may not reflect current UK behaviour.

1.4.1.3 Environmental Tobacco Smoke (ETS)

ETS can be considered as an environmental irritant with pro-inflammatory effects (Gold, 2000). Determining the effects of chronic ETS exposure on CYP with asthma is challenging due to reliance on observational data, but based on existing data, there is evidence to causally link ETS exposure and CYP's asthma attacks (Kanchongkittiphon *et al.*, 2015). Prevalence of indoor smoking in the homes of CYP with current asthma is not well documented, but evidence has shown that parental smoking is associated with more severe asthma in CYP (Strachan and Cook, 1998), and causally with asthma development and numerous other conditions in childhood (Royal College of Physicians, 2010). Although national campaigns and various interventions have led to increased quit rates for smokers, prevalence of smoking is disproportionately elevated for those

living in the most deprived areas of England (ONS, 2018), those with lower education levels, working in manual occupations and those who are long-term unemployed and/or have never worked (NHS Digital, 2019). Although this may arguably correlate with higher exposure to ETS for those living with smokers, contemporary estimates of prevalence of CYP with asthma exposed to ETS at home, in the UK, are needed.

Reductions in paediatric asthma hospitalisations have been associated with smoke-free legislation introduction in England (Been *et al.*, 2014; Millett *et al.*, 2013) and in Scotland (Mackay *et al.*, 2010). Recently, Turner *et al*., (2020), reported a continued association between decreased asthma admissions for under 16s since Scotland's Take it Right Outside mass-media campaign for smoke-free homes. However, UK legislation does not include private environments, leaving some CYP exposed, and parents often reluctant to disclose home-smoking (Passey et al, 2016). Prevalence of indoor smoking in the homes of CYP with asthma remains undocumented.

1.4.1.4 E-cigarettes, Electronic Nicotine delivery systems (ENDs) and vapour

Recent survey evidence suggests that second-hand exposure to vapour from e-cigarettes (or similar devices) has been noted as a trigger for 26% of the (n=12,876) respondents surveyed (Asthma UK, 2019b). Although under 17s were included in the survey, they made up only 8% of all respondents, suggesting further research in this area may be needed. This is supported by evidence that vapour exposure is proinflammatory and leads to bronchoconstriction (Hickman and Jaspers, 2020).

There is evidence that viral infection and indoor allergens appear to act in synergy and increase the odds of asthma attack (Murray *et al,* 2006). It may be plausible that vapours could contribute synergistically with other triggers. The World Health Organisation (2021) acknowledges that second hand vape generally includes toxins. However, where ENDs are used for smoking cessation, many argue exposure to vape is preferrable to tobacco smoke, since there is no evidence that second-hand vape causes harm (NHS, 2019). Others argue evidence cannot confirm that long-term health effects of ENDs use or vapour exposure are fewer or less severe than combustible tobacco (Gotts *et al.*, 2019).

1.4.1.5 First-hand smoking & ENDs use in CYP with & without asthma

Smoking combustible tobacco alters the inflammatory processes that usually occur in asthma, cause earlier decline in lung function and impairs the response to corticosteroids, when comparing smokers and non-smokers with asthma (Thomson *et al.,* 2004). The impact of teenage smoking on asthma control continues to be noted by specialist asthma nurses (McMurray, 2017), and health professionals acknowledge teenagers rarely reveal smoking during medical consultations, often due to parental presence (Holley *et al.,* 2018). The uptake and impact of ENDs use in CYP with asthma remains unclear in UK epidemiological data, which focuses on CYP population data rather than CYP with asthma. Such evidence shows an increase in experimental uptake of ENDs use for 11–18-year-olds but with regular use remaining low (estimated at 1.7% of the UK population) (McNeill *et al*., 2019). Although, recent prevalence data suggests reductions in CYP smoking cigarettes, but increases (9% of the population, compared with 6% in 2018) in 11–15-year-olds vaping in England (NHS Digital, 2022). In contrast, the USA estimates current CYP's ENDs use at 14.1% (high school students) and 3.3% for middle school students (FDA, 2022). There are worrying trends in USA prevalence of ENDs and hookah use amongst CYP with asthma, with cross-sectional studies showing CYP with asthma have higher use-prevalence than those without asthma (Reid *et al.,* 2018; Fedele *et al.,* 2016). Furthermore, CYP with asthma in the USA, had significantly stronger beliefs (than those without asthma) that e-cigarette or hookah use enabled fitting in with peers and looking 'cool' (Fedele *et al.*, 2016, pp.867). Whilst the UK has less stringent laws for ENDs use and purchase, with the legal sales age at 18+ years (21 in the USA) and although vaping in under 18s is not currently illegal in the UK (ASH, 2022), there are calls for policies to restrict affordability and appeal of devices to CYP (ASH, 2023). It may be that multiple socio-cultural factors explain the differences in youth ENDs-use prevalence across these nations and further research in the UK would usefully elucidate whether CYP with asthma hold similar beliefs and practices to those shown in the USA.

1.5 Interventions to reduce trigger exposures

This section outlines what is known about the effectiveness of interventions to reduce airborne indoor triggers. Interventions can be broadly grouped as single (targeting one allergen or irritant and/or using one method to reduce allergen/trigger presence) or

multi-faceted (targeting more than one irritant or allergen or using more than one method). Interventions can be further sub-divided as methods to reduce or attempt to eliminate the allergen/irritant presence and/or interventions to increase education of CYP and families to promote allergen avoidance. The following subsections will describe the literature in this area.

1.5.1 Interventions that mechanically reduce allergen presence

Systematic reviews and meta-analyses of interventions for HDM remediation (Gotzsche *et al*., 1998; Gotzsche *et al*., 2004; Gotzsche *et al.*, 2008) and pet allergen remediation and/or pet removal have suggested intervention ineffectiveness (Leas *et al.*, 2018). However, Gotzsche *et al.,* (2008), highlight several issues in the studies included in their systematic reviews and meta-analyses: Adherence to the HDM reduction methods was not measured in all studies. Yet, the reduction in HDM presence shown would suggest measures were adhered to. The lack of statistically significant effect on asthma outcomes may also be explained by differences between the included studies methods of measuring HDM count reduction, for example, some counted HDM on pillows and mattresses but not blankets and other bedding. Furthermore, HDM allergen lies in the faecal matter of HDM, which once airborne (by movement of bedding etc) will collect in dust reservoirs in other areas of the room, thus only removing and counting remaining HDM on certain surfaces may miss others, which could continue to contribute to asthma outcomes and skew intervention trial results (Gotzsche *et al.*, 2008). Other areas HDM allergen may collect include the scalp (Naspitz *et al.*, 1997), soft toys (Nagakura *et al.*, 1996), clothing (Tovey *et al.*, 1996) and dogs (Jackson *et al*, 2004), which could contribute to asthma and trial outcomes. Gotzsche *et al.,* (2008) also highlighted that low levels of allergen can affect bronchial hyperreactivity and report the most likely reason for intervention ineffectiveness is failure to reduce allergen presence sufficiently in the included studies. These systematic reviews and meta-analyses have informed clinical guidance on HDM remediation, particularly only Leas *et al.,* (2018) is referred to in BTS/SIGN guidelines (2019). Leas *et al.*, (2018) systematic review included 37 single interventions including one (nonrandomised) study of pet removal (cats, dogs, hamsters, ferrets) and notably this study only included adults with asthma in Japan, with a limited sample of 20 participants (Shirai *et al.*, 2005), limiting generalisability. Of the 37 single component

interventions, none were associated with improved asthma outcomes. A further 30 multi-component interventions including intervention methods to reduce HDM and/or pet allergen presence in homes of people with asthma were included. Some outcomes were improved by multi-component interventions, but the study designs did not allow for determination of which component produced the effect (Leas *et al.*, 2018). This echoed findings of earlier reviews, including an integrated review of environmental remediation trials specifically for CYP with allergen sensitivity living in urban areas, which also reported greater effectiveness from multi-component programs compared with single component interventions (Townsend and George, 2011).

However, with evidence that HDM presence exacerbates asthma (Custovic *et al*., 1996; Murray *et al*., 2006; 2017) there have been calls for clinicians to take a practical and personalised approach to clinical advice on HDM avoidance for the following reasons: Systematic reviews and meta-analyses (Leas *et al.*, 2018; Gotzsche *et al.*, 2008) authors have not separated studies of children and adults for analyses. Different outcome measures have been inappropriately grouped together for analyses, as have short studies and longitudinal studies (Custovic, *et al,* 2019; Zuiani and Custovic, 2020).

The literature does not provide evidence on what actions families of CYP with asthma take to reduce HDM following advice under usual NHS secondary care, outside of trial settings. This is important as during intervention trials, necessary materials (such as HDM-proof bedding or specialist vacuum cleaners) would have been provided. In a real-life family setting, an investment in the items would have to be made by families, if this has been suggested to them, and arguably they will have needed to understand that HDM control measures may improve asthma control.

As mentioned, prior cat presence in the home (up to 5 years prior) has been associated with elongated presence of cat allergen (Munir *et al.*, 1994). However, Wood *et al*., (1989), collected dust samples in 15 homes within four weeks of cat removal and repeatedly every 4-6 weeks (up to 43 weeks). By 20-24 weeks post cat-removal, 53% of homes had levels consistent with pet-free households. In those implementing more robust cleaning (post-cat removal) levels fell faster (Wood, *et al*., 1989). Although the advancement in HEPA filter vacuum cleaners since these studies may reduce this time, the recent literature focuses on reducing dander levels amongst those who continue to keep pets (BTS/SIGN, 2019). However, a systematic review concluded that in homes

containing pet dander but no pet, HEPA filter vacuum cleaning may be beneficial (Leas *et al.,* 2018).

As mentioned, maintaining relative humidity of 35-50% is recommended reduce HDM prevalence (Portnoy *et al.*, 2016). A systematic review including two studies, examined the effectiveness of dehumidifiers in homes of children and/or adults with asthma, using a range of clinical asthma outcomes. The systematic review showed no statistically significant reduction in HDM counts, or improvements in clinical outcomes or asthma QOL, except for a statistically significant improvement in evening peak flow. The authors highlighted that such trials are complicated to conduct and expensive to fund (Singh and Jaiswal, 2013).

Regarding pets, many interventions have been reported beyond those included in the systematic review (Leas *et al*., 2018) already outlined. An earlier systematic review of pet allergen reduction interventions included two studies which also combined data from both adults and children with asthma. The studies used air filtration units in homes of children and/or adults with asthma and allergic sensitisation to their furry pets. No statistically significant differences between intervention and placebo groups were found and authors concluded further studies are needed to allow adequately powered meta-analysis (Kilburn, *et al*., 2010). Other studies proposing allergen reduction strategies (not meeting systematic review inclusion criteria) have been conducted, with varying outcomes. For example, research has included dog washing to reduce the presence of dander. This produced a statistically significant reduction of the presence of dander in homes if dogs were washed at least three times per week (Hodson *et al*., 1999). However, the effectiveness of this intervention was not assessed in the homes of people with asthma. Although many pet owners are reluctant to re-home pets, this remains the surest method of allergen removal (Portnoy *et al.*, 2012) but the contribution of such pet removal to asthma control is also undetermined.

Systematic reviews have identified that differing outcome measures across primary studies limit aggregation of results. A systematic review of 50 randomised controlled trials (RCTs) sought to identify the outcomes selected in RCTs using educational or behavioural interventions and identify any differences in the make-up of the interventions used. This systematic review included adult interventions as well as

paediatric and examined additional components beyond interventions to reduce trigger exposures. However, the authors highlighted that healthcare usage and symptom reduction were the outcomes that warrant greater focus in future intervention trials (Clark *et al.*, 2010).

1.5.2 Multi-component interventions, including educational components

Educational interventions have also been reviewed and synthesised. Crocker *et al.*, (2011), reviewed 23 (20 targeting CYP with asthma) community-based interventions to reduce trigger exposures in the home. Such home-based interventions involved home-visits to assess triggers and a multi-component intervention that aimed to target a minimum of two allergic or irritant triggers in homes. Some (21 studies/91%) included asthma education and thirteen included some level of ETS reduction support. For CYP, the interventions were effective in enhancing QOL. However, it was not possible to conclude intervention effectiveness by other asthma outcomes due to the limited number of studies and inconsistency across outcome measures. Crocker *et al*., (2011) also noted the possibility of the Hawthorne effect in such interventions, whereby participants may alter usual behaviours due to being involved in studies and/or observed, and thus a home-visits by researchers or interventionists may be a motivator for change (albeit temporary for some), which may apply to many of the interventions outlined in this chapter.

Postma *et al*., (2009), conducted a systematic review of eight RCTs of home-based multi-trigger reduction interventions delivered by community health workers to families with children with asthma (aged 2-16 years). Due to heterogeneity in outcomes measured in primary studies, the review synthesised results narratively. Education regarding the role of triggers in asthma management was delivered in seven studies. All studies were conducted in the USA and provided participants with HDM mattress and pillow covers, pest control (based upon a needs assessment) vacuum cleaners with high-efficiency particulate absorbing (HEPA) filters, HEPA air purifiers, cleaning kits, shower curtains and door mats (ETS was mentioned but it was unclear on what the intervention was). Seven of the eight studies included, provided individualised interventions (with some dependent upon participant preferences), skin prick test outcomes and/or community worker home assessments. The main findings for those who had undergone the intervention were, improvements in asthma

symptoms, limitation of day-time activity, and use of emergency medical care. It is difficult to attribute outcome improvements solely to trigger remediation, since their uptake (reflected in allergen measures) was variable, and where there were improvements, these were dependent upon which resources were provided by the community health worker delivering the intervention. Numerous sources of bias were identified by the review authors, including the Hawthorne effect, lack of blinding and differential dropout (whereby participants who complete an intervention may differ to those who drop out). Social learning theory was referred to for use in intervention delivery for four included studies and the transtheoretical stages of change model for one smoke-free intervention, but it was unclear how theories were used. Postma *et al*., (2009) concluded that future interventions should tie theory that underlies the intervention to the outcomes.

Another systematic review sought to 'identify the common educational parameters' used in multicomponent educational interventions to reduce trigger exposures. Belice and Becker (2017, pp.186) sought to review these parameters for minority and/or underserved children with persistent, sub-optimally controlled asthma. Seventeen articles met the review inclusion criteria, and all reported statistically significant results. However, more than half of included studies did not include a learning assessment or measure of health literacy. Only four studies used behaviour theory in their development. Belice and Becker (2017) stressed the importance of understanding beliefs and attitudes of those expected to undertake interventions, to direct interventions and provide foundations for future interventions.

1.5.3 The role of behaviour theory in interventions

Numerous behaviour theories and behaviour change theories (BCTs) exist and selecting a suitable theory for intervention design, development and/or delivery is complex and should be justified (Prestwich *et al*, 2017). Here, theory can be defined as a means to systematically *"understand events or situations. It is a set of concepts, definitions and propositions that explain or predict these events or situations by illustrating the relationships between variables"* (US dept. of Health & Human Services, 2005, pp4). BCT, or techniques can be employed to aid behaviour change in many areas of health.

Belice and Becker's (2017) conclusions are reinforced in the wider psychological literature, which often cites attitudes, self-efficacy, threat assessment, and intentions as the most common influences on behaviour (Prestwich *et al.*, 2017). Much attention has also been given to whether interventions should always be theory based. Meta-analyses in other areas of health were unable to prove that theory-based interventions were any more effective than atheoretical interventions. However, accounts detailing how theory was used and to what extent were limited (Prestwich *et al.*, 2014). Although it may be possible to develop effective interventions without a theoretical base, it is argued that theory provides a means to understand what has led to in/effectiveness (Prestwich *et al*, 2017), that atheoretical interventions do not provide. Yet, this is complicated in asthma interventions, firstly because multi-component interventions have been advocated as most effective in changing asthma outcomes and secondly, this would necessitate very complex study designs to test both multi-component (educational and mechanical allergen reduction, for example) and use of theory. Furthermore, Chapter 2 will highlight that contemporary, and contextualised data is needed to be certain whether behaviour change is necessary for CYP, parent/carers or both and whether different behaviours would require different interventions.

1.5.4 Summary: previous interventions

This section has shown that interventions are complex, challenging to systematically review or meta-analyse and thus challenging to draw clear conclusions from. As such, current UK asthma guidelines do not advocate specific interventions be recommended by clinicians, but allergen or irritant source avoidance continues to be advocated where possible (BTS/SIGN, 2019). However, how health professionals delivering avoidance advice can negotiate these complex issues with CYP and parent/carers likely requires a family-centred approach to complex intervention (CI) development.

1.6 Complex intervention development

The Medical Research Council (MRC) (Craig *et al.*, 2008; Skivington *et al*., 2021) defines a CI as one with several inter-linked elements and/or addressing several behaviours. Both the MRC (Craig *et al*., 2008; Skivington *et al.,* 2021) and intervention mapping approaches (Bartholomew *et al*., 1998; Kok *et al.*, 2017) to developing interventions

highlight the use of theory in development of CIs. Moreover, the intervention mapping approach highlights the evidence needed prior to commencing intervention development: identification of the target population, understanding of the environmental and behavioural issues and evidence of their key influences (Bartholomew *et al.*, 1998; Kok *et al*., 2017). Earlier sections of this chapter (1.2.3), have shown that CYP of secondary school age have higher rates of severe asthma and increased mortality. This, together with evidence that this period of multiple challenges in CYP's lives presents a difficult time for managing asthma (de Benedictis and Bush, 2017), suggests that this group would benefit from targeted interventions. However, a good understanding of current behaviour and what influences it is needed to design interventions.

1.6.1 Identifying influences on behaviour in cases of continued trigger exposures

There is a larger evidence base about the influences on ongoing adult smoking and the challenges of quit attempts and smoke-free home creation (Passey *et al.*, 2016), which has in-turn resulted in interventions to aid cessation or creation of smoke-free homes. However, this evidence is largely from a wider sample, not limited to parents of CYP with asthma. Whilst there has been increased use of theory in smoking cessation interventions (Michie and Abraham, 2004), evidence that theory-based interventions for smoking cessation are more effective is limited, and unproven for the transtheoretical model (Taylor, *et al.*, 2006). More recently a review of smoke-free home interventions for adults who struggle to quit smoking has highlighted that few report a theoretical basis (O'Donnell *et al.*, 2019).

Far less is known about influences on behaviours such as continued exposure to pets despite known sensitivity and asthma. Moreover, how much families understand about HDM sensitisation and its relation to asthma (which is arguably less visible to them) remains unknown.

Since current guidance used in the UK (BTS/SIGN, 2019), suggests clinicians advise trigger and allergen avoidance rather than specified mechanical interventions, for those with severe, sub-optimally controlled asthma, this is likely to include re-homing of pets (where sensitisation to the pet is shown), advice that HDM remediation methods *may* improve outcomes and smoke-free home promotion, alongside

management of any other triggers identified by CYP and family in addition to skin prick test results. All such avoidance likely requires behaviour change. Although some BCTs have been used to deliver some asthma interventions, their use for intervention design and development is much less frequent or is less well reported. Additionally, where BCTs have been used, the reason for the choice of one theory over others is rarely outlined or justified.

In summary, although there is a clear need for robust interventions to reduce trigger exposures, decisions to design and develop interventions with or without theory use are only possible if there is a good understanding of the current targeted behaviour and the reasons for behaviour. There are many influences on behaviour and on adherence to medical advice. Greater understanding of current behaviour and influences would allow for either pragmatic interventions or theory-based interventions to promote behaviour change.

In considering these complex issues, the next step in the process sought to understand what CYP with asthma and their parent-carers beliefs and current practices were regarding asthma triggers and trigger remediation.

A broad literature search was conducted to discover whether there was likely to be sufficient evidence of current trigger avoidance behaviours and the influences on behaviours, to fulfil part of the first step in an intervention mapping approach (Bartholemew *et al*., 1998; Kok *et al*., 2017). Searches revealed scant research in the area.

A scoping review was deemed appropriate to capture broader literature that may be used to inform intervention development or to determine research gaps in the area. The scoping review methods and findings are presented in the next chapter.

Chapter 2 Scoping review

The complex issues involved in developing interventions to reduce indoor environmental asthma triggers highlighted in Chapter 1, led to the decision to examine the extent of the literature that would be required to provide a suitable foundation for a CI, or study to address research gaps. Details of this chapter have been published (Lewis *et al.,* 2022).

An initial search of the literature on CYP and/or parents' beliefs and perceptions about indoor asthma triggers and how beliefs impacted trigger avoidance was performed. There were few articles on this. However, broader studies of CYP and parent-carer asthma (self)-management included evidence related to beliefs and actions regarding indoor triggers. A scoping review was determined as an appropriate method to describe the existing evidence and detail pertinent research gaps.

Scoping review uptake and methodology has advanced in recent years (Pollock *et al.*, 2021). They are useful to map key concepts, explore evidence gaps and are particularly useful when an area has not been comprehensively reviewed, or for complex areas with heterogeneous evidence (Arksey and O'Malley, 2005). It has been increasingly recognised that scoping reviews can be conducted rigorously and encompass many techniques used in systematic reviews to infer rigour and reliability (Peters *et al*., 2020). Other review options were considered. However, after initial search trials using Ovid Medline, it appeared highly likely that there was scant literature on this topic (beliefs about asthma triggers and allergic sensitisation and explanations of current related behaviours) and that wider asthma-self management would have to be explored to extract what was known. Had literature been available, a narrower question and systematic review or qualitative synthesis may have been possible. Also, had there been a range of literature (empirical and theoretical), available, an integrative review (Whittemore and Knafl, 2005) may have been appropriate. Integrative reviews often focus on evidence for policy or practice (Stetler, *et al.,* 1998), but for the current project, evidence regarding family beliefs and behaviours was sought to inform intervention development. Scoping reviews can be used as a pre-cursor to other review types, if necessary, or can stand-alone as evidence syntheses (Lockwood, *et al.,* 2019).

A priori protocol was developed and made available online (Lewis *et al.,* 2020) and the following scoping review was guided by the framework proposed by Arksey and O'Malley (2005), which was specifically developed for identifying research gaps, with acknowledgement of continual updates in the methodology from others (Levac *et al.*, 2010; Colquhoun *et al.*, 2014; Peters *et al.*, 2015; Peters *et al*., 2020).

2.1 The scoping review process

2.1.1 Identification of the scoping review research questions and objectives

Objectives:

1. Clarify CYP and/or parent/carers beliefs and practices related to home-trigger and/or allergen exposures
2. Explore whether the current literature explains behaviours sufficiently to enable design of a new intervention (or adaptation of an existing intervention) to enable home-trigger avoidance.

The scoping review questions were developed considering the populations (CYP and parent/carers), concept (management of indoor environmental asthma triggers) and context (home) of interest, which were also used for the search strategy development.

1. What is known about CYP's and parent/carers' views and beliefs about indoor environmental asthma triggers in homes?
2. Do beliefs inform trigger exposure reduction strategies? What else informs avoidance/non-avoidance behaviours or adherence to avoidance advice?
3. Are CYP and/or parents/carers motivated to reduce environmental asthma triggers in the home? If not, what may motivate avoidance?
4. Are there research gaps to address prior to developing/adapting interventions?

2.1.2 Identifying relevant studies: Development of the search strategy

The PCC (populations, concepts, and context) method was used as outlined above. The university of Leeds Library service and scoping review guidance recommends this method (Peters *et al.*, 2015). Tricco *et al*., (2018), also suggest pre-defining a target population, concept, and health outcome of interest, increases the effectiveness of the search strategy.

Participants: CYP with asthma and/or parents

Concept (phenomena of interest): Asthma trigger beliefs/perceptions and behaviours

Context: Indoor environment, with a focus on the home, where possible (any country)

The search terms and synonyms were developed and piloted in Ovid Medline with guidance from an academic librarian in the field. After four preliminary searches, the broadest terms were found to produce the most relevant key articles, since narrower searches, such as including allergens or individual trigger names in the title or abstract searches, (these were searched for in the main text body), missed broader articles that touched on triggers and trigger management. These terms were then used to search additional databases (2.1.4), including relevant Mesh/subject headings/terms (Appendix 1).

Citation searching (using Scopus, Google Scholar, and web of Science), and reference list checking was conducted for key and included articles.

2.1.3 Search limitations

The following limitations were applied to database searches. Only papers available in English language were searched for. This was partially due to time and budgetary constraints but also, on piloting the search strategy, non-English language articles with titles and abstracts in English were scanned, and none had clear, key relevance to the review questions. Although it is acknowledged that this strategy may introduce a level of language bias (Hemingway and Brereton, 2009), this restriction provides another means of reducing the large number of potentially irrelevant articles (Colquhoun *et al.*, 2014; Pham *et al.*, 2014).

The search was restricted to articles published between 1993 to 2020. This was due to a change in the BTS guidance in 1993: advice was altered to include avoidance of the acquisition furry or feathered pets for those with asthma and known pet-allergy (BTS, 1993). This restriction aimed to reduce the number of unmanageable search hits and increase the relevance to most recent UK asthma management guidelines. Balancing breadth with practicality is regularly reported in scoping review methodology (Colquhoun *et al.*, 2014; Pham *et al.*, 2014).

2.1.4 Databases searched

Ovid Medline, Cochrane Library, Embase, CINAHL, PsycINFO, Web of Science and Google Scholar were searched. These databases were included for breadth across a range of disciplines. Conference/theses repositories searched included Zetoc and EThos and Opengrey, which were selected to avoid missing unpublished studies or contributions from theses. Citation searching (using Scopus, Google Scholar, web of Science) and reference list checking was also conducted for key articles. Systematic reviews were not included in the scoping review but were searched for and were read if the abstract suggested they may include primary studies meeting the eligibility criteria; primary studies were assessed and included if these met the scoping review eligibility criteria, as this reduced the chances of missing potentially relevant details that may not be included in systematic reviews.

Duplicates were removed during searches, in databases with this function. Citations were imported into Mendeley, and duplicates were removed. Searches were re-run, and no further searches were made after 27/09/2022 (database alerts remained enabled until thesis submission).

2.1.5 Study selection: Eligibility criteria

Primary qualitative, quantitative, or mixed methods studies of any design, outlining beliefs, opinions, and behaviours related to indoor asthma triggers were included. Studies reporting intervention outcomes were not included, since the aim of the review was to explore opinions and behaviours and not individual intervention outcomes. However, if a study was conducted in advance of an intervention to assess beliefs and/or behaviours prior to intervention, this could be included. Laboratory based animal studies and editorials were excluded. Research studies with aims and objectives seeking only information regarding psychological, or outdoor environmental triggers were excluded. This decision was based upon preliminary screening during piloting of the search strategies, since numerous articles relating only to psychological asthma triggers (e.g., stress, panic, anxiety) were noted.

Following preliminary searches there was an apparent scarcity of research focusing only indoor asthma trigger beliefs, but evidence on beliefs regarding broader asthma self-management uptake and success was found. Results of such studies sometimes

included beliefs surrounding asthma triggers. Maintaining broad search terms and eligibility criteria increased the presence of these studies in the search hits and allowed mapping from a broader evidence base.

2.1.5.1 Participants

The aim of the scoping review was to explore beliefs or influences behind practices in the homes of CYP with asthma. Since beliefs of CYP and their parents are likely to influence whether triggers are avoided, the review included studies that mentioned CYP and/or parents' beliefs and/or behaviours. Studies including adults with asthma as participants, or those that did not report findings according to age groups (allowing younger (under 18 years) participant results to be extracted separately), were not included. The decision to exclude studies with only adult participants with asthma was made since research has shown numerous differences between childhood and adult asthma and its treatment (Gelfand, 2008; Trivedi and Denton, 2019).

Participant age boundaries for the term CYP were those under 18 years of age, and any age for those including parents/guardians/carers. Any study including children/parents of those only age 5 years and below was excluded, due to difficulty in accurately diagnosing asthma in preschool children (Chipps, 2008; BTS-SIGN, 2019).

Studies that described CYP with doctor diagnosed asthma or those detailing asthma-specific outcome measures were included. Those that included participants diagnosed with wheeze, rather than asthma were excluded. This inclusion/exclusion criteria were developed during early search strategy piloting. The eligibility criteria is summarised in Table 1.

Table 1: Summary of eligibility criteria & justification for inclusion/exclusion criteria

(also used in Lewis *et al.,* 2020 (protocol) and used in Lewis *et al*., (2022, pp.89)

Restriction area	Inclusion	Exclusion	Explanation
Study design:	Any study design highlighting beliefs and opinions about asthma triggers and/or avoidance in CYP and/or parents of children with asthma	Studies designed to evaluate effectiveness of an intervention. However, if baseline measures were taken to establish beliefs prior to an intervention, these could be included if they could be extracted in isolation	The aim of the scoping review is to understand whether triggers are noted by CYP/parents under usual care, rather than those who have undergone an intervention. Incorporating all designs allows for broad evidence scoping
Studies exploring other triggers:	Those including indoor triggers, where findings relating to these can be extracted separately	Studies exploring only beliefs around psychological triggers or outdoor triggers	Numerous studies were noted exploring only psychological or outdoor triggers on developing and piloting search strategies
Participants:	CYP (under 18 years) or parents/caregivers of CYP with asthma or asthma and co-existing allergic sensitisation- if reported	Adult only participants or unclear descriptions of diagnoses (e.g., wheeze rather than asthma). Studies including only those under the age of 5 years/parents of under 5s with asthma, will not be eligible	Due to differences in asthma and asthma management between adults and those under 18 years (Gelfand, 2008; Trivedi & Denton, 2019). Pre aged 5 years, asthma is difficult to diagnose (Chipps, 2008; BTS-SIGN, 2019)
Language of publication:	English language articles	Articles unavailable in English	Due to time restrictions. Also, on refining search terms and piloting these, articles in another language with an English abstract, these were screened, and none were relevant
Date restriction:	Articles published between 1993 and 2020 (A final search was re-run in September 2022 and	Articles stating data collection preceded 1993, or those published prior to 1993	BTS guidelines were changed in 1993 (BTS, 1993) to include indoor trigger avoidance advice. Articles prior to this likely have

	alerts were in place until thesis submission)		limited application to current practice

2.2 Scoping review results: overview

Thirty-three studies met the inclusion criteria. Thirteen studies were independently screened by a second reviewer (LM), and uncertainties were discussed and resolved by referring to the eligibility criteria, and/or discussing with an additional member of the supervisory team. Included studies recruited both CYP and parents (n=12); parent/carers only (n=13); and CYP only (n=8).

Twenty-seven studies were qualitative, two quantitative and four mixed methods. Six studies were conducted in the UK; further details are shown in a summary table (Appendix 2).

Figure 1 shows a PRISMA flow diagram detailing the broad searching strategy and exclusion/inclusion processes applied (Moher *et al.,* 2009; Aromataris and Munn *et al*., 2020).

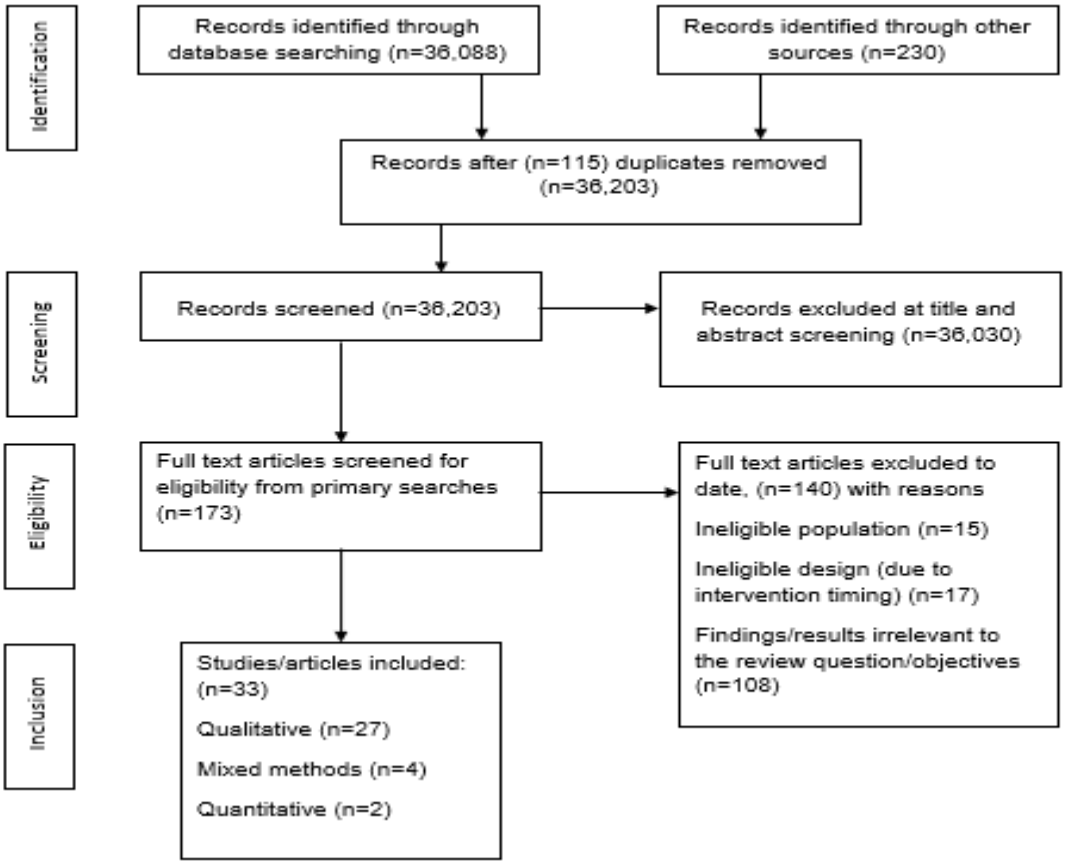

Figure 1: PRISMA (Preferred reporting items for systematic reviews and meta-analyses (extension for scoping reviews) flow diagram (Lewis *et al.,* 2022, pp.90)

2.2.1 Charting the data

A data extraction chart was devised using guidance from Arksey and O'Malley (2005) and updated to include further details (the chart is shown in the protocol: Lewis *et al.,* 2020). A summary of key study aims, populations, and study designs is presented in Appendix 2. During data extraction, the CASP appraisal tool (2018) was used to appraise study designs (example in Appendix 3). The CASP tools were selected because they are available for a variety of study design. However recently published tools, such as the Joanna Briggs Institute appraisal tools would also be appropriate (JBI, undated).

Due to heterogeneity in study designs and outcomes relevant findings are presented narratively, grouped according to themes identified to answer the scoping review questions (Arksey and O'Malley, 2005; Tricco *et al.,* 2018; Pollock *et al.,* 2021). Analysis, such as thematic analysis, was not used since some mixed methods and quantitative studies are included. Furthermore, the aim of scoping reviews is not to analyse or synthesise, but to summarise and chart information, and recently experts have stated, *"It is common to see attempts to thematically analyse information in scoping reviews. This approach is not inherently wrong, but it does conflict with the purpose of scoping reviews."* (Pollock *et al.,* 2021, pp.8).

The following sub-sections outline the findings of the scoping review. To place further findings on avoidance behaviours in context, the first sub-section outlines what was reported regarding how well CYP and parents recognise indoor environmental triggers, related beliefs, and any information showing their understanding of triggers that may explain avoidance uptake.

2.2.2 Narrative results

2.2.2.1 Possible explanations for trigger (non) avoidance behaviours

Considering whether CYP and parents/carers could identify asthma triggers was viewed as an important basis to contextualise and understand further findings of the scoping review. Broadly, CYP and parents were able to recognise triggers. Indoor triggers mentioned included, ETS and dust, particularly for UK studies (Crosland, *et al.*, 2009; Gabe, *et al.*, 2002; Edgecombe *et al.*, 2010; Lakhanpaul *et al.*, 2017; Holley *et al.*, 2018) but also the USA (Gibson-Scipio and Krouse, 2013; Gibson-Scipio *et al*., 2015;

Mammen *et al.*, 2018). Pets/animals were noted as triggers in all but one study (Edgecombe *et al.*, 2010). Beyond the UK, cockroaches, ventilation, and mould were mentioned, particularly in studies sampling socioeconomically disadvantaged communities: In American low-income settings, triggers were understood but financial restrictions meant reduction strategies were not implemented (Laster *et al.*, 2009). Difficult choices between exposure to poor indoor air quality (for example, lead paint presence) and ventilating by opening windows, thus exposing children to outdoor irritants, such as dust from local construction work, were described by parents of children with asthma (aged 5-12 years) in an American inner-city qualitative study sampling varied socio-economic groups (Yinusa-Nyahkoon *et al*., 2010).

Less frequently, where parents struggled to identify asthma triggers, parents acknowledged that information seeking was hampered by being uncertain about information needed (Shaw and Oneal, 2014; Archibald *et al.*, 2015). Whilst trigger recognition was common, beliefs about risks attributable to triggers varied; for example, 16-18-year-olds described adults over-emphasis of triggers (Jonsson *et al.*, 2017). Whereas parents suggested difficulty identifying risks of each trigger where many existed (Parikh *et al.*, 2018).

Norwegian children as young as seven years-old with co-existing allergy, were able to describe triggers, in a phenomenological study with 7–10-year-olds with asthma. The researchers used children's drawings to focus interviews and found that some included pets in drawings. One dog was caged whilst the child was pictured using a nebuliser. However, avoiding triggers was not discussed regarding the home environment. Rather, exposures when visiting family or friends who have pets were described and how, at times, this limited activities. Participants mentioned additional allergic responses, such as facial oedema. This, and their appreciation of how allergies and asthma symptoms were connected and fear surrounding repeats of previous experiences with allergic reactions and acute asthma attacks (Trollvik *et al.*, 2011), may suggest that having other allergic symptoms may be a factor in decisions to avoid triggers or places with triggers, when possible. Furthermore, such fear also led to fear of missing out on activities with peers. That triggers in the home were not mentioned may suggest that these were well avoided, or as Trollvik *et al*., (2011) suggest, that the interviewers focussed less on the home than on school or other locations. Mammen *et*

al., (2018), also reported that CYP noted other allergic responses (facial oedema) rather than changes to asthma symptoms. Whereas others suggested parents often fail to notice signs of allergy (Archibald *et al.*, 2015).

A qualitative study that used two types of interview with (n= 32) 7–12-year-olds with moderate-severe asthma in the USA, described how two younger children identified pets (one cat, one dog), as triggering symptoms such as cough. However, one recalled knowing this because the doctor had told them they were allergic to cats and reported not knowing what to do about it. The other reported coughing in the presence of the dog but not knowing why or what to do about it. Older children in the study were generally able to list more environmental triggers (including, pets, dust, HDM, and smoke), than younger children. However, the authors believed that children generally did notice causal relationships between triggers and asthma attacks but lacked knowledge on avoidance strategies. Although one child reported moving away from pets (Pradel, *et al*., 2001), it was unclear whether this related to a pet in their home. In contrast, an English qualitative study using focus groups and semi-structured interviews, revealed that parents believed that CYP with asthma (16-18 years) were unable to identify triggers for themselves (Holley *et al.*, 2018).

An earlier sociological study informed by the adaption framework, reported qualitative findings for nine English families in the northeast midlands. All families included a child with moderate-severe asthma (aged 7-12 years) from both middle and working-class families. The authors findings reflected that families largely viewed asthma as unproblematic, despite one child having spent time in an intensive care unit for asthma. There were variations in beliefs regarding what triggered asthma, with some unable to identify any triggers and others identifying several. Additionally, families emphasised medicinal management over environmental remediations, and asthma severity was discussed in comparison to other conditions and families' experiences and beliefs about those (*Prout et al*., 1999). However, Prout *et al*., (1999) did not describe methods of analysis.

Some triggers (particularly HDM), were less obvious until health professionals described them to families, and mothers described feeling guilty at not previously understanding this (Maltby, *et al*., 2003). Although Prout *et al*., (1999), did not report participants mentioning HDM directly, one family discussed placing soft toys in the

freezer (to kill HDM) at selected times when the child would not miss them, to minimise the upset this could cause. More generally, Prout *et al.,* (1999) suggested only one of nine families made significant remediations and others focussed on medication to achieve asthma control, which was viewed as less upsetting for family life than environmental control strategies. Continued pet-keeping (e.g., rabbits and dogs) was reconciled due to emotional attachment (Prout *et al.*, 1999) but it remained unclear whether some pets were kept indoors or outside of the home. Fewer articles (n=3: Edgecombe *et al.,* 2010; Holley *et al.,* 2018: Parikh *et al*., 2018) reported difficulties with identifying triggers. Those that did suggested greater difficulty pinpointing whether any one trigger was most symptom-inducing: One American qualitative study with parents (of children ≤12 years, with asthma), described nine of ten participants' uncertainty around triggers. Parents could name potential triggers but were uncertain which were important, particularly if CYP had been exposed to high pollen, and animals in the same day, for example (Parikh *et al.*, 2018).

In a qualitative study of (n=14) parents' perceptions of asthma in Singapore, dust was a frequently identified as a trigger, but no mention of allergic triggers was made beyond dietary-based restrictions, which were described by the study authors as unsubstantiated beliefs that were sometimes perpetuated by health professionals (Soo and Tan, 2014).

Only one British qualitative study of 11-18-year-olds with severe, uncontrolled asthma highlighted that none avoided triggers. The exception was that most avoided ETS. However, some described smoking tobacco themselves, despite understanding health implications. Many had a pet at home and were unaware that this could affect asthma (Edgecombe *et al.*, 2010). This was the only study suggesting CYP did not avoid triggers. Known risk-taking, particularly related to smoking was also noted by Hughes *et al*., (2017) in their classic grounded theory (GT) study. The theory explained how CYP self-manage asthma in ways that limit disturbances to everyday life. Although some environmental triggers were mentioned in the article, the focus was on broader self-management and the CYP's main concern of limiting restrictions to their daily lives and activities (Hughes *et al*., 2017). Whether the theory can explain other trigger non-avoidance by CYP and/or parent/carers is unknown.

Parental confusion between asthma aetiology or underlying causes and asthma triggers existed in some studies (Van Dellen *et al.*, 2008; Lakhanpaul *et al.*, 2017). Some parents believed exposures triggering asthma symptoms or acute attacks were also the single underlying cause of asthma (Lakhanpaul *et al.*, 2017). Similarly, in other studies, this linked to confusion around asthma as only occurring when triggered (rather than being a chronic condition with acute episodes), and therefore being linked to locations with triggers. Children's descriptions of their asthma included parents' opinions; for example, believing dusty schools caused asthma only when at school (van Dellen *et al*., 2008). Children highlighting parental views could suggest CYP are influenced by parents' beliefs, although, this was not explored in the article. Similarly, other parental misconceptions included beliefs that trigger removal may cure asthma altogether (Archibald *et al.*, 2015).

Parents (of 8–12-year-olds with asthma) participating in a qualitative study in Taiwan, highlighted confusion over whether allergies or asthma were responsible for causing symptoms. The authors described parents' belief that children should be responsible for recognising allergies and that mothers were unaware of allergies. However, some were aware that HDM can exacerbate symptoms and had purchased and used HDM-proof bedding. A good understanding of ETS risks and the role of immunology was reported (Jan *et al*., 2014). Although the article referred briefly to beliefs about allergies, their inclusion/exclusion criteria or participant description did not mention allergies/allergic sensitisation. However, gatekeepers were based at a paediatric allergy and Immunology department, suggesting presence of atopy or allergic sensitisation was likely in the sample.

In an American inner-city qualitative study of 47 parents (of children aged 5-12 years with asthma), many parents had some knowledge of triggers but felt they could not control triggers within the home. Examples given were lack of control over presence of pets or smokers. However, the reasons behind these challenges were not clarified, although the authors suggested barriers were related to parents' health beliefs. It was proposed that for parents with strong beliefs and concerns about medication, environmental control measures may be a more acceptable means of intervening (Mansour *et al*., 2000).

Another urban American qualitative study of African American caregivers' beliefs and concerns about teens (14-18 years) with asthma, described misconceptions about ETS exposure. Some parents believed that exposure would increase tolerance, whilst others promoted smoke-free homes as part of asthma management. Parents believed it was important for CYP to begin taking more responsibility for trigger management in this age group and that the timing of this shift in responsibility was determined by age. The exception to this was one mother whose son had learning difficulties and so appreciated that taking responsibility for asthma self-care was not only age dependent (Gibson-Scipio and Krouse, 2013). In a later publication, Gibson-Scipio *et al.,* (2015), reported a similar study with 14–18-year-olds with asthma. Again, the population was African Americans living in an urban area. Thirteen CYP attended one focus group. The study aimed to explore asthma beliefs and self-management goals. Most teens had a long-term goal of mitigating their asthma diagnosis as they moved into adulthood. Shorter-term goals related heavily to the management of acute symptoms, with 'some' (not specified) mentioning trigger avoidance as a short or long-term strategy. However, there was mention of avoiding or discontinuing activities that triggered asthma, in an effort to enable medication avoidance. These activities were not elaborated upon in the authors description of that point. Conversely, one example quotation the authors used to highlight moving to independent self-management, illustrated one teen's preparations for visits to a friend's house where cats were present, by ensuring her rescue inhaler was in her pocket. Moving toward greater self-advocacy (a theme in the authors' findings), was exemplified by one male's explanation that when his father smokes, the CYP asks him to go outside. Generally, these goals were described as determined by the teens themselves, but also others with asthma to whom they were close, provided valued guidance. Another more general belief was that health professionals' role was mostly for acute asthma management (Gibson-Scipio, *et al*., 2015); if this is a widely held belief, advice for trigger management may not be tied by CYP to health professional visits. Whilst this study highlighted some important contrasting issues, even within a small sample, the authors acknowledge limitations of their convenience sample, that findings may not be transferrable to wider groups, and that there was a chance participants 'merely agreed' with one-another in the focus group (Gibson-Scipio *et al.*, 2015, e58-59). In addition, within the sample (n=13), eight were 11-12th graders and one attended

community college. It is arguable that the lower age groups were underrepresented and that the findings may therefore likely over-represent the older ages included. Gibson-Scipio and Krouse's (2013), earlier study with caregivers of CYP with asthma also provided examples illustrating that goals were focussed on managing acute situations, for example where an EpiPen was needed. However, caregivers also noted that teens needed to learn to avoid triggers, with animals used as an example. Smoke-free homes were also emphasised by caregivers, with the exception (previously mentioned) that some believed that exposure could build tolerance. Cleaning, including the use of oils rather than spray-based products and regular washing of bedding was also emphasised for dust minimisation and to reduce the risk of viral illness. Ventilation and carpet removal was also mentioned by some caregivers (Gibson-Scipio and Krouse, 2013). One study that contradicts self-advocacy for ETS avoidance suggested that teenagers avoided confrontation over parental smoking by leaving the space or using inhalers (Velsor-Friedrich *et al.*, 2004). The difference may reflect a cultural shift in the USA towards smoke free homes between 2004 and 2015 when Gibson-Scipio, *et als*., (2015), study was published.

2.2.2.2 Cultural beliefs

Four studies explored or reported findings that were attributed to or explained by cultural norms by the authors and/or their study participants (Van Dellen *et al.*, 2008; Martin *et al.*, 2010; Jan *et al*., 2014; Lakhanpaul *et al.*, 2017).

Martin *et al*., (2010), used community based participatory methods to explore Puerto Rican (living in the USA) parents', and CYP's asthma self-management behaviours and identify beliefs underlying those behaviours. Focus groups were run with parents and CYPs. Triggers discussed included heat/cold (transitions from one to the other), emotions, exercise and ETS exposure. The role of allergic triggers was not discussed in the article and so it remains unclear whether these were not raised by the researchers or participants and therefore it is not possible to ascertain whether there is a gap in family knowledge of allergic triggers for this demographic group. However, children emphasised the need to educate adults in the importance of eliminating ETS. Fear of death due to asthma was reported and becoming aware of triggers was noted as a response to this fear, alongside having medication to hand (Martin *et al.*, 2010). However, avoidance was not mentioned in this context, indicating that reactionary use

of medication after trigger exposure was perhaps more frequent than trigger avoidance.

Lakhanpaul *et al*., (2017), qualitatively explored self-management barriers and facilitators in matched white and Asian families managing CYPs' asthma, living in England. Trigger avoidance strategies across groups included increased cleaning, changing flooring, ventilating, and not having pets for some. Not having an asthma action plan to refer to was common across participants. British South Asians also advocated keeping CYP warm and indoors as an asthma control strategy. Barriers for misunderstanding asthma triggers were compounded by not having English as a first language and Lakhanpaul *et al*., (2017) promoted increased availability of information in other languages and at other locations frequented by different ethnic groups.

Jan *et als'.,* (2014), qualitative study exploring parents' asthma experiences in Taiwan, reported mixed findings on parents' beliefs about the age children can take responsibility for asthma self-management, including trigger recognition and management. Whilst some parents reported believing children should take responsibility as parents were not always with them, others felt this was inappropriate for younger children; some cited children's naughtiness and over-energetic characteristics as barriers to taking responsibility for their own asthma care. These findings together with Jan *et al* 's., (2014) literature review led them to suggest that Asian children (also living in Asia) may be less able to self-manage asthma at ages younger than 10 years, citing that 8 years has been reported as suitable and possible in western countries (Jan *et al*., 2014).

Explanations for continued smoking around CYP with asthma were sometimes cultural, as CYP explained it was inappropriate in their culture, to ask guests to refrain from smoking indoors (Van Dellen *et al.*, 2008).

Some articles exploring minority populations also described groups as disadvantaged or low-income. Those living in sub-optimal conditions described lack of control over neighbours waste leading to pest presence and landlords refusal to exterminate pests (Yinusa-Nyahkoon *et al.*, 2010).

Whilst only one study included in this sub-section was conducted in England (Lakhanpaul *et al.,* 2017), the other studies highlight issues the authors and/or participants attribute to ethnicity, across a range of settings from a range of cultural

perspectives (Appendix 2 shows that these studies included Dutch, Turkish, Moroccan and Surinamese participants living in the Netherlands (Van Dellen *et al*., 2008); Taiwanese participants (Jan *et al.,* 2014); Puerto-Rican participants living in the USA (Martin et al., 2010), and African American parents in Boston, USA (Yinusa-Nyahkoon *et al.*, 2010), perhaps supporting that socio-cultural influences warrant attention in intervention planning (O'Cathain *et al.,* 2019).

2.2.2.2.1 Race and environmental trigger management

One study investigated differences between White Americans' and African Americans' knowledge and environmental control actions, since African American children have both higher risks of asthma diagnosis and increased incidence of hospitalisation for asthma in the USA. Biksey *et al.,* (2011), conducted a small mixed methods pilot study with twelve parents of children (aged 4-8 years) with asthma. Eight White American parents and four African American parents participated. White parents reported having received information about triggers from doctors, but the African American participants did not receive information. African American parents were described as less knowledgeable about triggers and therefore made fewer adaptions to their environment. Demographic findings suggested that the African American participants had slightly higher education levels and household incomes (although not statistically significantly higher: Appendix 2) than the white participants (Biksey, *et al*., 2011), perhaps in contrast with other articles suggesting that socio-economic factors may determine strategy uptake (Laster *et al.*, 2009), as well as limited control over some aspects of the home environment (Yinusa-Nyahkoon *et al.*, 2010). Biksey *et al.,* (2011), note that their sample size was limited, but that differences in communication between health providers and families may partially explain disparities in asthma management and outcomes across racial groups in the USA. The sample is particularly limited by the lack of matching, since eight African American parents participated and four White American parents. This could be examined further in a larger sample using a matched-pairs design. Additionally, as Biksey *et al's*., (2011) study was conducted in the USA, which operates a different healthcare system, it is difficult to determine the extent to which these results may be generalisable to the UK. Citation searching did not reveal any further studies building on the pilot work by Biksey *et al.,* (2011), nor similar studies in other contexts.

2.2.2.3 Uptake & descriptions of strategy use to reduce indoor trigger exposures in homes

A study quantifying uptake of exposure reduction strategies suggested there are areas for improvement. However, this is now twenty years old and may not reflect present practices. Finkelstein *et al.*, (2002) conducted a mixed methods study with parents of 3-15-year-olds with asthma (n=638), in the USA. Their cross-sectional survey revealed no correlation between parents having received trigger avoidance education (by usual clinical advice) and employing exposure reduction strategies at home. Other results relating to common indoor triggers showed 30% of households included a smoker, 71% were concerned about ETS, and 59% kept a furry pet, indicating trigger exposures continued. Additionally, Finkelstein *et al.*, (2002) reported no association between trigger avoidance and asthma symptoms. However, the researchers did not control for medication use. Therefore, lack of association cannot be used to infer that strategies did not work, firstly as other reasons could explain this lack of association, such as poor inhaler technique or medication adherence variation. Secondly, because authors relied on participant reports on home-smoking and pet/pest presence, recall bias is possible.

In an American mixed-methods, community-based participatory study, the impacts of different triggers were prioritised differently by parents compared with CYP, in an underserved community. CYP recognised and prioritised managing emotional triggers, including concerns about neighbourhood violence threats. In contrast, parents often had not considered emotional triggers, but prioritised mechanically reducing trigger exposures by frequently changing bed linen and changing air duct and air conditioning filters (Yonas *et al.*, 2017).

Neighbourhood violence limited younger children's (5-12 years) time spent outdoors and was therefore viewed as restricting exercise (Yinusa-Nyahkoon *et al.*, 2010), perhaps suggesting increased time spent indoors and further potential exposure to indoor environmental triggers.

Amongst qualitative studies, the most frequently reported avoidance strategies included increased and adapted home-cleaning (Maltby, *et al*., 2003; Raymond *et al.*, 2012), pest extermination (Yinusa-Nyahkoon *et al.*, 2010), and carpet and soft toy removal (Soo and Tan, 2014). In one qualitative study (focus groups), of four ethnic

groups, mothers believed having clean, pet-free homes resulted in fewer asthma symptoms for CYP. However, CYP's accounts suggested that other trigger exposures, such as ETS, remained unchecked (Van Dellen *et al.*, 2008). One qualitative interview study of 15 parents of children with asthma in Taiwan used content analysis and described the use of dehumidifiers and air purifiers in addition to home-cleaning, particularly on rainy days. However, effects of allergens on asthma were not known by parents and that may suggest dehumidifiers were used for climate control rather than allergen reduction. Yet, parents reported purchasing and using HDM protection covers due to being told about sensitisation to mites but reported uncertainty about their effectiveness. Additionally, parents expressed a wish that children learn to avoid allergens and control their environment as part of children's own daily self-management. Parents also expressed wishes to better understand the role of ETS exposure and sandstorms in exacerbating asthma (Jan *et al.,* 2014), suggesting some airborne irritants are recognised as triggers but are not well understood.

Pets and animal contact were noted as triggers for some. Some CYP described avoiding animals (Stewart *et al.*, 2012; Holley *et al.*, 2018), largely where allergy co-existed. Parents mentioned avoidance but no clear reference was made to re-homing pets, making it uncertain whether these families simply had never had a pet in the home anyway. Only one qualitative study of 11-18-year olds refuted that CYP understand pets can trigger symptoms (Edgecombe *et al.*, 2010). Some papers referred to reducing exposure by not allowing pets into CYP's bedrooms (Holley *et al.*, 2018; Archibald *et al.*, 2015) or by parents asking CYP to stay away from pets at home and reduce associated risks by hand-washing (Prout *et al*.,1999); although these decisions were not described in detail or with explanation. Some younger children (12 or under) reported moving away from pets or not knowing what to do about symptoms they believed related to pets (Pradel, *et al.*, 2001). Although this study only included interviews with younger children and parental perspectives were not sought.

Some studies described variability in avoidance implementation leading to partial strategy uptake, despite knowing other strategies exist, and others describe an iterative approach. In a GT exploration of 12 families, parents described making their own effectiveness judgements of lifestyle changes on asthma outcomes, alongside clinicians (Horner, 1998). Other studies reported parent/carers incomplete strategy

implementation for HDM. Mammen *et al*., (2018) used interviews with CYP and parents and voice diaries for CYP, with the aim of understanding how teens manage asthma and what was considered important by teens and their parent-carers. One example illustrated that parents used HDM proof bedding but had not removed carpets, and acknowledged that this would be ideal (Mammen *et al.*, 2018); perhaps suggesting that despite knowledge for optimising avoidance, these cumbersome multi-step procedures were only partially implemented. Trigger avoidance was referred to broadly rather than in the context of specific triggers. However, Mammen *et al*., (2018, pp.1319) reported a schema conceptualising asthma self-management. Broadly the schema includes processes of first assessing, deciding, and then responding to contexts to reach individually desired outcomes. The schema encompasses multiple factors and trigger avoidance is mentioned at the response level. However, trigger avoidance is not listed as part of the "non-pharmacologic strategies" which lies in the decision-making phase. The conceptual model is described as iterative, yet, if assessing symptoms occurs earlier but is not linked by CYP or parents to triggers, this may present an opportunity for targeted intervention, should this be transferrable to other groups with asthma. Although Mammen *et als'*., (2018) sample included a range of asthma severities in CYP aged 13-17 years, with some racial and socio-economic diversity, allergic sensitisation status was not documented.

In an American focus group study with 14-18-year-olds, participants described triggers but did not consistently carry reliever inhalers outside of the home. Participants also described understanding the potential seriousness of an attack but felt that their parents took the link with triggers less seriously; for example, parents continued smoking around teens (Velsor-Friedrich *et al.*, 2004). Similarly, older teens described their own risk assessments and acknowledged taking known risks with trigger exposures (Stewart *et al.*, 2012).

The studies included in the scoping review present contrasting findings over whether awareness of triggers informed uptake of avoidance strategies. Additionally, there appears to be discordance between CYP's and parents' prioritisation over which triggers impact asthma control the most. This may suggest communication issues within families, although, this or other explanations were not explored in the articles. Other studies (not meeting inclusion criteria) have described variation of the age CYP

take responsibility for asthma management, with some suggesting this is as young as eight years old (Ekim and Ocakci, 2013). This contrasted with Jan *et al*., (2014), where some mothers believed CYP should be aware of allergens, rather than parents. It may be important for future intervention planning to explore how age and responsibility for triggers is understood within families in the UK context.

2.2.2.4 Motivating and enabling trigger avoidance

No studies set out to explore what could motivate CYP and/or parents to reduce trigger exposures. Shegog *et al.,* (2012) conducted a study to investigate the causal attributions CYP with asthma and their parents ascribed to successful or failed self-management. Results showed success and failure to avoid triggers was generally viewed as controllable by parents, but internal and external factors affected behaviour; internal factors included internal motivation and personal effort. External factors included stable effort, which was attributed to success by parents, as was others' help. Failure was connected to exhaustion and varied according to others' help, which in turn increased motivation. Children also viewed triggers as controllable, but both groups attributed success or failure in avoidance to unstable causes. Parents also noted children under-recognised asthma symptoms. Some triggers were recognised as extremely difficult to avoid (e.g., pollen) since they are seasonally abundant (Shegog, *et al*., 2012), and as acknowledged in Chapter 1, may not be limited to outdoor exposures, and thus require a host of additional strategies to minimise effects (window closure, showering and washing clothes that may be pollen laden). Although Shegog, *et al.*, (2012), discussed asthma triggers broadly, (the only individual trigger mentioned was pollen), this was the only study identified by the scoping review searches that explored motivation to avoid triggers in this way, and presented results that may be interesting to consider for the context of individual triggers. However, it was somewhat unclear whether Shegog *et al.,* (2012) followed an established methodology.

Some studies explored general barriers and enablers to CYP asthma self-management in the USA (Parikh *et al.*, 2018), and UK (Holley *et al.*, 2018). Parikh *et al.*, (2018), highlighted needs to address parental misconceptions and weak health provider-parent communication, apparent after CYP's asthma-related hospitalisations. Indifference and low motivation for general asthma management routines amongst

older teens was described by Holley *et al.*, (2018). Similarly, "*ambivalence*" towards asthma self-care was noted in 16-18-year-olds in a Swedish qualitative study. Patient-centred care was highlighted as useful to tackle imbalance between asthma care duties and living usual teenage lives (Jonsson *et al.*, 2017, pp.23). Others refuted low motivation and suggested CYP attempt to create balance between avoiding triggers and living lives aligned closely to those of peers without asthma (Hughes, *et al*., 2017). Further communication challenges were highlighted by CYP, parents and health professionals for self-management and trigger avoidance, with good communication as a facilitator and poor communication as a barrier to self-management (Holley *et al.*, 2018).

One Canadian mixed-methods study of CYP and parents aimed to inform online intervention development. Teens sought peer guidance from older teens in similar circumstances, for example those with atopic asthma (Stewart *et al.*, 2012), suggesting peer-support may aid general asthma self-management.

Three studies proposed grounded theories broadly describing asthma experiences. One specifically outlined how asthma was assimilated into family lives (Horner, 1998). Another aimed to develop an intervention to reduce hospitalisations and emergency visits (Shaw and Oneal, 2014); this theory recognised parents whose children had been hospitalised (within preceding six months), balanced on a precipice of asthma control, where trigger exposure might tip control toward an attack. However, some parents felt unable to recognise what or which trigger tipped this balance, leaving families anxious between asthma attacks. Whilst motivated to minimise triggers, a balance for maintaining family life and normality around peers was also sought (Shaw and Oneal, 2014). However, these theories were broad theories of asthma experiences (rather than being focussed only on environmental triggers) and did not provide explanations about trigger avoidance/non-avoidance for those able to recognise triggers. Hughes *et al*, (2017) developed a classic GT explaining the processes involved in broader self-management and that these were centred around CYPs' concerns about reducing the effects of asthma.

One qualitative study described parent typologies regarding how parents responded to triggers. Parents were described as "*preventors, reactors or compensators*". Parents were motivated to preserve family normality but their methods and timing for

intervening differed across typologies (Crosland, *et al.*, 2009, pp109), suggesting parents find their own coping mechanisms to balance family life with adjusting for triggers. Aspects of Crosland *et al's* (2009) typology are similar to qualitative findings in a mixed methods pilot study conducted in the USA, investigating differences in African American and white parents' knowledge of environmental asthma control. Qualitative findings described parents with knowledge of asthma triggers as eager readers of medical literature, in contrast with those who were less knowledgeable. Being less knowledgeable was accompanied by parental mistrust in health care provider medical decision-making, particularly where diagnoses had changed or initially been uncertain (Biksey *et al.,* 2011). Horner (1998, pp.359), described a GT of "*catching the asthma before it got out of hand*", initially by "*learning the ropes*" of general (not only triggers) family asthma management. Eventually these efforts became part of daily lives, whilst balancing this with wider family needs. Whilst this might suggest high motivation to manage asthma triggers, determining how best to change behaviour and improve asthma control remains uncertain. Similarly, a phenomenological study of fathers' experiences of parenting children (7-11 years), with asthma, also discussed "*learning the ropes*", including learning about triggers from other parents' experiences (Cashin, *et al*., 2008, pp377). These articles presented detailed explanations of families' daily lives coping with asthma but a greater understanding of what informs behaviour and decision-making is needed to develop interventions to reduce trigger exposures.

Across findings, theories, and typologies, parents appeared motivated but perhaps restricted by balancing family needs. Whilst communication was a facilitator for self-management (Holley *et al.*, 2018), communication improvement needs were highlighted for acute and primary care (Shaw and Oneal, 2014), primary/secondary care (Holley *et al.*, 2018), and school nurses (Parikh *et al.*, 2018). Slightly fewer studies recruited both CYP and parents (n=12), (parent/carers only n=13; and CYP only (n=8). Where described, CYP and parents highlighted different triggers (Yonas *et al.*, 2017), or had different opinions over the importance of triggers in asthma management (Jonsson *et al.*, 2017; Van Dellen *et al.*, 2008). Research to understand communication within families to confirm parents are addressing the triggers that CYP believe contribute most to asthma appears underexplored.

2.2.2.5 Summary of gaps in the evidence

The scoping review has shown the following gaps in the evidence. No included studies provided sufficient evidence on; CYP's/parents' health beliefs related to indoor environmental asthma triggers; understanding of the role of allergic sensitisation in asthma control or their opinions about it; motivations to avoid triggers; explanations for pet-keeping/re-homing decisions. Most included articles investigated asthma management broadly, offering one or two sentences on triggers. Three studies aimed to investigate environmental triggers (Crosland, *et al*., 2009; Finkelstein *et al.*, 2002; Biksey *et al*., 2011). Of the three, none used GT (as outlined in Chapter 3), or mention extant theory use and none sampled CYP with co-existing allergic sensitisation and severe/sub-optimally controlled asthma.

Low income or socio-economically deprived groups may be underrepresented in UK research into asthma trigger beliefs and behaviours, since only Crosland *et al.,* (2009) explored parents' risk perceptions in this group.

Shegog *et al*., (2012), aimed to study triggers amongst other aspects of self-management and results showed that CYP and parent/carers believed triggers were largely controllable, but this was not specified for individual triggers, nor can it fully explain non-adherence to trigger avoidance. Most studies were descriptive, not explanatory. Taking responsibility for asthma management was mentioned regarding medication but less so for trigger exposures. If or how responsibility is considered or negotiated is underexplored for triggers. Epidemiological data has shown that families rarely (4.7% Svanes *et al*., 2006; 8% Bertelsen *et al.*, 2010) follow advice to remove pets from the home when children's asthma may be exacerbated by the presence of animal allergen, but to date no studies have sought to understand the beliefs and thought processes behind these decisions.

2.3 Discussion of the scoping review

The narrative findings section has outlined what is known about beliefs, opinions and motivations that may be informing behaviours related to indoor asthma trigger avoidance. Research in the field of asthma self-management has focused on psychological triggers, co-morbidities, medication, or overarching approaches which aim to include all components of self-management, more so than trigger avoidance.

2.3.1 How the scoping review sits within broader asthma self-management evidence

To date, evidence syntheses and reviews have included broader barriers and facilitators (Lakhanpaul *et al.*, 2014; Holley *et al.*, 2017; Miles *et al.*, 2017; Fawcett *et al.*, 2019), for improving asthma management and/or self and family management of asthma (including monitoring and medicating). These were identified by the scoping review searches and checked for articles meeting the inclusion criteria. This section will outline the findings regarding indoor environmental asthma triggers from these systematic reviews and discuss them in relation to the current scoping review.

Lakhanpaul *et al*., (2014), conducted a systematic review of barriers and facilitators to improving asthma management in South Asian CYP under 18 years of age (specifically those of Indian, Bangladeshi, or Pakistani backgrounds). The purpose was to uncover whether barriers and facilitators to asthma management were linked to ethnicity or culturally embedded beliefs. Fifteen Studies of families (parents), with CYP under 18 years with asthma, CYP themselves or health professionals treating them were included. Fourteen studies used questionnaires and quantitative methods and one used qualitative methods. Eight took place in the UK. Lakhanpaul *et al.,* (2014), presented the review findings thematically and these detailed multiple barriers including; lack of knowledge and information about asthma (largely reported amongst health professionals outside of the UK) and Lakhanpaul *et al.*, (2014), highlighted issues of bias in the primary study designs, including low preventative medication use and poor adherence to medication; denial or under-acceptance of an asthma diagnosis and reasons for this included stigma associated with asthma and concerns in some minority groups that asthma may be contagious; a tendency to over-rely on emergency services for acute asthma attacks which was generally related to under-recognition of asthma symptoms and/or their severity and in some, and beliefs that care is of higher standards in acute settings or was more easily accessible. Barriers regarding communication were in part related to limited English language both for understanding health professional guidance and questioning in consultations and issues with understanding and interpreting questionnaires used in the primary studies the review reported on. Lakhanpaul *et al*., (2014, pp7), suggested "*language barriers reflect being in a minority position rather than an ethnicity-specific issue."* Triggers

were discussed in relation to dietary changes made by parents to counteract concerns about allergies and the importance of a healthy diet. Avoiding specific food-types was reported by parents of CYP with asthma, in studies outside of the UK (India and Pakistan). The systematic review determined very few facilitators for improving asthma control in South Asians, due to limited evidence (Lakhanpaul *et al.*, 2014). The review did not mention environmental asthma triggers or the lack of evidence on these for the groups studied.

Miles *et al*., (2017) conducted a systematic review and thematic synthesis of barriers and facilitators of effective asthma self-management including studies of adults and CYP with asthma, parent-carers of CYP with asthma, and health professionals. This large review covered many barriers and facilitators from different patient, carer, and professional perspectives, collected under eleven themes. However, where environmental triggers were mentioned, these were with reference to studies with adults with asthma or studies of health professional knowledge or beliefs. Concerns from parents/carers were that school staff and teachers were not able to recognise asthma symptoms and deal with these appropriately or recognise triggers. However, triggers in the home environment were not mentioned for CYP in the review. More generally, Mile's *et al*., (2017) systematic review echoed some findings of Lakhanpaul *et al*., (2014), where inability to identify triggers was a barrier. Amongst the review conclusions, it was recommended that more education is needed to aid trigger recognition (Miles *et al*., 2017).

Holley *et al*., (2017) conducted a similar systematic review of barriers and facilitators of self-management from adolescent, parent, and health professionals' perspectives, including 16 studies. Their minimal findings related to triggers overlapped with those included in the scoping review, including difficulty avoiding some triggers, particularly ETS (Velsor-Friedrich *et al.*, 2004; Edgecombe *et al.*, 2010), and that one study (also identified in the scoping review) noted adolescents did not recognise pets as an asthma trigger (Edgecombe *et al.*, 2010). Broader health beliefs related to asthma medications, reported as barriers to self-management by the authors, included patients' beliefs that they are the best judge of their own bodies reactions to medications and therefore believing they were safe in non-adherence (Holley *et al.,* 2017). Although these factors were not discussed in relation to asthma triggers, it may

be plausible that these beliefs could affect decisions and behaviours about trigger non/avoidance and may align with the trial-and-error approaches mentioned in the current scoping review. Similarly, where asthma was not considered serious by participants, this belief affected their approach to self-management and although this was not mentioned with reference to triggers apart from smoking, it may plausibly apply to other triggering exposures. Allergic triggers were not mentioned in the review by Holley *et al*., (2017), which may support the findings of the current scoping review, that there is a paucity of evidence. Furthermore, whether this paucity reflects that previous research has not focussed data collection on allergic triggers or allergic sensitisation and asthma or that participants may not consider trigger or allergen management as part of their self-management routines is uncertain. The systematic review highlighted some limitations, including lack of quality appraisal and that most studies included had not aimed to identify barriers or facilitators to asthma self-management, thus Holley *et al*., (2017) suggested further research needs to link beliefs to behaviour. Whilst the authors recognised the complication of co-morbid allergic conditions to asthma self-management (Holley *et al.,* 2017), the review did not address these issues.

A more recent qualitative systematic review of parent/carers' lived experiences of managing children's asthma reflected that there is sparse evidence on beliefs, views or behaviours related to environmental asthma triggers, particularly in comparison to other areas of asthma self-management. Fawcett *et al*., (2019), reviewed 77 studies meeting their inclusion criteria (which included studies with parents/carers caring for CYP with asthma, wheeze, or bronchiolitis, under the age of 18 years), and synthesised and reported seven themes regarding parent-carer experiences. Their categories reporting findings related to triggers have overlaps with the findings of the current scoping review: Fawcett *et al*., (2019) reported some parents were unable to identify triggers and others believed triggers had been responsible for causing asthma. The two studies referenced for this point were PhD theses that had not met the scoping review inclusion criteria (Hook, 2017; Kealoha, 2012). However, these issues were identified by other studies included in the scoping review (Edgecombe *et al.*, 2010; Shaw and Oneal, 2014; Jan *et al*., 2014; Archibald *et al.*, 2015). Other categories in Fawcett *et al's* (2019), review hinted towards triggers but were not explicit. These included the need for "*constant vigilance"*, and awareness of surroundings

(particularly outside of homes). More explicitly, the labour included in trigger exposure prevention by increased cleaning was evident in the review (Fawcett *et al.*, 2019, pp806), which echoed findings of studies included in the current scoping review (Maltby *et al*., 2003; Shegog, *et al*., 2012). The financial burden of asthma from the parent-carer's experience also included the cost of HDM barrier products (Chiang, *et al.*, 2005; Fawcett *et al.*, 2019), a burden also described for some strategies in lower-income households in a study included in the scoping review (Laster *et al.*, 2009).

Educational needs identified by parent-carers at diagnosis included trigger education and the need to learn the ropes was also identified (Fawcett *et al.,* 2019), through their inclusion of Horner (1998), and Cashin *et al*., (2008).

The systematic reviews discussed show persistence of numerous barriers to asthma self-management, including some challenges around trigger knowledge and control. However, asthma triggers and adherence to advice regarding triggers has received far less attention than other aspects of asthma self-care, such as medication adherence. This may be a manifestation of how asthma triggers are prioritised within asthma self-management regimens, or it may reflect other influences affecting decisions to reduce trigger exposures in the home. Finally, it may reflect research priorities, questions, and/or designs.

2.3.2 Allergic sensitisation

Whilst none of the studies included in the scoping review addressed beliefs or understanding of allergic sensitisation and how it relates to asthma control and self-management, other publications have raised related issues. A quantitative study of 253 CYP in New York used questionnaires to establish perceived sensitisation to ten common aeroallergens (questionnaires were completed by CYP and parent/carers together). Questionnaires also determined whether CYP had doctor diagnosed asthma, asthma symptoms, medication, and/or doctor diagnosed allergic rhinitis/hay fever and family history of atopy and included lung function assessment. CYP then underwent serum IgE testing to establish the presence of allergen sensitivity. Actual versus perceived sensitivity was statistically compared. The results showed a good agreement between perceived sensitisation and actual sensitisation to cat, dog, dust, and grass. However, those who did not perceive sensitisation still showed high levels of (IgE) sensitisation, particularly to indoor aeroallergens. Actual sensitisation varied

by individual triggering allergen from 5% to 30% in those who perceived no sensitisation. Since this study included children with and without asthma, it also showed that in their cohort, CYP with asthma had greater agreement between perceived and actual sensitisation to at least one aeroallergen. The study authors adjusted for confounders and acknowledged the influence of parents in the questionnaire completion and highlighted that findings reflected the importance of both history-taking and testing in clinical settings (Pham, *et al.*, 2019). This study may go some way to corroborate some of the findings in the scoping review; that there is varied recognition of indoor aero-allergic triggers and that this may relate to varied appreciation of sensitisation. Yet, for those who are tested (by skin prick testing or serum IgE) and given results and explanation of these where sensitisation is detected, the variable uptake of strategies to reduce aeroallergic triggers remains underexplained by the literature.

Other research has shown high levels of accuracy of recall of skin prick test results amongst parents of CYP with asthma. Parent/carers of one hundred children with persistent asthma, between the ages of 6 and 14 years who had used the *"Breathmobile, school based mobile asthma clinic"* participated in structured interviews. Overall parents showed greater awareness of positive results over negative results. Of interest, when asked an open question to identify what parents believed triggered asthma attacks only a minority identified the allergen to which the CYP was sensitised. Richardson *et al.,* (2004, pp200) hypothesised possible reasons for this but these had not been part of their data collection and so were not substantiated by evidence:

1. That knowledge of the skin prick test was lower than the other results had indicated
2. Parental non-appreciation for the link between sensitisation, exposure, and asthma outcomes
3. Exposures may not have been of a significant enough dose to trigger attacks
4. Lack of visibility of some allergen sources, such as HDM.

Richardson *et al.*, (2004) also reported that they were unable to link exposures with actual sensitisation; those with sensitisation were no more likely to have a cat or dog for example. However, 23 (of n=100) in the study had a dog and 4 kept a cat

(reflecting the popularity of dogs over cats in their population of study), further reflecting the need to better understand beliefs and understanding that may inform decision making regarding aeroallergic exposures.

2.3.3 The role of symptom recognition

Janssens *et al.*, (2009), suggested a cognitive affective working model of asthma as a framework to enhance understanding of varying levels of perception (accurate/under/over perception) of asthma symptoms. In 2015, Janssens and Harver studied whether an intervention to improve asthma symptom perception affected asthma trigger recognition and asthma related QOL. 227 CYP aged 8-15 years with diagnosed asthma (in the preceding two years) participated. Baseline measures of asthma QOL and identification of asthma triggers from a pre-set list of 12 were taken. CYP were also asked to rate how much they relied on asthma symptoms to determine whether their asthma was deteriorating. CYP were randomly assigned to three intervention arms:

1. Peak expiratory flow rate (PEFR) training and feedback
2. PEFR training, no feedback
3. No intervention (control).

All groups recorded symptoms in a diary. 75% mentioned allergic triggers at baseline, although these were not further broken down into individual allergens. Trigger identification increased in arms 1 and 2, more so in those receiving training and feedback. The increased trigger recognition was also associated with a decrease in QOL, suggesting that the increased perception may have been burdensome (Janssens and Harver, 2015).

The issues of symptom recognition and ability to identify deterioration in asthma control, in addition to understanding of allergic sensitisation status potentially link to issues with adherence to medical advice. Non-adherence to asthma self-monitoring and lack of understanding of the importance of self-monitoring has been reported (Miles *et al*., 2017). Indoor trigger exposure avoidance is varied (as highlighted by the scoping review) and symptom under-recognition amongst CYP has been recognised by parents (Shegog, *et al*., 2012). Although the reasons behind non-adherence to avoidance (when advised), have not been explained by current literature, wider

literature on chronic disease may be of relevance, as outlined below. In summary, if trigger non-avoidance is tied to symptom under-recognition, new interventions may need a dual approach to these issues.

2.3.4 Multi-factorial influences on exposure decisions

Taking the example of non-adherence to advice to rehome a pet that a child is sensitised to, multiple factors may come into decision-making. In taking a broad definition of health, McNicholas *et al.*, (2005) argue that whilst people may not often acquire pets with a view to improving their health, they often recognise the benefits of pets to QOL and emotional wellbeing. Prout *et al.*, (1999) noted that families described keeping pets but added mitigations such as handwashing since this was considered less disruptive to family life. However, this was described for one family in their sample, and it was unclear what advice families had/not received about this and whether the children's allergic sensitisation status was determined. In taking a narrower view and focussing on the case of asthma in sensitised CYP, it is largely unknown if or how parents reconcile family emotional gain from pet-keeping against the advice from health professionals who warn that the pet may exacerbate the child's asthma. One article not meeting the scoping review inclusion criteria briefly discussed this: An American qualitative study of 50 middle school students with asthma used focus groups to develop an understanding of asthma and its management. The findings identified several barriers and levers to successful management, amongst these some respondents admitted that they knew cats or dogs could trigger asthma symptoms but believed this was outweighed by the benefits of pet-keeping (Ayala, *et al.*, 2006). However, as with all studies included in the scoping review mentioning pets (e.g., Prout *et al*., 1999) it was unclear whether the pets were acquired before or since asthma diagnosis or whether advice to re-home pets (or not replace them) had been given. Although CYP took responsibility for medication during school time, environmental trigger management was viewed as a parental responsibility. CYP also reported the ETS as an unavoidable trigger (Ayala *et al.*, 2006).

Trial and error approaches mentioned in the scoping review findings warrant further investigation to understand the details of such approaches in the context of environmental asthma trigger management. Whilst some studies mentioned partial implementation of strategies, these were not described in detail. For example,

disallowing pets into CYP bedrooms was mentioned in the scoping review articles (Archibald *et al.*, 2015: Holley *et al.*, 2018) and beyond (Jones *et al.*, 2001), but it was impossible to understand whether restricting pet movement to certain rooms had a sufficient impact on symptom reduction, or whether restricting pet movement struck a balance between family preferences to keep pets and attempts to minimise exposures. Night-time symptoms are common in paediatric asthma (Chipps, 2008), and although not discussed in the scoped articles, it may be that keeping pets out of bedrooms is believed to reduce night-time symptoms. Such measures are unlikely to be fully effective since allergens are easily carried through buildings via people (Ritz *et al.*, 2002). A recent study in the USA has shown that high levels of cat or dog allergens in bedrooms are associated with excessive asthma attacks in sensitised children (Gergen *et al.*, 2018).

One qualitative study of parents' asthma management understanding reported that parents prepare for CYP's contact with animals outside of the home by pre-medicating. This article did not meet the scoping review inclusion criteria but, "*trial and error*" approaches were adopted into overall family asthma management (Peterson-Sweeney *et al.*, 2003, pp121). This approach echoed other included studies, such as Horner (1998) who described families' effectiveness judgements of lifestyle changes on asthma outcomes, alongside clinicians. More detail explaining these trial-and-error approaches is needed; for example, the current evidence base does not elaborate whether families understand that applying short-term measures to reduce allergen exposure may not produce a change in asthma symptoms, control, or outcomes. Other research (outside of the scoping review) has shown that removal of certain allergen sources (mostly for pets/animals), does not have an instant effect on allergen load presence in homes. A lag of many months is reported (Kanchongkittiphon *et al.*, 2015), thus understanding family experiences of commonly used partial strategies (e.g., not allowing pets into CYP bedrooms; or seeing no/little change after a holiday without a pet), and perceived outcomes in detail, are of interest to inform future interventions to reduce exposures.

Few articles mentioned medication use in response to trigger exposures, but those that did noted how as experience with managing asthma increased, having reliever inhalers accessible allowed continuance of activities (Gibson-Scipio, *et al*., 2015). A

better understanding of possible trial and error approaches involving medications is important, as reliever inhaler overuse became a national concern following the NRAD report (Levy *et al.*, 2014). Although mentioned for anti-allergy medications in an article (not meeting the scoping review inclusion criteria: Peterson-Sweeney *et al.*, 2003), inhaler use in response to uncontrolled trigger exposures was rarely mentioned in the scoping review. In fact, some CYP who were aware of triggers, consistently did not carry reliever inhalers (Velsor-Friedrich *et al*.,2004).

Others have shown that where triggers have been misunderstood, parents/carers may adopt ineffective strategies. Whilst such strategies were categorised as harmful in a minority in one study (Cabana *et al.*, 2004), further research could explain misconceptions behind adoption of ineffective strategies and elaborate on whether ineffective strategies lead to ambivalence or low motivation to try other strategies, particularly since the literature describes feelings of futility when attempting to avoid numerous triggers (Parikh *et al.*, 2018), and awareness of how avoiding all triggers can restrict CYP significantly (Bellin *et al.*, 2017).

2.4 Discussion of strengths and limitations of the scoping review

More qualitative studies were included than quantitative. However, since the aim of the review was to explore what is known about trigger beliefs and how beliefs inform actions, qualitative designs were arguably suited to these aims (Barbour, 2000). Some quantitative/mixed-methods studies were included, providing numeric representation of how frequently triggers are recognised and/or strategies are employed at home.

The broad search strategy could be considered as both advantageous, for including as much relevant literature as possible, but unfavourable, since large numbers of irrelevant articles may have been avoided by further narrowing the search terms and relying on citation searching and reference list checking.

Only three studies included directly aimed to answer research questions about asthma triggers or trigger remediation strategies (Finkelstein *et al*., 2002; Crosland *et al*., 2009; Biksey, *et al.*, 2011). Of those three, none actively sampled CYP with allergic sensitisation or allergies (or parents of) or with severe, difficult-to-treat asthma. Furthermore, these three studies sought parents' perspectives only, leaving research gaps for CYP beliefs and behaviours. Shegog *et al's* (2012) study had a sub-aim to

explore causal attributions for trigger avoidance in CYP and parent/carers. However, their findings were not specific to individual triggers.

Low-income groups appear understudied in the UK, with only Crosland *et al*., (2009) sampling this group. Most studies described a range of participant educational backgrounds and socio-economic groups (SEGs), suggesting diverse samples, possibly transferrable across settings. This may indicate a gap for lower SEGs. This is important for ETS, since smoking prevalence remains highest in lower SEGs and children's exposure to ETS is also higher in this group (Moore *et al.*, 2012). However, the opposite is true for atopy: as described Chapter 1, paediatric atopy is associated with higher SES (Gupta *et al.*, 2018). It is also noteworthy that the included articles did not comment on ENDs or vapour exposure. This may reflect that many articles pre-date the surge in ENDs popularity. As mentioned in 1.4.1.4, second hand ENDs/vapour exposure has been identified in older age groups as a trigger (Asthma UK, 2019b), and further research could provide insight and knowledge for future interventions to reduce exposures.

Most scoped studies sought to answer broader self-management questions or explore broader asthma-related experiences. Although triggers were mentioned, more attention was given to medication. Sub-optimal medication adherence and inhaler technique are persistent challenges, but with less research on triggers, knowledge gaps persist.

Studies were largely conducted in westernised countries (summarised in Appendix 2). This may reflect exclusion of non-English language articles, which perhaps resulted in some language bias (Hemingway and Brereton, 2009). However, on piloting search strategies, non-English articles with titles and abstracts in English were scanned, and none had relevance to the review questions. This restriction reduced the large number of potentially irrelevant articles. Lack of articles from middle/low-income countries may reflect other publication biases or lower research rates.

Scoping reviews are not usually used to identify areas requiring further research due to limited quality of existing research, since quality is often not appraised in scoping reviews (Arksey & O'Malley, 2005). Scoping reviews generally include wide, heterogeneous study designs and outcome measures, therefore validated, comparable quality scales usually employed for systematic reviews become difficult to use

accurately in scoping reviews. There is acceptance that scoping reviews differ distinctively from to systematic reviews (Brien *et al.*, 2010; Pham *et al.,* 2014), and therefore perhaps cannot encompass the same measures of quality appraisal. Yet, lack of quality appraisal has been repeatedly recognised as a limitation of scoping reviews (Arksey and O'Malley 2005; Pham *et al.*, 2014), and some suggest inclusion of validated appraisal techniques (Daudt, *et al*, 2013). The CASP tool (2018), was used to guide appraisal of included studies. Since a gap was emerging in the evidence, having quality appraisal was deemed useful to inform future primary study design for the next stage in the project (Chapter 3). Some limitations were encountered in interpreting methodological reporting of included studies, which made quality appraisal challenging. Whilst CASP (2018) tools were used to appraise included articles, it is appreciated that their use must be balanced and that over-reliance on rigour checklists (for qualitative studies) can be problematic (Barbour, 2001). Most qualitative studies neglected to report researcher positionality or reflexivity. Although, reflexivity is often integrated into or inherent in methodologies (for example, memoing in GT outlined in 3.4.2), or is assumed (Malterud, 2001). However, others promote reporting of reflexivity to demonstrate researchers have considered their potential influences on the research (Finlay, 2002). Only Jonsson *et al.*, (2017), and Horner (1998) noted bracketing preconceptions. Both also gave detailed rigorous accounts of their methods, which was somewhat lacking in other papers. Under-reporting of methodological detail was common, for example, Crosland *et al's*., (2009) article mentioned a pilot intervention to reduce HDM load, but the timing of the qualitative study alongside the pilot was unclear and details of the intervention were not outlined or referenced. Such issues complicate inclusion/exclusion decisions for reviews.

Although two used participatory methods (Martin *et al*., 2010; Yonas *et al.*, 2017), no other articles referred to patient and public involvement (PPI). This may also be due to non-reporting, but inclusion of PPI has been recognised as a vital component for production of good quality, person-centred research for some time, and there have been calls for improved PPI reporting (Staniszewska *et al.*, 2011).

A further limitation of the scoping review could be that stakeholder consultation was not conducted. Arksey and O'Malley (2005) outline consultation as an optional step in their methodology. This was considered against the time constraints of the full

project. Also, the scoping review objectives focussed on family beliefs, behaviours, and their influences.

The scoping review findings highlight research gaps, particularly for the UK setting. These were used to inform the next stages of the project outlined in subsequent chapters.

2.5 Scoping review conclusions

The scoping review has shown CYP and parents are aware of some indoor environmental asthma triggers, but that how knowledge or other factors inform behaviours remains unclear. As identified in rationalising the scoping review questions (2.1.1), the purposes of the scoping review were to explore the existing literature to identify whether evidence outlined explanations of behaviours related to asthma trigger avoidance in the homes of CYP with asthma. Understanding the role of individual triggers in a heterogeneous condition, with multiple exacerbators remains challenging for families, and how their understanding impacts trigger avoidance is under-researched. The limited evidence means selecting from extant BCT to develop a new intervention to aid indoor environmental trigger avoidance risks a poor, unsubstantiated choice. The next chapter outlines the rational and methods for a primary study to explore beliefs and behaviours amongst CYP with allergic sensitisation and sub-optimally controlled asthma, to address the gap in the literature discussed in this chapter and inform future interventions to increase trigger and allergen avoidance.

Chapter 3 Research design

3.1 Introduction

This chapter presents the research design, methods and methodology for a qualitative study conducted to explore CYP's and parent-carers' beliefs, opinions, and behaviours related to indoor asthma triggers and exposure avoidance. Chapter 1 and Chapter 2 outlined the complexities of asthma and environmental asthma triggers and current clinical advice to avoid these. However, the scoping review brought attention to a gap in the evidence regarding what is known about understanding, beliefs, and opinions, how these are communicated within families, and current behaviours related to allergic sensitisation and asthma triggers from CYP and family perspectives. To contribute to this gap the following design, methods and philosophical foundations are presented for a qualitative GT study. The research question reflects a broad, open area for exploration, narrowed sufficiently for practicality (Strauss and Corbin, 1998).

3.2 Aim, research question & objectives

3.2.1 Aim

Develop an explanation of beliefs, processes, and behaviours involved in asthma trigger avoidance decisions, in the homes of CYP with severe or sub-optimally controlled asthma and allergic sensitisation.

3.2.2 Research question

What are the explanations for trigger avoidance decisions and strategy uptake in families with a CYP with asthma and allergic sensitisation?

3.2.3 Objectives

1. Develop an explanatory understanding of CYP's and parents' beliefs about allergic sensitisation, asthma triggers, and their perceived impact on symptoms, control, and asthma attacks

2. Develop an explanation of whether (and how) beliefs inform trigger avoidance strategies, to explain the processes involved in decision making

3. Explore CYP's and parent-carers' opinions on what may facilitate avoidance strategies

4. Develop substantive theory to explain processes involved in family management decisions in the context of a CYP with severe asthma and allergic sensitisation.

3.3 Methodological design

3.3.1 Rationale for a qualitative design

Qualitative research was selected since the research question, aims, and objectives were concerned with understanding and explaining how and why processes involved in decisions and actions to follow advice to avoid asthma triggers or not. Qualitative research uses participants' accounts of experiences to present *"rich, thick description"* (Morrow, 2005, pp252). Some methodologies, such as GT, delve further to describe explanations and processes participants go through to make health-related decisions (Strauss and Corbin, 1998). Qualitative research allows description and explanation of individual experiences, beliefs, and behaviours, and similarities are often observed across participants and can be used to represent the phenomena under study (Mays and Pope 1995). Individual differences (or negative cases; Morse and Clark, 2019) are also of interest, as these permit fuller accounts of what can be known about a group of sampled individuals and can help explain complex phenomena. Furthermore, qualitative research is useful when little is known empirically about a situation or phenomena, as highlighted by the scoping review (Chapter 2). This can lead to theory or hypothesis generation for further investigation. However, qualitative research in health has gained credence in recent decades and has many practical uses without further hypothesis or theory testing (Bryman, 2016), such as informing intervention development (Kok *et al.,* 2017), as this study aims to.

Other qualitative approaches (such as case studies or ethnography) could have been adopted to explore the area, particularly if the aims were to understand cultural processes (ethnography) or explore contextual phenomena using a variety of data-sources (case studies) (Padgett, 2014). However, the aims and objectives of the present study were to develop a theoretical explanation of the complex phenomena of family management of indoor environmental asthma triggers, and therefore, GT developed from qualitative data was appropriate.

3.3.2 Introduction to grounded theory

GT methodology can be viewed as a collection of principles and procedures to develop concepts and theory from data (Corbin and Strauss, 2008). GT originated with Glaser and Strauss' (1967) study of death and dying. Their texts sought to outline a rigorous methodology for exploring the social world. The outcome of GT application is traditionally a theory that usefully explains phenomena and processes and remains grounded in data (Glaser and Strauss, 1967). Glaser and Strauss' (1967), approach was inductive, and concentrated on working from data to build theory, with an appreciation that "*all is data*" during fieldwork, a concept that Glaser maintained (Glaser and Holton, 2004, no pagination). GT has been identified as most useful where phenomena are scantly researched, or under-explained (Birks and Mills, 2015). Moreover, GT can explain how and why people behave in particular ways in similar or dissimilar contexts (Dey, 1999), and can sometimes be used to predict behaviour (Urquhart, 2019).

Qualitative researchers, including grounded theorists, can employ a variety of philosophical approaches and methodological variations. The following subsections outline the approaches to the study described in this chapter and discuss these in relation to the chosen methodological approach, as outlined by Strauss and Corbin (1998), and elaborated in Corbin and Strauss (2008).

3.3.3 Researcher position

Qualitative researchers often consider their position related to research (Bryman, 2016). Researcher experiences and beliefs about the social world and how knowledge can be generated or extracted, are inextricably linked to how researchers design, undertake, and interpret research findings (Holloway and Tordes, 2003). Two broad areas of consideration will be discussed: 1) position on research with CYP 2) philosophical position.

3.3.3.1 Research with CYP and their parent-carers

How adult researchers view children, childhood, and adolescence can affect every stage of the research process (Punch, 2002). The researcher position on research with CYP is that CYP are knowledgeable about their asthma experience and have a right to be included in research which may affect their future and other CYP. Historically, CYP

have been considered relative to adults in research, with views that their status is one moving toward adulthood, rather than recognising their current position, thus limiting their current, pre-adult citizenship (Lister, 2007). CYP's rights to be involved in decisions affecting them is reflected in UK law, including the Children Act, 1989; 2004, and Health and Social Care Act, 2012. However, evidence is lacking as to whether these rights lead to measurable improvements for CYP (Brady and Graham, 2019). Despite difficulties in establishing whether inclusion of CYP as research participants translates to better health outcomes for CYP, CYP have reported preferences for inclusion in decisions about their health (Moore and Kirk, 2010). Moreover, interventionists aim for evidence-based (O'Cathain, *et al.,* 2019) and patient-centred approaches, therefore, including CYP beliefs and behaviours in the present study is vital.

Despite researchers' best efforts to give equal weight to CYP's participation and data, CYP may still be aware of the role that adults often ascribe to them in wider societal contexts, as such CYP are arguably more vulnerable to coercion, so-called unreliable responses, and power imbalances (Punch, 2002; O'Reilly and Dogra, 2017). Furthermore, attempts to equalise CYP and parents-carers' accounts of their experiences can be challenging; there are complex debates suggesting where children's voices may be privileged as consistently accurate this may minimise others' contributions. In contrast, CYP may be viewed as less competent or too vulnerable to include, and when included, tendencies toward over-reporting "*educated, articulate voices over others, downplaying individuality and diversity*" are noted (Spencer, *et al*., 2020, pp3). Moreover, how CYP are viewed may affect methodological choices, and may lead to appearance of methodological and philosophical inconsistencies: for example, believing CYP's have sufficient competence to participate, whilst selecting different, often creative methods for CYP, may be perceived as less methodologically coherent (Punch, 2002). Similarly, language used and techniques to build trust in interviews may differ in research with CYP compared with adults (Punch, 2002). However, interviewers regularly adapt vocabulary and questions styles to suit individual adults, whilst covering the same broad topics across an adult sample (Kvale, 2007). Due to these issues, some still consider CYP research contentious, thus inclusion of CYP as research participants must be ethically justifiable (Davies *et al*., 2019), as outlined in section 3.5.

Considering the aims and objectives of the study, parent-carers were also viewed as important stakeholders. Although some CYP in the age group sampled may assume many responsibilities, including asthma self-management, environmental factors in the home are potentially under the control and influence of adults. Understanding whether CYP and parent-carers' beliefs were similar was also recognised as important if theory developed might inform future interventions. Exploring both groups' beliefs and behaviours aimed to uncover whether any necessary intervention should be family-based, or necessary for both groups separately. The researcher was conscious that the research topic involved discussion of medical advice, adherence to it and subsequent uptake of trigger remediations, and that this may be perceived as checking up on families or looking to assign blame where asthma remained sub-optimally controlled. As such, the researcher set out to focus on experiences with such advice and its potential influences on family actions to remediate asthma triggers, and other factors affecting adherence to advice.

However, the researcher did not aim to hold either groups' accounts as superior or more accurate than one another. Researcher position regarding experience with the topic is also discussed alongside the methodological selection for the study in section 3.3.4.

3.3.3.2 Theoretical and philosophical basis for the study

3.3.3.2.1 Philosophical position

The issue of philosophical position and its importance in qualitative health research has been debated. Smith, *et al*., (2011, pp.44) reviewed complex debates between qualitative research based upon theoretical frameworks versus use of a "*generic*" approach as a practical means to answering research questions, rather than over-absorption in philosophical perspectives. Dey (1999) acknowledged that GT inspires many questions, including whether it should be based on a specific ontological and epistemological foundation. However, consideration and disclosure of philosophical perspectives allows transparency and permits readers to assess coherence between researcher position and methodological choices (Annells, 1996); such coherence is necessary for research rigour (Koch, 1994; 2006) which is discussed further in section 3.4.2. Despite debates over the necessity of acknowledgement and disclosure of

epistemological (researcher's theory of knowledge, and their belief about how that knowledge can be determined (Carter and Little, 2007) and ontological positions (beliefs about the nature of reality and nature of being (Bryman, 2016; Dey, 1999), many methodologists agree that GT grew from traditions of pragmatism and symbolic interactionism (Strübing, 2007; Corbin and Strauss, 2008; Bryant, 2009; Chamberlain-Salun *et al*., 2013).

3.3.3.2.2 Pragmatism

The philosophical paradigm for this study is pragmatism. Pragmatism originated with the work of Peirce, which was furthered by James and Dewey, between the mid-1800s, and 1900s (Corbin and Strauss, 2008; Chamberlain-Salaun *et al*., 2013). Pragmatism, purports that truth can be found by using the most practical means of answering a question (McCaslin, 2012). Although, this is often considered a rudimentary summary of pragmatism (Morgan, 2014).

A pragmatic philosophy was selected for the clinically guided foundation of the research questions and objectives, and the desire to select methods that can provide practical answers. Pragmatism recognises that real world scenarios may not consistently align with a single theory, and that knowledge is only useful if it can be applied (Morgan, 2014). Lincoln (2010) questions the adoption of pragmatism without further discussion of researcher position. Yet, Morgan (2014) discussed pragmatism as a paradigm, or broader philosophy, which is a departure from traditions of subscribing to an ontology and epistemology. Rather than the nature of reality dictating the types of attainable knowledge, pragmatism suggests beliefs and actions, or behaviours are in a state of "*continual interaction*". Further, if "*knowledge is not about the abstract relationship between the knower and the known; instead there is an active process of inquiry that creates a continual back and forth movement between beliefs and actions*" (Morgan, 2014; pp5), in a pragmatic paradigm. The back-and-forth nature of constant comparison used in GT (explained in 3.6.4.1.1) and focus on uncovering processes in a phenomena (Strauss and Corbin, 1998), alongside the nature of human decision making and behaviours coheres methodologically with pragmatism. Moreover, this coheres with the aims of this research since asthma is not a static condition and as such it is necessary to explore any continual interaction between beliefs and behaviours. However, others have critiqued the notion of pragmatism as a paradigm,

stating it lacks paradigmatic clarity (Corry, *et al*., 2018). Pragmatism arguably does describe how researchers view research and the social worlds in which it is studied; pragmatists believe that reality may exist, but that how people understand reality is dependent upon their experiences: "*for pragmatists, reality is what people make of it*" and "*knowledge is not a thing, but rather a process*" (Williams, 2008, pp3). Corbin and Strauss (1990, pp5) drew on pragmatism and symbolic interactionism, and clearly rejected determinism (that all causes are pre-determined) and nondeterminism, describing that "*actors are seen as having, though not always utilizing, the means of controlling their destinies by their responses to conditions"*. These concepts are important to the current research aims and questions (3.2.2) which overall, aim to understand the processes involved in decision making about family uptake of indoor asthma trigger/allergen remediations.

Although pragmatism has become almost synonymous with mixed methods research (Morgan, 2014), Strauss' and Corbin's work exemplifies qualitative studies drawing on pragmatism. Morgan (2014), noted pragmatisms usefulness in qualitative research and others noted that pragmatism is not dependent upon one methodology, or method; instead it emphasises selection of a methodology and methods that are suited to answering the research questions (Feilzer, 2010; Kaushik and Walsh, 2019). This focussed methodological choices outlined in section 3.3, which seek to pursue explanatory theory to pragmatically address the current scarcity of empirical knowledge on the topic of beliefs and behaviours regarding allergen remediation uptake.

In summary, pragmatists view reality as fluid, and as such pragmatism can be regarded as an epistemology (Stürbing, 2007) and ontology (McCaslin, 2012) for research. Chamberlain-Salaun, *et al*., (2013), elucidated Strauss' and Corbin's philosophical assumptions (particularly noting Mead, Dewey, and Blumer's influences) and how these translated to their analytic methods (outlined in sections 3.4). Dewey and Mead believed knowledge develops through action and interaction, and Mead noted behaviourism's roots in pragmatism (Corbin and Strauss, 2008). GTs are usually substantive, and thus contextually and culturally linked (Bryant, 2009), aligning with pragmatic principles. Strauss and Corbin also drew upon the concept of symbolic interactionism (SI) (Corbin and Strauss, 2008; Chamberlain-Salaun, *et al*., 2013).

Strübing (2019, pp.66), believes Strauss took his experience of pragmatism and SI, and researched as a "*pragmatist interactionist*" and thus the application of pragmatism, and SI to the current study coheres with the choice of Strauss' and Corbin's methodology.

3.3.3.2.3 Symbolic interactionism

As noted, SI provided a theoretical basis for GT and this study. SI was developed as a concept by a well-known philosopher, Mead and first published by some of Mead's students in the 1930s (Williams, 2008). Blumer (1969), promoted the term SI and explained it in a series of writings alongside explanations. Blumer (1969, pp1), described SI as "*a label for a relatively distinctive approach to the study of human group life and human conduct*" it is a "*down to earth approach to the scientific study of human group life and human conduct.*" Blumer (1969, pp47) described three principles of SI:

1. Humans' actions (and reactions) toward others and things are dependent upon the meanings those things or people have for them. "Things" may include, other people, items, objects, or institutions
2. This meaning is derived from social interplay
3. Meaning is subjected to interpretation and is therefore iterative, and context dependent.

Blumer (1969; pp13) emphasised that the second point distinguishes SI from similar concepts or approaches used in social sciences. Blumer (1969) acknowledges that whilst interaction and social influences are important, the self is also recognised as important in SI.

Despite scholars acknowledgement that GT can be generated under pragmatism (Morgan, 2004), and interactionism (Strürbing, 2019), others call for clearer epistemological and ontological consciousness (Birks and Mills, 2015), and suggest its discussion reflects reflexivity, since researchers inevitably have beliefs about epistemology, whether consciously or not (Carter and Little, 2007). Use and acknowledgement of underlying theory (beyond methodological theory, such as GT), helps protect against critiques that qualitative description may be seen as informal and overly subjective (Avis, 2005). Birks and Mills (2015) argue that the importance of

considering epistemology and ontology reflects researcher beliefs about their own role in research, as either a co-constructor, objective observer, or between the two. Moreover, Goldkuhl (2012), identified SI as a perspective that brings together pragmatism and interpretivism. Therefore, the next sub-section will discuss the role of interpretivism in the study described in section 3.4 and the researcher position on the subject matter will be described in 3.3.4.

3.3.3.2.4 Interpretivism

Interpretivism dates back to the work of Kant and fellow anthropologists, and asserts that knowledge is based upon experiences and how experiences are interpreted and understood (Ryan, 2018). Bryman (2016) described interpretivism as an epistemological position, which refutes the application of traditional (basic/physical) scientific, objective (positivism) values to the study of human experience and behaviour. Interpretivists can draw on a variety of approaches to research, including SI (Bryman, 2016), which has been reflected in the work of Strauss and Corbin and Strauss, which evolved and gradually moved from an initially post positivist, objective researcher stance, towards an interpretivist perspective (Levers, 2013). Strauss' and Corbin's earlier publications were not explicit in their epistemological or ontological assumptions. Whilst Charmaz saw objectivism in their early work (Timonen, *et al*., 2018), a chapter written in the 1990s, before Strauss' death, to explain Strauss and Corbin's philosophical stance (Chamberlain-Salaun, *et al*., 2013), was not published until Corbin and Strauss' most recent methodological text (Corbin and Strauss, 2008): Here pragmatism and SI are presented as their methodological epistemology. Dey (1999) noted Strauss' and Corbin's (1998) use of a revised form of interpretivism in their research; such that there may be a single objective reality, but we may only partially know and uncover it and it may vary according to context. However, Strauss has been identified as a relativist (pragmatist and symbolic interactionist) (Mills *et al.*, 2007), in his earlier works, which suggested Strauss believed suggested there was no single truth to be discovered and that all truths are equal (Oliver, 2012a). Yet, Strauss' later work with Corbin has been described as moving toward constructivism and influential on the development of Charmaz's constructivist GT (Mills *et al.*, 2007).

For the present study, an interpretivist perspective was taken. Interpretivism is closely aligned to SI since its aim is to understand social worlds in particular contexts, which

can change through time, and be dependent upon changing situations (Hughes, 2010). Where epistemological and ontological perspectives taken under the different GT methodological variants exist, a commonality is that pragmatism has influenced most (Timonen, et al., 2018), which as aforementioned, views reality as changeable and context dependent, and therefore suggests reliance on the interpretivist and constructivist end of the epistemological spectrum. This is viewed as important for asthma, which is a changeable condition with symptomatic episodes and choices made about self and family management may be influenced by changeability and families' social context.

3.3.4 The evolution of GT approaches

In the years following the 'discovery of grounded theory' (Glaser and Strauss, 1967), Glaser and Strauss worked separately, and Strauss' work evolved, with a departure from some of the stricter inductive demands of Glaser's ongoing methodological stances, now known as classic, traditional or Glaserian GT (Birks and Mills, 2015). Others have furthered the evolution of different GT variants (Charmaz, 2014; Clarke, 2019), although many exist, these are most common in health research. These differences allowed for assessment of which methodological variant of GT the current study would suit, and these will be discussed.

Glaser and Strauss (1967) began with a post-positivist approach (Charmaz, 2014; Rieger, 2019), that purports that a single reality exists and can be objectively uncovered (Ryan, 2018). Other grounded theorists have moved away from pure objectivism, for example Charmaz (2014) adopted a constructivist approach, which recognises the researcher as an essential research tool and emphasises data co-creation. Strauss and Corbin (1994, pp275) arguably fall between Glaserian and (Charmaz') constructivist GT and described their GT methodology as "*a way of thinking about and conceptualising data."* The influence of pragmatism and interactionism on Strauss' methodology was clear and in their evolving methodological guidance, Strauss and Corbin continued to demonstrate this, but also acknowledged that previous theoretical works allowed theoretical sensitivity for subsequent GTs (Strübing, 2019). Theoretical sensitivity regards being sensitive to or developing insight into which data are pertinent to an emergent theory (Glaser and Strauss, 1967) and this can be strengthened by researchers increasing knowledge through reading literature (Strauss,

1987). Recognition that some objectivist stances are extremely challenging to consistently apply in research exploring human behaviour, and that although researchers have access to tools to recognise and minimise effects of their preconceptions, a purely inductive approach is arguably impossible; researchers can rarely begin data collection without some form of prior knowledge on the subject (Strauss and Corbin, 1998). Furthermore, considering that the discovery of GT was influenced by SI (Williams, 2008), which has been described by founders as a methodological position and approach (Blumer, 1969), and subsequently referred to as a social theory (Chamberlain-Salaun, *et al*., 2013; Oliver, 2012b), and theoretical perspective or '*conceptualisation of a social theory*' (Williams, 2008; 2012, pp2), and by (Corbin and Strauss, 1990, pp5) as a '*theoretical underpinning'*; GT is arguably not fully inductive, even in its original form since it draws from a theoretical basis. The methods encompassed in commonly used forms of GT can be described as '*housing deduction'*, since the methods used emphasise back and forth (constant) comparison throughout analysis, thus employing some deduction (Amsteus, 2014; pp81). These issues were important for designing the primary study embedded in this thesis, because the scoping review identified the research gap and focussed research questions and objectives. Strauss and Corbin (1998) recognised that early literature reviews are often necessary in academia and that later in analysis, literature can verify developing theory. However, Glaser maintained that literature reviews should be conducted after fieldwork to preserve objectivism (Glaser and Holton, 2004). Furthermore, Glaser (1999) continually emphasised GT must achieve a theory attending to a main concern and how concerns are resolved. However, this project began with clinically formulated questions, from which it was impossible to determine whether indoor airborne triggers were the main concern of CYP and parent-carers. Moreover, if they were not the main concern, using Glaser's approach may have steered the project far from addressing the clinical issue, that suggests some patients do not avoid triggers consistently at home. The decision to follow methods outlined by Strauss and Corbin (1998) rather than others was considered at length against the research questions, objectives, researcher philosophical positioning, timing of the literature review, and researcher position as neither an asthma clinician nor patient or carer for a CYP with asthma. The researcher position in the current project is neither an insider (such as someone with first-hand asthma experience, or a respiratory

clinician may be), or absolute outsider (having observed asthma clinics and read extensively in the field), but possibly occupying the "*space in between*", (Corbin Dwyer and Buckle, 2009, pp54). Although interpretivism is close to constructivism (Schwandt, 1998), and constructivist GT (Charmaz, 2014) may have also suited the study, it has been described as best suited where researchers have first-hand or specialist knowledge of the topic (Singh and Estefan, 2018). Constructivism emphasises the researcher as an integral research tool (Charmaz, 2014), whereas Strauss and Corbin (1998) acknowledge the researcher role, and the need to identify preconceptions that may affect data generation and analysis, whilst maintaining enough objectivity to enable data to reflect participants' accounts and allow a wide view to explore unanticipated leads.

3.3.5 Induction, deduction, abduction & verification

As mentioned, the earliest GT text emphasised induction, building theory objectively from the data only (Glaser and Strauss, 1967). However, whilst earlier accounts echoed a focus on inductivism (Corbin and Strauss 1990), Strauss and Corbin's (1998), methodology included inductive and deductive analysis (Heath and Cowley, 2004), and verification (Birks and Mills, 2015). As described, induction relies solely on data and denies other influences (Glaser and Strauss, 1967). In contrast, deduction utilizes extant theory or hypotheses to examine new data against in qualitative research (Kennedy and Thornberg., 2018).

Reichertz (2011) argued that Strauss and Corbin also employed abduction. Abduction takes a further step, using both new data and deduction to make theoretical abductions to provide most appropriate explanations for phenomena. Constant comparisons made in GT and moves to include induction and deduction, alongside pragmatic philosophies employed by Strauss and Corbin (1994), suggest abduction. Bryant (2009) and Reichertz (2011) highlighted Strauss' (1987) acknowledgement of Peirce's influence (the founder of abduction), and that Strauss and Corbin's descriptions of verification displayed the hallmarks of abduction and align with their pragmatic approach.

3.3.5.1 Sensitising concepts

Blumer (1954) introduced two concepts used in sociological research, that became part of GT methodology: definitive and sensitising concepts. Definitive concepts are those that are used to define an object or concept and are clearly prescribed. Sensitising concepts are more commonly used in qualitative research (Blumer, 1954), and recognised in GT (Clarke, 1997), and are concepts that less clearly specify or define ideas (Blumer, 1954).

Sensitising concepts can be considered as ideas researchers begin with as a potential research puzzle or problem (Charmaz, 2003), which are built upon and refined using empirical data, whilst attending to negative cases that contradict the developing categories and theory (Strauss 1987; Clarke, 1997; Bowen, 2006); illustrating that researchers rarely begin without some level of deduction, but that reflexivity and maintaining a wide lens to view the data and avoid missing aspects outside of researcher's sensitising concepts is important.

3.3.6 Why develop new theory?

Illustrating why new theory was needed, justified the methodology and the decision taken to adopt Strauss and Corbin's (1998) approach over others. First it is necessary to explain how theories are distinguished to show their potential applicability to the phenomena under study.

3.3.6.1 How are types of theory distinguished?

GT generally produces substantive theory, which explains and describes processes of a phenomena studied in a particular group or context (Birks and Mills, 2015). In contrast, formal theories have been developed for specific areas of sociology, such as stigma (Glaser and Strauss, 1967). Whilst formal or substantive theory may be developed in GT, substantive theory is developed by comparison between concepts from one substantive area, whereas if formal theory is sought, analytic comparison within that formal (larger) area must be made (Dey, 1999). However, whilst formal theories are considered more transferrable, Dey (1999) argues that the difference between formal and substantive theory is dependent upon the extent of abstraction (the study of concepts outside of their initial, substantive context), and so is a matter of degree. Whilst formal theory may be regarded generalisable, substantive theory

was considered applicable for the group selected for study, who were those regarded as in greatest need of interventions to enable trigger avoidance.

Others may distinguish levels of theory as small, mid-range ('big'), and grand theory. Grand theory, like formal theory, requires greater abstraction and is usually transferrable. Merton, a sociologist, outlined mid-range theories (now sometimes described as models), in the 1960s, to describe theories limited between basic 'working hypotheses' and those more conceptual with greater inclusivity than 'small theory'. Small theory are contextually bound (Davidoff *et al.*, 2015, pp229), and are akin to substantive theory.

Glaser and Strauss (1967) advised against utilising extant formal theory before generating and analysing new data, to maximise induction. However, Strauss and Corbin (1998) noted the use of extant theories (substantive or formal), for later analytic verification. For the study described later in this chapter, this meant beginning with an open approach and following leads in the data to develop concepts and then verifying these against any relevant extant theory (in Chapter 6). Working from new data to propose a substantive theory and then comparing this to formal theory allows verification of GT and leaving this until later analytic stages allows better informed selection of formal theory (Strauss and Corbin, 1998; Dey,1999) should one apply to the phenomena of interest.

3.3.6.2 Complex interventions (CIs)

Despite there being little evidence that following one CI development guidance produces more effective CIs than others, there is consensus amongst interventionists, that use of theory and generation of new research is necessary, where there is little empirical evidence to examine and explain a problem. Further research also allows assessment of whether new interventions are necessary, have potential real-world applicability, and permit openness to acceptance that an anticipated intervention may be unnecessary (O'Cathain *et al.*, 2019); this, together with MRC (Craig *et al*, 2008) and intervention mapping guidance (Bartholomew, *et al*., 1998; Kok, *et al*., 2017), usefully informed decisions to generate both new empirical evidence and explanatory theory, to avoid recommending CI development without necessary evidence. Moreover,

Davidoff *et al*., (2019) identified that employing differing levels of theory (substantive and formal) can be complementary in CI development, as such employing methods that use extant theoretical verification seemed logical.

Application of extant theory versus developing new theory was a vital consideration in the design of the study, since numerous formal theories and behaviour theories may aid explanation of the phenomena of adherence to trigger avoidance advice, yet behavioural scientists advise against making uniformed theoretical selection (Prestwich *et al*., 2017). The gaps shown by scoping review were invaluable in finalising design decisions. Had there been clear explanation of behaviour and behavioural explanations at an early stage, CI development may have been possible.

3.3.6.3 Challenges with use of extant theory without further explaining influences on behaviour

Although exhaustive reading of the high number of extant BCTs was not possible prior to conducting the study, and could have influenced analysis unduly, some widely used behavioural theories were explored and challenges in their application to the phenomena under study were noted:

- Broader literature on family dynamics and functioning with CYP with chronic conditions may have relevance and relate to cultural and social influences (Bruhn, 1983). However, the scoping review (Chapter 2) highlighted how asthma has unique features that are frequently misunderstood and sometimes bound by perpetuated myths, such as misunderstanding asthma as only episodic rather than chronic. Furthermore, it was unknown what CYP/parents understand about allergic sensitisation, which is also complex. Such misunderstanding in asthma means that applying extant theory is complex and any problems requiring interventions are difficult to define without further explanatory research to understand individualised behaviours.
- The generalisation of extant behaviour theory to a range of conditions has been questioned (Conner and Norman, 2015), and many of the critiques of broader behavioural theories apply to the context of asthma and allergic sensitisation, as illustrated in the following examples. Many behavioural theories do not

address the gap between intention and behaviour (Prestwich *et al.*, 2017): First, it had to be determined whether CYP/(parents of) with asthma and allergic sensitisation have the understanding to inform an intentions to avoid triggers, and if there is good or poor understanding does this inform intentions?

- Adherence research in asthma has been dominated by the need to understand poor medication adherence. Medication adherence is complex and affected by many factors (physical, cognitive, emotional, psychological), including fears around side-effects that are less relevant to trigger management. Adherence to trigger avoidance advice is harder for health professionals to monitor objectively than medication use, which can be somewhat verified (although not always accurately) against prescription orders and digital inhaler use monitoring (De Simoni *et al.*, 2017). Self-regulation theory has been utilised and recommended in asthma self-management intervention development and to inform practice (Clark, *et al.,* 2001; Clark and Zimmerman, 2014), including a brief mention of trigger management (Zimmerman *et al*., 1999). Yet, if experimenting with trigger avoidance is based on misconceptions, this could be a barrier to implementing useful behaviour change, thus, warranting further research. Self-regulation theory has been successfully applied elsewhere, for example, lack of self-regulation with diabetes can produce a fast and severe, detrimental outcome, giving cues to change future behaviour (Clark and Zimmerman, 2014). However, failure to avoid environmental triggers can produce varying degrees of effect in asthma, often with a slower effects on asthma control that builds over time, making it more challenging for CYP/parents to link exposures clearly with changes in asthma control.
- Action-outcome expectancies mentioned in social cognitive theory (Bandura, 1977) is another challenging concept to apply to those with allergic sensitisation: Research shows that removal of certain allergen sources (mostly for pets/animals) does not have an instant effect on allergen load presence. A lag of many months is reported (Kanchongkittiphon *et al*., 2015), thus understanding family experiences of commonly used partial strategies (not allowing pets into CYP bedrooms) and perceived outcomes are of interest. Are families' interpretations of incomplete strategy outcomes informing other

decisions without families' full knowledge/understanding of the time lag effect?

- Social cognitive models of behaviour have broadly been critiqued as inadequate in descriptions of how individuals make decisions (Conner and Norman, 2015). This project aimed to understand the decision-making processes regarding trigger avoidance for the specified sample. Additionally, many theories imply rational decision-making (Prestwich *et al*., 2017), which may be unrealistic in real-life settings, and is particularly questionable given the CYP age-range (during which time logical, abstract and rational thought is developing; Piaget, 1969), and external socio-cultural influences mentioned in Chapter 2. Bandura (1977) described emotional effects on tasks which may be applicable to asthma; symptoms may cause anxiety, and pets (for example) may be seen as emotionally supportive, thus the thought of pet removal becomes distressing. This had not been explored in the asthma literature.

These examples of the challenges of applying extant theory to an area that was ill-defined and unexplained confirmed that further primary research was warranted prior to intervention development being possible. Additionally, there is limited evidence that interventions based on BCT are more effective than those that are not. This is partially due to inadequate reporting of behavioural theory use (Dalgetty *et al*., 2019). Yet, a strong theoretical understanding of a substantive target groups' beliefs and behaviours may usefully inform CI development (Kok *et al.,* 2017).

Summary of methodology

GT can be regarded as a set of research methods that can be used to generate theory. Frequently, GT is used partially to explore phenomena in health and beyond, and descriptive findings are often presented without construction of theory (Birks and Mills, 2015). However, in this case, theory generation was an aim of the project and as such, GT was a suitable option. Moreover, GT seeks to explain phenomena and/or processes, also suiting the aims and objectives of the study. GT is acknowledged as particularly useful where little is known about a phenomena, which was highlighted by the scoping review (Chapter 2) and generally, by evidence regarding CYP asthma self-management. The study fostered the philosophical paradigm of pragmatism and drew

on the concepts of symbolic interactionism and an interpretive perspective to develop an explanatory GT of processes families go through in making decisions about home-asthma trigger management, to inform future interventions.

Subsequent sections outline the methods employed and considerations made in their selection, including ethics, and attendance to rigour.

3.4 Methods

This section describes the methods adopted to generate data to usefully inform theory development. GT was the selected methodology, which allowed selection from a range of methods and emphasises rigorous practices. Finally, GT techniques can give guidance to novice researchers who seek to develop theory, particularly those with technical guidance, such as Strauss and Corbin (De-Beer and Brysiewicz, 2016).

3.4.1 Patient and public involvement (PPI)

PPI was embedded in the project from inception. Meetings with a (broad health-related) young person's advisory group and a group of adults with asthma (or who cared for a person with asthma) allowed project discussion and external assessment of study materials. Groups were run by professionals following the National Institute for Health Research (NIHR) INVOLVE PPI guidelines (NIHR, 2019). There were difficulties engaging involvement of young people with asthma that may relate to the COVID-19 pandemic in the study planning stage. However, engaging CYP who knew little about asthma allowed assurance that study materials should be understood by all, including those with less asthma knowledge, perhaps in cases of recent diagnosis. CYP and adults with asthma contributed suggestions to improve the lay summaries of the study findings that were written for participants (Appendix 4).

3.4.2 Ensuring quality in qualitative research

Research rigour in qualitative research refers to a collection of procedures or tools used to enhance trustworthiness by transparency and replicability (Birks and Mills, 2015). Trustworthiness can be further subdivided by considering credibility, dependability, confirmability, and transferability (Denzin and Lincoln, 2005). A historical overreliance on presenting qualitative compared to quantitative research (Mays and Pope, 1995; Sandelowski, 2008), resulted in altered terminology for

qualitative quality. Whilst qualitative quality criteria can be useful (Tracy, 2010), others have noted specific criteria depend upon methodology; Creswell (2007), suggested paying attention to the categories in GT assessment, for example.

GT memoing is considered a central tool in analysis and provides an audit trail of researcher decision making throughout a project (Strauss and Corbin, 1998). This simpler form of writing reminds researchers to identify analytic gaps and illogical inferences (Corbin and Strauss, 2008). Memos are notations capturing analytic decision trails, researcher's analytic ideas and reflexive notes, addressing concerns that researcher preconceptions may taint analyses (Elliott and Lazenbatt, 2005). Memos vary in length and depth and build iteratively on one another and can be tracked chronologically throughout analysis (Strauss and Corbin, 1998). These provide evidence of consideration of subjectivity, through recording analytic decisions that demonstrate findings are grounded in data (Bowen, 2009). Furthermore, Bowen (2009) suggests that Strauss' and Corbin's (1998) diagramming techniques are another example of an audit trail, and alongside memoing, allow researchers a wider lens to view analyses. Recording analytic decisions can demonstrate theoretical sensitivity (researcher use of insight and topic knowledge: Glaser and Strauss, 1967; Birks and Mills, 2015); researchers ask questions of the data and remain open to new concepts and therefore develop theoretical sensitivity throughout, which can be further developed by discussion with other researchers (Corbin and Strauss, 1990). Memos can be further sub-divided into those related to coding, or decisions taken throughout projects (operational memos), and theoretical memos (Strauss and Corbin, 1998). However, later Corbin and Strauss (2008) acknowledged a less structured approach is also appropriate. Both structured and unstructured memos were used in the study outlined in this chapter.

Whilst Corbin and Strauss (1990) suggested methodological flexibility, they noted careful attention to their approach confers rigour. A structured approach and provision of explanations grounded in participants' accounts, is recognised as rigorous, where clearly reported (Mays and Pope, 1995; Elliott and Lazenbatt, 2005).

3.4.3 Sampling & recruitment setting

The setting participants were recruited and sampled from was Leeds Children's Hospital Respiratory Unit. The unit comprises a multi-disciplinary team (MDT) caring

for CYP with respiratory conditions, as in-patients or outpatients. This study aimed to sample those attending or due to attend asthma clinic within the subsequent six weeks. Under pandemic conditions, and during most of the recruitment period, approximately 24 outpatients were consulted per week (18 by telephone).

The planning and conduct of the study occurred during the COVID-19 pandemic. Planning began in 2020 at the height of pandemic restrictions and uncertainty. As such, many of the options for recruitment and the setting for data collection were adapted. Research Ethics Committee (REC) and Health Research Authority (HRA) approval were granted in March 2021 (ethical considerations are described in section 3.5 and Figure 2 shows study timelines and adaptations).

3.4.3.1 Sampling

Sampling in GT often appears complex, beginning with either convenience or purposive sampling and moving to theoretical sampling, a central tenet of GT (Corbin and Strauss, 1990). This section will outline the strategy adopted and its rationale.

3.4.3.2 Purposive sampling

Initially, purposive sampling was used to select participants meeting an inclusion criteria. Purposive sampling is frequently used in qualitative research and enables selection of participants based upon the research aims and objectives (Morse and Clark, 2019). In GT, purposive sampling is often used first to select participants the researchers believe have experience of the phenomenon under study (Morse and Clark, 2019). It is noteworthy that the sample also reflects natural differences between participants, rather than fully representing a population (as quantitative sampling aims to), the aim being to represent the research phenomena (Morse and Clark, 2019). Palys (2008) elaborates on variants of purposive sampling and describes criterion-based sampling; this is the purposive sampling technique employed for the present study, whereby patients meeting priori criteria were invited to participate. Convenience sampling could have been selected and seeks participants who are most accessible (Braun and Clarke, 2013). However, the scoping review and background literature (Chapter 1 Chapter 2) shaped the inclusion criteria, giving a foundation for purposive sampling. Later theoretical sampling was employed and is discussed in 3.4.6.

3.4.4 CYP Sample decisions

CYP were sampled based upon their age, asthma, and allergic sensitisation status. Since the development of a GT aimed to usefully inform future interventions, the first consideration was which groups of CYP with asthma may benefit greatest from an intervention. The following subsections describe the initial inclusion criteria.

3.4.4.1 Asthma severity

Those with ongoing symptoms and sub-optimally controlled asthma, defined by presence of one or more of the following, were invited to participate in interviews:

1. Two or more acute asthma attacks requiring medical attention within the last 12 months and/or
2. Regular asthma symptoms and/or
3. Over-use of short-acting beta-agonist (SABA-a rescue/reliever inhaler), indicated by use of SABA to relieve symptoms more than twice per week.

Those with two or more attacks per year or unrelenting symptoms, SABA use at least twice weekly and receiving expert treatment are defined as having severe asthma and are at greater risk of further serious attacks (BTS/SIGN, 2019). Although the inclusion criteria did not stipulate a diagnosis of severe asthma, the inclusion criteria closely reflected the severe end of the spectrum and those struggling to optimise control. This best represented those who stood to benefit most from an intervention to improve trigger avoidance, whilst maximising recruitment opportunities.

3.4.4.2 Allergic sensitisation

CYP with allergic sensitisation to either domestic pets and/or HDM, defined by a ≥3mm wheal on skin prick testing (BTS/SIGN, 2019), was an inclusion criterion. Since the study aimed to understand the explanations for indoor environmental trigger/allergen avoidance behaviours (or non-avoidance), it is most likely that those with co-existing allergic sensitisation would have been advised that trigger avoidance, particularly to the allergens they are sensitive to, may benefit their asthma control.

3.4.4.3 Age

CYPs target-sample age was determined by the epidemiological data discussed in 1.2.3: 13–14-year-olds appeared susceptible to higher prevalence of severe asthma

(Lai *et al*., 2009), and adolescence is known to complicate self-management (Holley *et al.*, 2017). Yet, in the UK, CYP begin the transition to adult care from around aged 16 years. Another consideration was that understanding the phenomena of asthma trigger self-management decisions from the ages either side of the 13-14 years target, could provide useful insight for intervention timing, where a pre-emptive intervention may be better suited that a reactive approach. As such, an initially broad approach, with some homogeneity was adopted: 11-16 years was viewed as both narrow enough to allow some homogeneity and broad enough to begin to understand the phenomena of interest (all living in a home environment and in full time education). This was considered important since the purposive sample was used a pre-cursor to theoretical sampling (outlined in section 3.4.6) (Morse and Clark, 2019), and so a balanced approach allowed for greater understanding of the phenomena across this age group. Moreover, since evidence suggests that the age CYP take responsibility for asthma self-management varies but is often at least partially undertaken during secondary school years (Jan *et al*., 2014), this age group presented the potential to include CYP (and parent-carers) who may have already experienced and made changes to their environment to increase trigger avoidance and some who may not. Additionally, since little was known from existing literature on how decisions are made in this area, it was decided that time since diagnosis should be discussed at interview but not be criteria for inclusion. Yet, some argue that such retrospective style interviews to explore experiences should only explore those in participants who have fully experienced a condition (Morse and Clark, 2019). However, the nature of asthma is variable and whilst it is a chronic condition, symptoms are commonly episodic, and so each experience within time elapsed since diagnosis likely differs. Although this meant participants were potentially at different stages of their asthma experience, this provided a starting point from which to gain an overview of the phenomena and consider whether sampling should need to adapt to focus theory. Moreover, this provided understanding of the processes participants undergo during their experiences, which is considered important in GT (Corbin and Strauss, 2008), and important when considering whether theory may inform interventions to support those in similar contexts.

3.4.5 Parent-carer sample

Parent-carers of CYP meeting the inclusion criteria were invited for interview. A carer was defined as those deemed to be a main care giver by parents/guardians.

The final limitation was that interviews could only be conducted in English. Therefore, all participants had to be able to speak and understand English.

Inclusion/exclusion criteria are summarised in Table 2.

Table 2: Inclusion/exclusion criteria

Inclusion	Exclusion	Justification of criteria
CYP aged 11-16 years	Other age groups: Over 17s are likely to be beginning transition to adult asthma care	Age selected for some homogeneity: all secondary school age (or close to) and living with parent(s)/guardian(s). This age group was highlighted in the background section as inclusive of those with more severe asthma in England (Lai *et al*., 2009)
Asthma severity: Asthma that is difficult to treat or sub-optimally controlled asthma, defined by presence of one or more of the following- 1. 2 or more acute asthma attacks requiring medical attention within the last 12 months and/or 2. Regular asthma symptoms and/or 3. Over-use of short-acting beta-agonist - (SABA-a rescue/reliever inhaler), indicated by use of SABA to relieve symptoms more than twice per week (BTS/SIGN, 2019)	Other co-existing chronic respiratory conditions (e.g., Cystic Fibrosis, Bronchiectasis)	The scoping review has shown the suggested inclusion group has not been specifically sampled regarding triggers. Also, those with more severe or sub-optimally controlled asthma will likely benefit most from interventions
Co-existing allergic sensitisation, defined by ≥3mm (or greater) wheal on skin-prick testing (BTS/SIGN, 2019) for at		This group has not been specifically sampled for research in this area previously (as found in the scoping review)

least one of the following: HDM, or pets/animals. (Other additional sensitivities will not lead to exclusions)		
Parent(s)/guardians/carers of CYP recruited (Carers will be classified as a main caregiver as identified by the parent/guardian)		Knowledge, understanding and beliefs of parents are also likely to affect whether avoidance strategies are in place and future home-trigger avoidance facilitation will need support of parents. Parents and CYPs' intervention needs may differ.
English language spoken	Those who feel unable to participate in interviews in English	Offering interviews in additional languages would necessitate use of translators, adding time and financial demands to the project that were not pre-planned in the funding application. Concerns are that misinterpretation at each level (asking and answering interview questions and at data analysis) can threaten validity, (there are risks that the researcher and participant's meanings are changed via the interpreter) when an interpreter is used and when the researcher does not have adequate understanding of the participant's culture (Kapborg and Bertaro, 2002).

3.4.6 Theoretical sampling

Theoretical sampling can be considered an iterative technique to enable researchers to adapt to ongoing findings to further delineate theoretical concepts and categories whilst working towards theory development (Strauss, 1987). The approach is flexible and is usually employed after initial coding of purposefully sampled data (Morse and Clark, 2019; Birks and Mills, 2015). Morse and Clark (2019, pp.4), describe theoretical sampling as a process that "*becomes more purposeful"* throughout analysis, as understanding of the topic increases. The initial purposeful sample shapes some level of understanding of the research topic or phenomena, and theoretical sampling is used for further refinement. The aim of theoretical sampling is ultimately abstraction and

saturation of the theory (Strauss and Corbin, 1998). Due to the sampling processes used for GT, a priori sample size is often not determined (Morse and Clark, 2019).

Theoretical sampling often includes use of wider literature to verify a developing theory or extend it. It also involves a back-and-forth analysis through data already collected and comparison with extant theory and most recently generated data, which can mean further recruitment is not always necessary (Strauss and Corbin, 1998). This can raise theory up from small, substantive, context bound theory, as most GTs are (Birks and Mills, 2015), by abstraction involved, to a transferable mid-range theory (Morse and Clark, 2019).

Theoretical sampling seeks theoretical saturation of the phenomena (the point where additional interviews do not bring new concepts to findings), with the view of producing a theory that is more transferrable to similar settings (Strauss and Corbin, 1998). However, defining and achieving saturation in practice is challenging to clearly demonstrate, as discussed in 3.6.4.1.1 and 6.10.2.

3.4.7 Recruitment

Recruitment options were adapted and reflect the COVID-19 pandemic restrictions. For the eight-month study period, potential participants were identified using two main methods.

1. An invitation slip was sent with paediatric respiratory unit appointment letters. The slip signposted families to an online study eligibility survey (available upon reasonable request). This could also be accessed via a poster displayed in asthma and allergy clinics: Appendix 5)**.** Potential participants could answer five questions to establish whether they met the inclusion criteria. If so, they were invited to contact the researcher or leave their contact details to discuss participation. Those meeting eligibility criteria (Table 2) were signposted to read the linked study information (Appendix 6).
2. Clinical gatekeepers in Leeds paediatric respiratory unit could also identify eligible potential participants during consultation. Families were then either offered a paper study pack or signposted to the online study information. Similarly, those consulting by telephone could also be advised of the link to the online study information.

3.4.8 Gatekeepers

As mentioned, clinical gatekeepers in Leeds paediatric respiratory unit outpatients negotiated access between potential participants and the interviewer. Gatekeeper involvement is frequent in research and facilitates recruitment (Holloway and Galvin, 2017). For CYP, parent-carers can also be considered as gatekeepers since those under 16 years old required parental/guardian consent to participate. Although the UK HRA state that Gillick competence can be assessed by those conducting research with CYP, outside of medicinal trials (HRA, 2018), the decision to request parental consent was taken and is discussed in section 3.5.1.1.2**.** As section 3.4.9 will describe, due to amendments to sampling and recruitment, mothers who participated in the study also became gatekeepers to the researcher's access to fathers, which had not been anticipated.

3.4.9 Evolving sampling and recruitment methods

The study began recruitment in the context of changing government messaging and public restrictions in response to the COVID-19 pandemic. This meant that many eligible patients were having telephone or online asthma clinic consultations in place of usual face-to-face appointments. Also, many clinics and appointments had to be re-scheduled due to staff illness and CYP illness/cancellation. Recruitment was delayed both by the local study approvals process and by slow recruitment uptake from a relatively small pool of potential participants. Amendments were made to the original ethical approvals to minimise the impact of these issues. Additionally, amendments provided the opportunity to attempt theoretical sampling, for example, prior to amendment one all parent-carers were mothers therefore part of the amendment aimed to increase recruitment of male parent-carers. In the case of amendment two, no female CYP had participated at that time and so the amendment allowed targeted recruitment of female CYP, to explore the limits of the developing theory and findings.

3.4.9.1 Amendment one

Table 3 summarises the approved amendment and the reasons for it.

Amendment requested & approved	**Reason**
Send reminder texts to parent-carers for up-coming interview appointments and	Parents were forgetting appointments

send a second invitation to interview for those who did not attend the first appointment	
Snowball sampling – ask each parent participant to ask their co-parent/carer if they would consider participation	No fathers participated and some CYP spent significant periods of time in two family households where they may have different exposures
Allow the PhD researcher to request the clinical team to confirm CYP participants' allergic sensitisation status according to hospital records (with parent-carer or 16-year-olds permission).	Participants who had self-identified were not always certain of all sensitisations. This allowed for adherence to the eligibility criteria.

Table 3: Amendment one details

3.4.9.2 Amendment two

Amendment two details are summarised in Table 4.

Amendment requested & approved	**Reason**
Widening of recruitment to include any family in the UK who fitted the original clinical eligibility criteria by use of additional advertising and further snowballing (in addition to ongoing sampling and recruitment in Leeds)	At this time no female CYP had participated, and theoretical saturation had not been achieved. Widening the target group aimed to increase participation
New sampling methods & design changes included: • Social media advertising calls for participants with permission for onward sharing using professional networks such as Asthma + Lung UK respiratory voices network (also via newsletters), and Asthma UK Centre for Applied Research • An amended self-eligibility survey (available upon reasonable request) was produced and wording for social media posts and email wording were submitted for approval (Appendix 7) • Removal of the upper limit of participant numbers to maximise the chance of female CYP participation. This was replaced with a time limit of 6 weeks.	

Table 4: Amendment two details

Figure 2 illustrates the timeline for the study, amendment requests, and how these fed into the process of generating GT through theoretical sampling and iterative analyses.

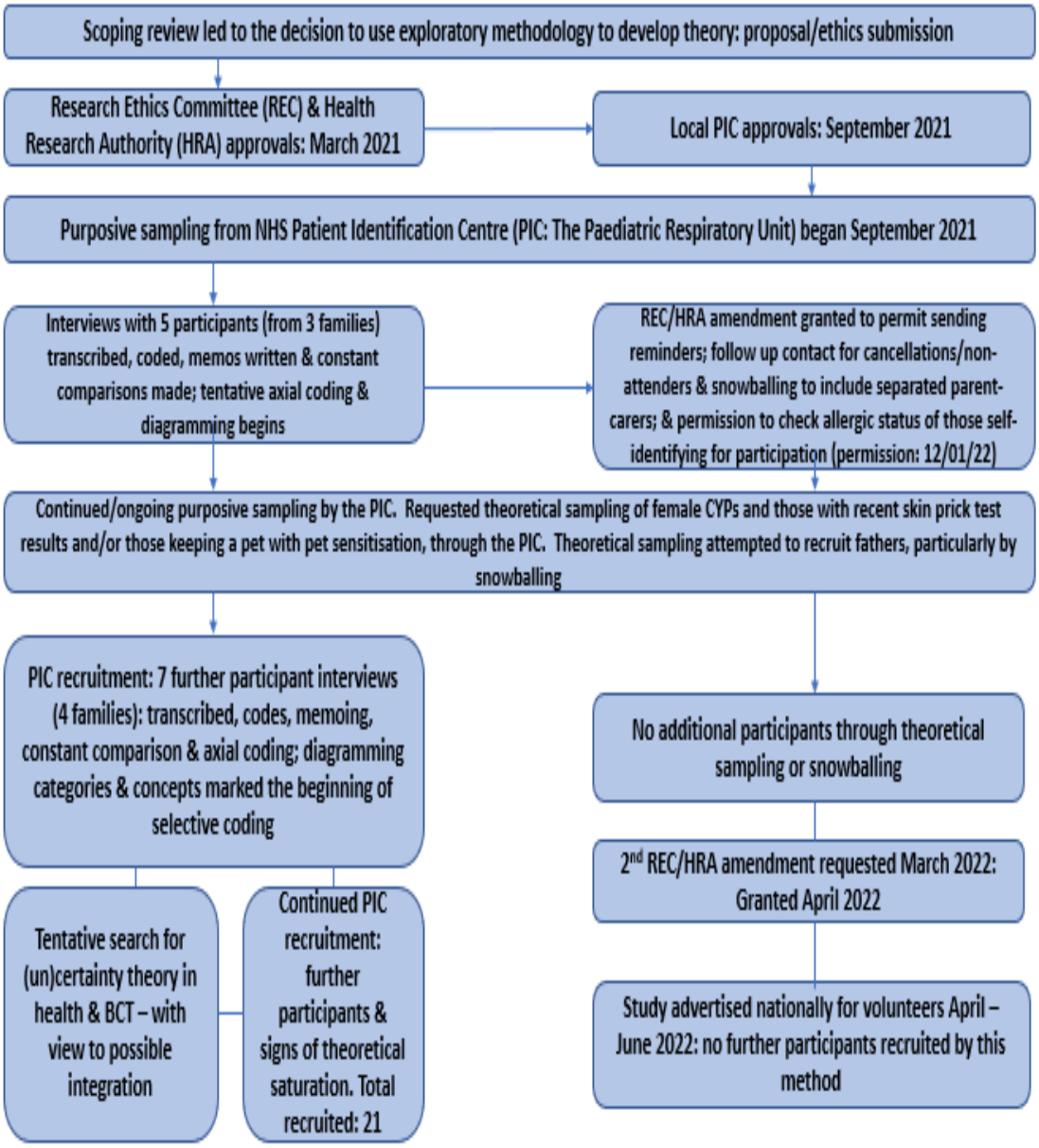

Figure 2: The evolving study design

3.4.10 Interviews

Qualitative interviews use conversation between the researcher and participants to understand the phenomena of interest. Semi-structured or unstructured interviews allow conversations to develop and include unanticipated areas (Brinkmann and Kvale, 2018). Semi-structured interviews were selected to ensure some coverage of similar topics with all participants. Although, these were treated flexibly and as GT methodology suggests, each interview informed changes to subsequent interviews plans (Birks and Mills, 2015).

GT interviews are often unstructured or loosely structured, starting by explaining the broad topic which the researcher is inquiring into and asking a very open question (Morse, 2007; Corbin and Strauss, 2008). A broad interview topic guide (Appendix 8) was discussed with PPI volunteers and was used for this study because, these (and prompts) may be necessary where participants are unsure where or how to begin to answer very open questions. Once participants become confident to speak without additional prompts, the researcher can return to active listening and observation (Corbin and Strauss, 2008). Corbin and Strauss (2008) also note the literature can provide cues for pertinent questions prior to interview. Here, lesser explored research areas identified by the scoping review were invaluable in focussing initial topic guides, alongside the research question and objectives. Other options, such as focus groups, were also considered. Focus groups may have been useful to encourage sharing opinions and experiences through discussion. As such, these are most useful where an existing group can be accessed (Asbury, 1995); unfortunately, there were no suitable local asthma support groups. Focus groups can also marginalise quieter individuals and must be carefully managed to ensure all participants can engage meaningfully (Asbury, 1995). Due to these issues and to avoid participants' potential concerns about discussing exposures in the home, interviews were chosen to allow in-depth exploration of participant experiences (Kvale, 2007).

Interviews allowed for open ended questions to elicit participant accounts and explanations, but also flexibility to clarify unclear points and ask participants to expand on explanations, where appropriate (Brinkmann and Kvale, 2018). Interviews with CYP and parent-carers were offered separately or together. Whilst CYP were invited to undertake an optional creative addition to help them feel prepared for the interview, (outlined in section 3.4.11), the basic topic guides for both groups were similar (initially), reflecting the researcher position, that CYP can make as valuable and credible contributions to research as adults, particularly regarding their own experience and beliefs. However, just as with adult interviews, individual participant openness, ability to articulate experiences, and willingness to share experiences for research purposes can differ (Kvale, 2007). Consideration of the wording of questions was made per individual, based upon initial early conversation and apparent comfort with questions. In qualitative research, open questions are often regarded as best practice in both eliciting accounts in participants own words and being less likely to

skew responses due to the phrasing of the question. However, closed questions are also useful, particularly If respondents find an open question challenging. This can apply to some adults, but has been noted particularly for CYP, who may need initial reassurance that they have useful responses to offer and may be able to do so more easily with initial closed questions to help start the conversation and subsequently to verify meanings with participants (O'Reilly and Dogra, 2017).

3.4.11 Optional creative interview prompts for CYP

Creative methods are increasingly utilised in research with CYP. Many options are available, as either an adjunct to traditional data generation methods or in some cases, as part of a fully participatory approach (Tisdall *et al*., 2009). For the current study, a creative option was given to CYP to potentially empower them to feel more prepared for interview, and to help engagement with the topic (Poku, *et al*., 2019). CYP were advised they could write a list of triggers, or draw picture(s), and/or take photographs of things that trigger their asthma at home. Whilst these were not considered as materials to analyse alone, they were considered an important option for CYP who may be concerned about feeling unprepared for interview or forgetting what they wanted to say. The CYP study information sheet emphasised this was an optional exercise for these reasons and that it remained important to speak to CYP who did not know what triggered their asthma or were unsure. The inclusion of this option was considered, as balancing the use of creative methods against researcher position (Punch, 2002), that CYP can legitimately offer data as useful as adults, against providing this different means of data prompt for CYP. The potential that creative methods may leave some CYP feeling patronised (O'Reilly and Dogra, 2017) was considered, and discussed with a young persons' PPI group (aged 9-17 years), who felt this optional inclusion was appropriate. The ethical issues surrounding creative methods are discussed in section 3.5.1.2.

3.4.12 Modes of interview

Remote interviews by teleconference or telephone were offered to all participants (individually or as a dyad). This decision was taken due to COVID-19 restrictions to protect the health of participants and the researcher and to reduce the need to travel for interviews. This allowed flexibility over the timing of interviews and options for

CYP and their parent-carers to be interviewed together or separately. Qualitative researchers have reported successful interviews online (Deakin and Wakefield, 2014; Archibald *et al.*, 2019). Telephone options were deemed appropriate for inclusivity of those without internet access and to minimise participant costs. Carr and Worth (2001, pp512), defined telephone interviews as a "*strategy for obtaining data which allows interpersonal communication without face-to-face meeting*."

The potential challenges of being unable or having a limited view to read body language and potential technical issues, and reduced or loss of visual context, means there are often differences to in-person interviews (Novick, 2008). However, it is arguable that some may prefer the relative separation and may find it easier to speak freely (Weller, 2017). There is also less control of the environment by the researcher. Where a researcher would plan for a private, quiet interview space, participants can be advised in advance, but the researcher cannot control this.

The potential feeling of greater anonymity is likely further increased with telephone interviews, and may reduce anxieties about participation (Sturges and Hanrahan, 2004). Although particularly sensitive topics were not anticipated in the current study, a greater degree of anonymity and removal of the perception of being watched and some formality being introduced by seeing research aids, such as Dictaphones (or the "*pressure of presence*": Weller, 2017, pp618), during interview may also minimise any discomfort. Qualitative studies comparing face to face and telephone interviews, have reported no clear differences in the amount of data generated (length of responses) or quality in terms of *"depth and nature".* Furthermore, some participants selected telephone interviews over in-person for greater privacy (Sturges and Hanrahan, 2004, pp112). Despite concerns about potential loss of rapport, developing trust and openness during online or telephone interviews is possible (including CYP), with some feeling more comfortable with open, honest conversation in an online setting (Weller, 2017).

Historically, telephones were used more frequently in quantitative research. A review of telephone interview use in qualitative research noted most methodological literature discussing telephone interviews, appears to hold it in lower esteem. In studies that used telephone interviews, authors often commented on their being surprisingly rich and able to generate data in line with in-person interviews, which

many had not expected. These issues led the reviewer to suggest there was a bias tending to steer researchers toward in-person interviews (Novick, 2008). However, some concerns remain, particularly around context, potential degradation of the audio quality (and therefore voice recording for transcription). Whilst privacy has been noted as increased by telephone interviewing (Sturges and Hanrahan, 2004), safeguarding issues may be more difficult to discern, particularly with CYP, when a researcher is unable to see their context, as even with online interviews, views are often restricted (Weller, 2017). However, had interviews taken place in a hospital setting (as planned as an option pre-COVID-19), the same may be true as participants would be seen only in the hospital setting, generally an unnatural context for them, and one that may have produced greater power imbalance. Whilst loss of visual cues is noted for researchers during remote interviews (Sturges and Hanrahan, 2004), the participants' potential loss of cues from researchers (nods, smiles, etc) appear un-noted. Verbal cues (and non-verbal when teleconferencing), to demonstrate researcher engagement were used as appropriate.

3.4.13 Demographic data

Qualitative research concerns groups of individuals that are expected have relevant experience of the phenomena of interest (Mays and Pope, 1995). Collection of demographic details provided context for qualitative findings and allowed consideration of transferability (Morrow, 2005). Participants were asked to disclose postcodes (if willing) during interview, and outline household composition. Adults were asked about their current profession. At transcription, postcodes were exchanged for a measure of multiple index of social deprivation, using UK government measures (Ministry of Housing, Communities & Local Government, 2019).

3.4.14 Context

Qualitative researchers acknowledge the importance of context; context influences respondents and reporting context facilitates rich findings (Barbour, 2000; Morrow, 2005). Contextual consideration provides readers with tools to assess researcher rigour; including transferability but also, dependability, via an audit trail acknowledging the role of participant (and researcher) context, such that if similar participants in a similar context were studied using the same methods and methodology, similar

findings would be anticipated (Morrow, 2005). Fieldnotes also aided contextual analyses (Phillippi and Lauderdale, 2018).

3.4.14.1 Fieldnotes

Fieldnotes allow researchers to create written records of observations to supplement interview transcripts and memos (Holloway and Galvin, 2017). Recording fieldnotes was minimised during interviews and elaborated on immediately after interviews. This allowed active listening during interviews. Most discussion of fieldnotes in GT methodology pertains to observational fieldwork. However, fieldnotes, alongside memos and transcriptions form part of data analyses, and fieldnotes include contextual details such as interview setting, and were cross-referenced to (or amalgamated into) memos and transcripts (Holloway and Galvin, 2017).

3.4.15 Building trust and openness

The development of an environment and researcher-participant interaction that promotes trust, openness and natural interaction is often defined as rapport in qualitative research (Weller, 2017). In GT, consideration of rapport is related to how the researcher is viewed methodologically. Glaser's (and Strauss' earlier) objectivist beliefs meant rapport was not always regarded as necessary (Glaser and Strauss, 1967; Birks and Mills, 2015), and perhaps reflected that observation dominated their early methods. Strauss and Corbin (1994) acknowledged updated positions, that researchers and participants interact, and where methods are intensive (such as interviews), researchers likely shape data to some degree. Building openness and trust can equalise power in interviews (Birks and Mills, 2015). For parent-carers this was established through initial phone calls to discuss the research and plan for interviews. For CYP, the interview was frequently the first point of contact with the interviewer/researcher. Where participants opted for online interviews, rapport was built by informal conversation, sometimes drawing on previous conversations with parent-carers, who often mentioned working around timetabling of hobbies or after school activities, which gave a starting point for conversation. Where this occurred less naturally, basic ice-breaking techniques were used, such as asking children to hold up their favourite object in the room to camera (if online/or describe this if on the telephone) and talk a little about it. The researcher also did the same first, as an example and to make participants feel comfortable.

3.5 Ethical considerations

Ethical approvals were granted by Southwest, Cornwall, and Plymouth REC and the HRA (IRAS no. 292697. REC:21/SW/0034: Appendix 9). Ethical considerations were central to planning the study, particularly due to the inclusion of CYP, who are considered a vulnerable research group (O'Reilly and Dogra, 2019). CYP may be more vulnerable to coercion due to perceived power dynamics with gatekeepers and researchers. However, it is arguable that for older children and teenagers, this view is outdated, somewhat overprotective, and gives CYP little credit for abilities to appraise potential costs and benefits of participation (O'Reilly and Dogra, 2019). Conversely, viewing CYP's competence as simply age-based has also been critiqued, since not all CYP at one age are universally competent to understand information given and make an informed choice (Mack, *et al*., 2009). These complex debates were considered alongside the declaration of Helsinki, updated by the World Medical Association (WMA, 2018), which sets out the central components for ethical practice at all stages of human research; minimising risks of harm and balancing potential benefits and harms; maintaining participant rights and management of safeguarding issues.

3.5.1 Maintaining participants' rights

Provision of appropriate information to enable informed consent and assent (forms available in Appendix 10) was checked using an online age readability tool (WebFX) and guided by two PPI groups, as described in 3.4.1. A minimum period of 24 hours between information provision and first contact was given and potential participants were encouraged to discuss decisions within the family.

3.5.1.1 Consent and assent

3.5.1.1.1 The study consent process

Consent and/or assent were either taken during the advance discussion and setting of the interview date (either by participants sending signed forms via email or audio recording consent/assent, with permission), or at the beginning of the interview, as a separate audio-recording. Audio recordings were transcribed to document this. Ongoing assessment of consent/assent was made by regularly checking with participants during interviews and reminding of withdrawal rights (discussed further in section 3.5.1.1.3).

3.5.1.1.2 Consent and assent considerations

The HRA (2022) define consent as *"a legally defined decision given by someone who is competent, who has been adequately informed (and has adequate understanding), and who is free from undue influence enabling them to make a voluntary decision."* Assent is generally defined as "*active agreement*" in older CYP. The decision to request assent from those under 16 years old and consent from those 16 years old and parent-carers was considered. Debates over whether CYP can and should provide informed consent before 16 years (the legal requirement for competence; Brady and Graham, 2019) are complex. For this study, whilst CYP are considered valuable contributors to research and capable of explaining their experiences and beliefs, this had to be measured against the challenges of a researcher being able to assess this in a timely manner when interviews were remote. Where it may be possible to assess cognitive ability when a researcher and potential participants had previously met in person, allowing decisions about young people's ability to consent by discussion with them and their parent-carer, this would have added to already potentially lengthy remote processes (already elongated where participants selected to provide consent/assent verbally). Due to this, assent was taken for those 15 years and under, and informed consent was planned for those aged 16 years and parent-carers participating. Although this may appear paradoxical to the researcher perspective of CYP (3.3.3.1), it was deemed pragmatic to pursue this option and avoid additional complex assessments of CYP's ability to self-consent. However, assent must also be carefully considered, since power dynamics may mean CYP feel unable to decline if parents provide consent (Brady and Graham, 2019). If CYP did not wish to participate parents were advised that they should not participate. Verbal and written information made clear that parent-carers or CYP could participate in the study irrespective of whether the other participated. Provision of choice and respect for participation decisions was important, particularly as CYP may not consider that any apparently negative findings may impact how the group under study is perceived (Brady and Graham, 2019), and as such, it may become difficult to argue that they successfully provided *informed* consent.

3.5.1.1.3 Withdrawal

All participants were advised and reminded of their right to refuse to answer specific questions or to withdraw from interview or the study. For online interviews

participants could use thumbs up/down emojis to note discomfort with a question without having to verbalise this. Visual and non-verbal cues were observed online, and longer pauses were discussed with participants having telephone interviews, as these may indicate discomfort or uncertainty about a question, and triggered checks for ongoing consent/assent.

Participants were advised that due to the nature of GT, a limit on withdrawal of data had to be applied. As GT analysis begins immediately at data collection (Corbin and Strauss, 1990), and such analysis affects further interviews and sampling decisions, participants were asked to notify the researcher if they wished to withdraw, within one week of the interview. This balanced allowance of time for participants to change their minds with the practicalities of ongoing analysis. This was discussed with PPI groups and approved by the REC. This also allowed full anonymisation of the data one-week post-interview. Whilst transcripts, fieldnotes, and any individual memos could have been removed post one-week, the effect of early analysis on analyses in entirety could not have been removed at later stages.

3.5.1.2 Anonymisation & Confidentiality

Identifiable demographic details (postcodes) were replaced by a measure of the index of social deprivation during transcription.

Ages and a letter code were assigned to protect anonymity. Use of pseudonyms was considered. However, only two female CYP of different ages participated, therefore identifying them as female would limit anonymity. Additionally, pseudonyms would not have reflected the ethnic diversity of the group and selecting names that did reflect this would potentially reduce anonymity (Heaton, 2022). Whilst some researchers allow participants to select their own pseudonym (Gallagher, 2009), this option was not given, since it risks selection of names of actual participants in the sample. Storage of all participant information followed HRA and general data protection regulation (GDPR) guidance, current data protection laws, and University instruction.

The option of creative preparatory methods for CYP included provisos of requesting parent/carer permission to take photographs in homes and avoidance of inclusion of faces in photographs, to preserve anonymity (Miller, 2015). Participants who sent

copies of drawings for potential use in reports/presentations, were asked to provide consent/assent for their use for descriptive purposes and as examples in the thesis or publications (rather than being considered as research data, which can necessitate consideration of copyrights: Miller, 2015).

3.5.1.3 Avoidance of distress

Unanticipated distress can occur in research with participants of any age. This issue has been a focus of researchers working with CYP participants, and Brady and Graham's (2019) following suggestions to reduce the likelihood of distress were followed:

- Anticipate and avoid expected distressing topics where these are not necessary (by judging potential harm versus benefit of their inclusion)
- Plan how to manage unanticipated distress (addressed by additional training in managing challenging interviews)
- Monitor for early signs of discomfort with a topic (as mentioned, longer pauses or observable changes in body language were triggers for the researcher to re-check how participants felt about a question).

Additionally, maintaining sensitivity and a gentle approach to questioning, that allows preservation of dignity and respect (BPS, 2020) was followed. An example of how this was done is explained in the appended memo (Appendix 11), in which further probing was avoided as it was considered ethically questionable during a dyadic interview.

3.5.1.4 Safeguarding

The study was deemed to be low risk to participants. However, if participants sought medical advice, they were asked to contact the respiratory unit they were recruited from. Sensitive issues were not anticipated, but due to the open interview questions, unanticipated disclosures were possible. Safeguarding concerns must be balanced with agreed confidentiality. Participants were advised via study information (Appendix 6) that any concerns raised that constituted a safeguarding risk would necessitate use of NHS safeguarding policy which provided guidance. Given that this may be challenging for younger participants to understand, it was reiterated that information should be read together with parent-carers.

3.5.1.5 Ethics during the COVID-19 pandemic

Particular attention was paid to ensuring ethical rigour throughout, including ensuring technological tools adhered to University and NHS/HRA and GDPR specifications.

Research should be conducted respectfully, maintaining participant autonomy and dignity. This was particularly important during the pandemic, since additional stresses and anxieties were likely for many (BPS, 2020), and were considered by gatekeepers and the researcher.

3.5.1.6 Thank-you payments

Participants were offered a £5 voucher for participation. This amount reflected balance between non-coercion and acknowledgment that online interviews necessitated broadband use and thanking participants for their time was deemed ethically responsible (Braun and Clarke, 2013).

3.6 Methods of analysis

GT analysis is an iterative and non-linear process, beginning as soon as possible after data generation. However, initial analysis begins with transcription (Morrow, 2005), repeated listening, transcript reading and coding, progressing to categorising, and theorising, whilst constantly comparing throughout the process (Strauss and Corbin, 1998). This is presented in corresponding sub-sections for ease, despite non-linearity in practice.

As discussed, memoing (section 3.4.2) forms a central part of iterative analyses. This was discussed earlier in the chapter, as whilst some believe it begins with data collection (Glaser and Horton, 2004), others note importance of memoing from project conception, to provide records of design decisions and allow reflection on preconceptions (Strauss and Corbin, 1998; Birks and Mills, 2015); this suited the researcher, and project, and allowed attendance to reflexivity (self-reflection, to avoid preconceptions unduly skewing data generation or analyses), which is pertinent to trustworthiness and integrity (Finlay, 2002). Memos were filed with transcripts and lists of codes and regularly re-read during constant comparative analyses. Returning to memos was helpful in reminding of the nuances of each interview and reflections upon these.

3.6.1 Transcription

All interviews were transcribed and anonymised by the researcher. This allowed immersion in the data through repeated listening and cross-checking the audio-recording and transcript (Morrow, 2005). However, Strauss (1987) suggested only transcribing what was necessary. Corbin and Strauss (2008) indicated a changed position, as professional and student transcription are discussed as if expected. For new researchers, immersion in the data by re-reading of transcripts is useful. Charmaz (2014, pp136; cites Fine, 1993), reminds that coding requires accurate, reliable data, and studies have shown that experienced ethnographers neglect detail if not noted or recorded for them to return to. Transparent explanation of transition of raw data to final datasets demonstrates rigour (Tracy, 2010). The portrayal of participants may depend upon how transcription is conducted, including whether phrasing and punctuation are corrected. Verbatim transcription may reduce researcher influence (Gill *et al.,* 2008), and accurately represent participants (including pauses and grammatical errors of speech) and thus is often deemed more ethical (Hewitt, 2007). However, presentation of CYP language and interaction with interviewers required consideration, since some argue adults' contributions are often favoured (O'Reilly and Dogra, 2017; and Davidson, 2009, cites Ochs, 1979), and simplified, or unpolished participant quotes, may affect reader perceptions of the value participant contributions.

3.6.2 Open coding

Corbin and Strauss (2008, pp.159) describe open coding as a relatively quick process of "*brainstorming*" to explore all lines of early inquiry. Concepts are seen as foundations for theory and conceptual boundaries can be identified and categorised (Strauss and Corbin, 1998). Following re-reading of transcripts repeatedly for immersion and familiarity, open coding involved reading and considering the data and applying labels to denote concepts. This was done by coding both word by word and line by line, as appropriate (Urquhart, 2017). Open coding was iterative throughout analyses (Wilson Scott, 2004) and was conducted using a combination of making comments in a word document (on copies of transcripts) and by pen and paper.

3.6.3 Axial coding & categorisation

Categories allow grouping of concepts with similarities. Corbin and Strauss (1998), describe the properties of categories, as those depicting the meaning of the codes included. Axial coding allows for categorisation by organising related concepts into categories that aid identification of boundaries of the concepts within a category. Categories may be inter-linked by sub-categories. During axial coding, grounded theorists ask of the data; "*who, when, why, how and with what consequences… to relate structure with processes*" (Strauss and Corbin, 1998, pp127). Concepts that become categorised are viewed as abstractions by Strauss and Corbin (1998), and concepts can only achieve categorisation if they are seen in many participants' accounts. The importance of presenting inter-linked concepts when seeking to develop theory, and not a list of themes is also noted. Attention to structure (context of a phenomena under study) and process (actions and routines involved in the phenomena under study) and how the two may be intertwined in analysis and in the phenomena under study is emphasised; researchers ask questions such as, *does the process change if the context changes?* (Strauss and Corbin, 1998). Analytic attention to process and structure is also ongoing, but often beginning at axial coding. Axial coding was also conducted in Word, using the 'comments' function and by pen and paper. Lists of open codes were grouped using colour coding in Word and later using post-it notes to aid diagramming. This assisted constant comparison as axial codes (which became preliminary categories) could be easily identified by the researcher and allowed exploration into whether these might apply to other participant transcripts.

Strauss and Corbin (1998) suggested the use of diagramming during axial coding, using a conditional relationship guide or an axial coding paradigm to guide analytic questioning. Diagramming (e.g., axial coding paradigms) or tabulating (often used for conditional matrices) can aid analyses by enabling the researcher to explore potential causal (e.g., what must be happening/true for the phenomenon to occur?) and intervening conditions: these are conditions or events that affect the causal conditions, which both link to consequences (Strauss and Corbin, 1998). Additionally, a reflective coding matrix can be used to aid movement to the next phase, selective coding (Scott and Howell, 2008). An example analytic diagram is shown later (Figure 8) with the theoretical model (Figure 7).

Selective codes provide explanations which integrate and refine the theory (Strauss and Corbin, 1998). These are also demonstrated using interview transcript excerpts alongside the qualitative findings in Chapter 4.

3.6.4 Selective coding: building theory

Selective coding allows for integration and refinement of developing theory (Strauss and Corbin, 1998). During this, grounded theorists "*develop the story line and interpret the emerging theory*" (Scott and Howell, 2008, pp12). Strauss and Corbin (1998) describe integration during selective coding as the process of data becoming theory. Similarly, Birks and Mills (2016, pp.181) describe integration as *"the pulling together of the abstract theoretical scheme into a final GT."* In keeping with non-linearity of analysis, integration continues through to writing up of theory, but several tools were used to aid theoretical integration:

1. Identifying a central or core category: A central category brings together ideas from several categories to provide cohesive explanation. Strauss (1987), listed criteria for a core category (see 3.6.5)
2. Descriptive writing of the story so far, aided integration and these became the foundation for writing the findings chapter. This included re-visiting memos alongside descriptive writing
3. Diagramming
4. Reviewing memos (Strauss and Corbin, 1998).

Refinement during selective coding includes reviewing for inconsistencies or less well-developed categories. Theoretical sensitivity (which is essential during later coding and developing theory), is the knowledge the researcher has on the phenomena, relevant personal experience, and brings researcher awareness that prompts constant comparison and theoretical sampling to maximise the density of theoretical concepts. Moreover, during analysis, the researcher becomes more theoretically sensitised, once again necessitating constant comparison and iterative analysis, with the aid of tools to enhance rigour to guard against unduly influencing theory (Corbin and Strauss ,1990; Strauss and Corbin, 1994).

3.6.4.1.1 Theoretical saturation

Theoretical saturation (defined in 3.4.6) is key to determining the end of coding and categorising (Dey, 1999). Although guidance on theory development is unclear in methodological texts (Wu and Beaunae, 2014), once the core category has convincing explanatory value, and other categories are connected, theory can be further clarified as noted by 1-4 above. Finally, all analytic elements are gathered to form explanatory theory (Strauss and Corbin, 1998). However, the concept of saturation is often critiqued, since it remains difficult to define and demonstrate and researchers may confuse a homogenous sample or data set with saturation (Morse and Clark, 2019). In practice (shown in Figure 2), saturation was suggested after data from nine families were analysed, where re-examination of the data using GT techniques was not suggestive of new ideas. However, to be as certain as possible, three further families were interviewed, and care was taken to reflexively examine whether additional concepts may have been missed, by using constant comparison across additional and previous datasets.

Constant comparison involves basic comparisons of incidents, similarities, and differences throughout analyses. During axial and selective coding, constant comparison at a theoretical level begins (Strauss and Corbin, 1990; 1998). Comparing concepts within categories and across categories (Baszanger, 1997: cited by Bryant, 2009), allows theoretical development through repeatedly comparing data sets (Timonen, *et al*., 2018), and leads to decisions regarding theoretical sampling (Strauss and Corbin, 1998). Making comparisons across the data aids rigour by forcing researchers to check for incidents or differences across the data and account for each, thus reducing subjectivity and providing *"specificity"* to categories (Corbin and Strauss, 1990; pp12). Constant comparison directs theoretical sampling (Birks and Mills, 2015).

Concepts gain status and should only be included in theory if they are repeated in interviews (Corbin and Strauss, 1990). Strauss and Corbin (1998, pp94-95), suggest techniques to aid theoretical comparisons and analysis (or comparison of abstract concepts):

1. *'The Flip Flop technique*': This involves examining concepts from multiple perspectives (exemplified in 4.11.5).

This involves '*systematic comparison of two or more phenomena'*: Incidents in the data can be compared to existing literature. Strauss and Corbin (1998) suggest that

this is useful to increase sensitivity to the data; for example, prior to data collection, the researcher may not have known what to search for in the existing evidence base.

2. *"Waving the red flag:*" Strauss and Corbin (1998) describe the importance of acknowledging researcher preconceptions and potential influences these may have on each stage in analyses. In doing so, and in acknowledging that preconceptions are not always damaging or obstructive to research, Strauss and Corbin (1998) show traits of interpretivism and recognise there is a balance between inability to remove preconceptions fully, and researcher position or assumptions over-encroaching into analyses and perhaps over-shadowing participants. To balance some level of objectivity, Strauss and Corbin (1998, pp98) advise that certain participant words may flag that greater analytical questioning is needed to understand processes and phenomena; for example, "*never, always, or sometimes*" should not be taken at face-value, they should lead to more questioning, on participants' meaning. These words were considered when interviewing and participants were asked to clarify their meaning and memos were used as a space to reflect upon these (for example, box 4: section 4.8.5).

These analytic techniques are consistent with an interpretivist perspective, since interpretivism accepts that meaning is present prior to it being researched, and to understand meaning, analysts must rebuild accounts without misrepresentation (due to undue subjectivity) and use them as a theoretical basis. Moreover, the same is true for pragmatism, if theory can be practically applied (Goldkuhl, 2012), as is suggested in the recommendations in Chapter 6.

3.6.5 Selection and development of the core category

The core category is considered an abstraction in GT; it should be considered sufficiently abstract that it could be extrapolated to a different condition or setting to explain phenomena elsewhere. However, it should also link closely with the findings it was developed from and inter-link with all other categories or sub-categories. Strauss (1987, pp.36) described six criteria for assessing whether a category should be considered core. These are summarised in points 1-6 in Table 5, alongside how these were considered when applying analytic techniques to develop the GT.

6 criteria for determining a core category (Strauss, 1987, pp.36)	***How this was applied***
1. *"Must be central"* and relate to as many other categories as possible	Diagramming aided examination of the inter-relation of categories and sub-categories. Additionally, asking questions of the data, such as 'what must be true for this to happen?' (Strauss and Corbin, 1998)
2. "*Must appear frequently in data"*	Once candidate categories were established, each participant transcript was re-examined for quotations (these were tabulated) exemplifying the category and subcategory, to ensure the categories were frequent and remained grounded in the data
3. Relates easily to other categories	Diagramming with explanatory notes aided this
4. *"a core category in a substantive theory has clear implications for a general theory"*	This is discussed in Chapter 6, where extant theories are compared, and the explanatory power of the theory presented in Chapter 5 is explicated as holding relevance for other behaviours involved in asthma self-management.
5. "*As the details of the core category are worked out analytically, the theory moves forward appreciably"*	
6. "*The core category allows for building in the maximum variation to the analysis"*	

Table 5: Application of Strauss' (1987) criteria for core category development

Strauss and Corbin (1998) and other grounded theorists (Birks and Mills, 2015) recommend continued writing as part of analyses and state theory is continually refined throughout writing. Storylines are also recommended, and this was attempted whilst making decisions about the core category. However, this writing naturally morphed into the findings chapter, rather than being a separate analytic process.

3.6.5.1 Section summary

This section has outlined the interview methods employed to generate qualitative data suitable to analyse and develop substantive GT, using Strauss' (1987) and Strauss and Corbin's (1990; 1994; 1998; 2008) methodological guidance. The next chapter will present the contextual and qualitative findings alongside examples of analyses.

Chapter 4 Findings

4.1 Contextualising the findings

This chapter will first outline recruitment rates, the participant sample, and demographic details. Secondly, the chapter will present the qualitative findings according to their conceptual categories and sub-categories. The core category and its interconnection to all other categories/subcategories will be explained in chapter 5, alongside the full theoretical model and explanation of its development.

4.2 Recruitment

29 families were approached by gatekeepers as described in 3.4.7. Of these, 17 families agreed for the researcher to contact them to discuss the study and participation. Twenty-one individuals agreed to participate (10 CYP, 11 mothers); additionally, three arranged appointments but did not attend; one cancelled interview appointments and was not contactable to re-book or confirm they wished to decline, and so withdrawal was assumed. One further family asked to contact the researcher if they wished to participate. Participants and interview types are summarised in Table 6:

Total no. of participants	**Total no. of parents**	**Total no. of female CYP**	**Total no. of male CYP**	**Total no. of interviews**	**Total no. of single interviews**	**Total no. of dyadic interviews** (1 parent, 1 CYP)	**Total no. of families /participants from different families**
21	*11 (Mothers)*	*2*	*8*	*13*	*5*	*8*	*12*
					Participant ID		
					13a; Mother of 13a; 15a; Mother of 12a; Mother of 13e	*11; 13b; 13c; 15b; 13d; 12b; 15c; 15d (+ mothers)*	

Table 6 Participants and interview types

4.3 The participant sample and demographics

4.3.1 Demographics

The sample includes a total of ten CYP, including eight males and two females. Ages ranged between 11-15 years (mean age 13 years). All parent participants were

mothers. A total of 12 families were represented: in one case only the CYP participated, and in two other cases only mothers participated without their children. White British ethnicity was most frequently reported, (seven CYP and nine mothers). Five participants from three different families identified as (three) other ethnicities, but due to the small numbers, ethnicities are not disclosed to preserve anonymity.

Participants came from the geographical area covered by Leeds Children's Hospital, including Leeds and surrounding areas of Yorkshire. Participants confirmed residential postcodes which were checked against the English indices of multiple deprivation (Ministry of housing, communities, and local government, 2019). Participants predominantly (seven of twelve families: 58%) lived in areas designated as most deprived according to this measure. These ranged from decile one, the most deprived, to eight (10 being the least deprived). This information is included in Table 7 which also summarises pertinent participant details and allergen/trigger remediations undertaken in the home.

Parents were asked about their current employment status and seven described themselves as not working, including two as full-time carers (including one former nurse), one full time University student, one working part time in administration and one as working full time (potentially too identifiable to disclose role). Due to the size of the sample further individual details are not disclosed to protect anonymity. One parent was unable to work due to their own health condition.

The sample can be further described in terms of the CYP's asthma and allergic status. All CYP were sensitised to HDM and either cat or dog dander, or both. All described pollen sensitisation and/or hay fever diagnosis. Within the sample, three CYP also had food allergies that necessitated they carry an adrenaline autoinjector.

There were variations in uptake of allergen and/or trigger avoidance/reduction measures. These are summarised in Table 7, since this provides context for the qualitative findings outlined in subsequent sections. Asthma severity is also presented in the narrative qualitative findings according to participants' perspectives. All CYP participants were under the care of a specialist MDT for their asthma and met the inclusion criteria (Table 2); severe or sub-optimally controlled asthma requiring specialist outpatient hospital care. All participants also confirmed eligibility in

describing their recent attacks; regular reliever inhaler use; and /or symptoms, or severe asthma diagnosis from a respiratory clinician.

Table 7: Table showing CYP participant age, residential multiple deprivation index (MDI) decile, remediations undertaken and ongoing exposures

(-- = removed: ++ = frequently)

CYP age years (& ID)	MDI decile	Allergen sensitisations	Allergies (severe)	Continued exposures at home (pets/ETS)	Air purifier	Avoids Foods	--Soft Furnishing	Carpet removal	HDM plug in	De-humidifier	Anti HDM bedding	Stopped ETS	Extra cleaning	Hot wash (bedding)	Vacuums ++	Freezes soft toys	Handwash	Avoid pets	Treats mould	Temp control	Tumble dries	Ventilates	--Soft toys	100% cotton bedding	No bunkbeds	Pet removed
15a	1	HDM, cats, dogs, pollen	Yes (foods)	No	X	X																				
13a	1	HDM, cats, dogs, pollen	No	Dogs			X	X	X	X	X	X	X		X											
11	8	HDM, cats, dogs, pollen	No	Dogs (father's home)							X		X	X	X											
13b	5	HDM, cats, pollen	No	No			X	X					X		X								X			
13c	1	HDM, cats, dogs, pollen	No	ETS unclear; co-sleeps with dog									X	X	X	X							X			
12a	1	HDM, cats, dogs, pollen	Yes (foods)	No		X							X	X			X									
15b	1	HDM, cats, dogs, pollen	No	No		X		X			X		X				X									
13d	2	HDM, cats, dogs, pollen	No	Cats, dogs										X			X									
12b	1	HDM, cats, dogs, pollen	Yes (foods)	No		X		X partial		X					X			X	X	X	X	X	X	X		
13e	6	HDM, cats, pollen	No	No									X	X	X										X	X
15c	3	HDM, cats, pollen	No	No				X			X	X											X			X
15d	1	HDM, cats, dogs, pollen	No	No							X		X													

4.4 Qualitative interviews: methods & contexts

Interviews were conducted between November 2021 and June 2022, spanning winter, spring, and early summer. This meant that seasonal variation in asthma may have been relevant to participants, although many reflected on how their/child's asthma had been since the school year began in September. This is important as mid-September (frequently known as 'week 38') presents a peak in asthma attacks soon after school terms begin (Henry, 2021). This also led to some families in the study postponing interviews due to illness.

Eight interviews were over the telephone and five were online. Five participants undertook single interviews (two CYP and three mothers) and eight were dyadic (summarised in Table 6). Interviews lasted between 20 minutes (single CYP participant) and one hour, seven minutes (dyad).

4.4.1 CYP optional pre-interview exercise

Only one opted to draw asthma triggers (Figure 5 and Figure 6).

4.5 Use of quotations in these chapters

Quotations are used to exemplify the qualitative findings and demonstrate how the developed theory is grounded in participants' accounts of experiences. During constant comparison, the researcher revisited transcripts to be sure that categories, sub-categories, and later abstracted concepts were evident in participants' words.

Quotations were edited minimally to remove repeated 'erms' for ease of reading. However, (laughs), emphasised words (<u>underlined</u>), or pauses (noted by …) remain for context, and to ensure quotations represent participants' words as closely as possible. Punctuation is also added into quotations (unlike the raw transcript data), to ease reading. Longer pauses are denoted by … with the number of .. showing the length of pause. Due to limited numbers of female CYP (n=2), where quotations mention he/she/her/him, these have been replaced with *** to maximise anonymity.

4.6 Analysis in practice

This subsection briefly introduces a map of conceptual levels in the analyses and guide to subsequent sections which will demonstrate how analyses (as described in Chapter 3) were conducted to achieve the GT that will be presented in Chapter 5 alongside data examples. Urquhart (2013) describes the need to present a chain of evidence. Throughout subsequent sections examples of the non-linear GT processes will be provided (including different coding techniques and memoing). Section 3.4.9 outlined how the GT study evolved to account for theoretical sampling, which also contributes to analyses. Figure 3 (adapted from Birks and Mills, 2015, pp88) summarises the techniques used to develop the GT at their corresponding conceptual levels. The key maps to examples in the chapters.

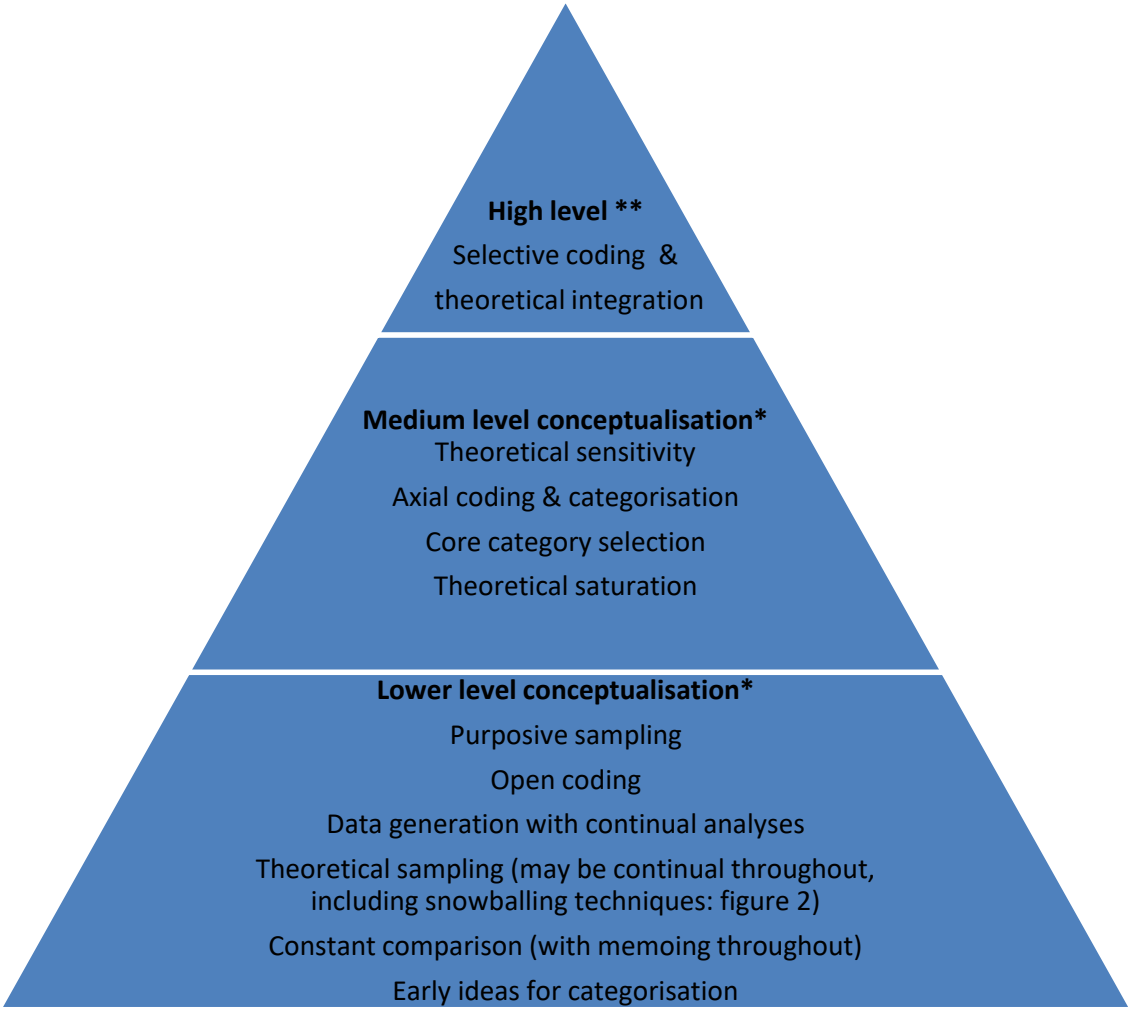

Figure 3: Summary & map of techniques used and corresponding levels of conceptualisation. Key: * exemplified in Table 8-Table 11, memo examples throughout this chapter. ** exemplified in Table 8-Table 11 , memos, and Chapter 6.

4.7 Qualitative findings

This section will present the qualitative findings developed using GT techniques. Findings are presented according to categories and sub-categories to explain what participants believe asthma triggers are and why. Additionally, how this conceptualisation leads to experience-based beliefs about asthma triggers and how these inform remediation uptake will be discussed in later sections.

Later in the chapter, other sub-categories are presented. These show beliefs about asthma triggers contribute to a host of other factors related to the uptake of trigger and allergen remediation. These include two categories, (one core), and further sub-categories, shown in Figure 4. Briefly, the core category, responding to shifting certainties, reflects how families observe and learn through experiences and respond iteratively with self-management decisions. The core category is fully introduced at the end of this chapter (4.16). Further explanation and diagrammatic representation of the theoretical model and its causal and intervening conditions (defined in 3.6.3) are given in Chapter 5.

Figure 4 shows that the core category and second category (seeing is believing, which emphasises that families often need to witness a phenomena to believe and act upon it) are central to explaining beliefs and behaviours. The surrounding sub-categories and interlinked with both categories, each being influential in family decision-making processes, with the core remaining most abstract.

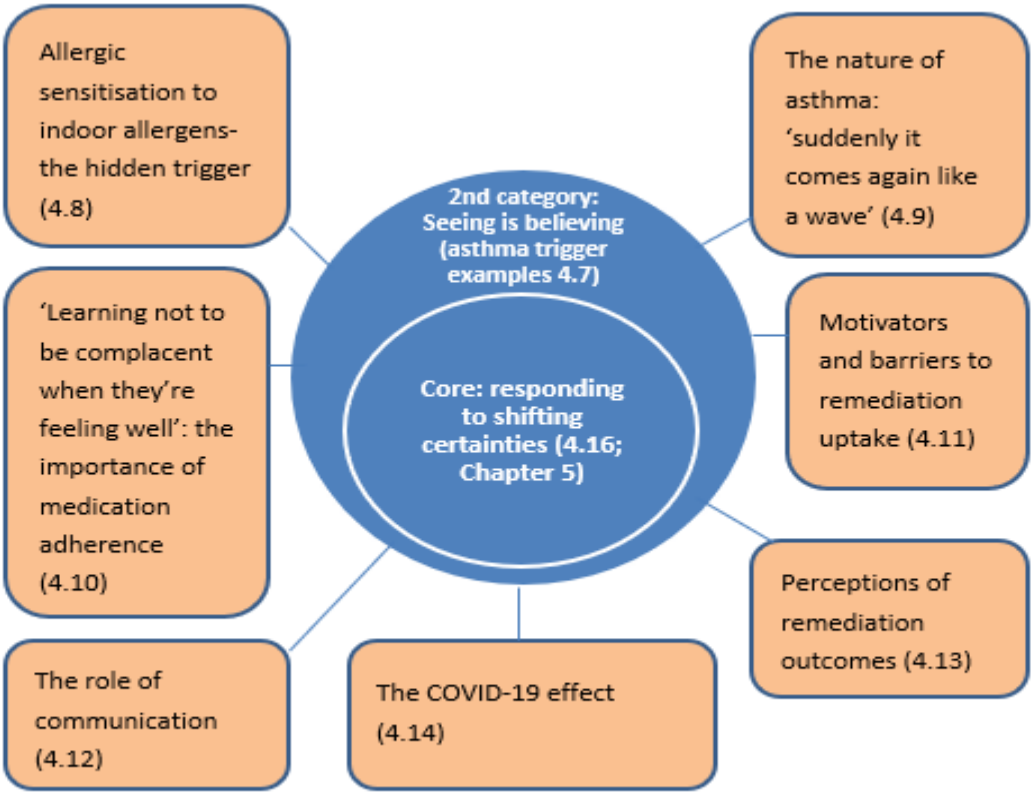

Figure 4: Overview of categories (in blue) & sub-categories (in pink)

Each element of figure 4 is expanded upon in subsequent sub-sections (as signposted in figure 4) by including quotations, code names, coding and memo examples throughout the chapter.

4.7.1 Category 1: Seeing is believing

This category, seeing is believing, recognises the importance of family experiences, beliefs, and judgments about asthma triggers. There were some asthma triggers that CYP and parent-carers were certain of. These were recalled quickly and easily and were supported by experiences that exemplified the route to which participants became certain that these were asthma triggers. To fulfil participants' conceptualisation of an asthma trigger these had to be seen (by parent-carers) and felt or seen by CYP, as having a clear causal link between exposure and symptom onset, either by immediacy of a reaction to an exposure or the absence of other potential triggers or explanations (such as forgetting medication, e.g., preventor inhalers; anti-allergy medications). The category seeing is believing encompasses several axial codes which can be condensed and divided by types of asthma trigger, as shown in

subsequent subsections, but also links to other sub-categories as will be discussed in later sub-sections.

4.7.2 Illness 'triggers it totally'

All participants noted illness, particularly viral illness including common colds, as asthma triggers:

> *"if *** gets a just a general virus, like a chest infection or ought like that, *** asthma does, it triggers it totally, yeah….or like *** actually has had flu in the past and that, yeah, *** were in hospital again" (Mother of 13(a)-year-old)*

Parents were clear that infection was tied to increased asthma symptoms, prolonged periods of being unwell with asthma, increased medication use, and sometimes hospitalisation. The following quotation reflects how a CYP was affected by recurrent illness triggering asthma attacks, prior to being prescribed prophylactic antibiotics:

> *"Normally if somebody had a sniffle (child's name) would get a full-blown chest infection but yeah, …*** was just getting infection after infection, and it was that that was making *** asthma so bad and it was just knocking *** out, ***'d just be bed ridden for like two weeks at a time, *** had no energy, *** couldn't breathe, like going up and down the stairs and it was like as soon as *** went back to school in September until sort of February March time, ***'d just miss so much school. I think *** school was down at 30% or something" (Mother of 13(b)-year-old)*

Across all participants there was certainty in their observation of illness, particularly viral illness as an asthma trigger, and consequent need for additional medications:

> *"you know it's a lot of things like that set it off and honestly if *** catches a virus or whatever's going around it sets *** asthma off…so 9 times out of 10 *** always gets antibiotics or steroids" (Mother of 12(a)-year-old)*

CYPs noted that viruses induced wheeze and difficulty breathing and that these were easily linked to viral infections by repeated experiences and the speed with which they noticed the effect of viral illness on asthma:

> *"I'd say it's quick it's pretty much as soon as I get ill.. I spose like COVID where it made me wheeze" (15(c)-year-old)*

Another 15-year old's mother explained further that a chain of events often preceded worsening asthma control when infected:

> *"when *** comes out in like a cold sore you think 'oh great' but then *** also suffers from croup still .. so sometimes *** can get a cold and then *** gets croup and then it triggers the asthma, so it just depends which way.. *** ends up on steroids, well the last time *** went to school [with croup]*

*they called an ambulance and they put *** on dexamethasone" (Mother of 15(b)-year-old)*

Croup was also mentioned as a viral trigger by another family.

The previous two excerpts from mothers show that the consequence of infectious triggers is often the need for oral steroids and/or antibiotics. Whilst parents recognised the need for these medications, there was a preference to avoid or reduce these, where possible, due to side-effects. The balance of needing medication versus wishing to avoid it is explored in 4.10.2.

Table 8: Example coding/analytic processes

Excerpt from Mother of a 15(b)-year-old	**Open codes**	**Axial codes**	**Processes observed (part of selective coding)**
"*when *** comes out in like a cold sore you think 'oh great' but then *** also suffers from croup still .. so sometimes *** can get a cold and then *** gets croup and then it triggers the asthma, so it just depends which way.. *** ends up on steroids well the last time *** went to school* [with croup] *they called an ambulance and they put *** on dexamethasone"*	Getting a cold sore Knowing/fearing a cold can be bad Suffering from croup still Cold 1st then croup then asthma triggered Varied order to trigger effects Ending up on steroids Went to school with croup School called ambulance Being put on dexamethasone	Infectious triggers are bad Predictable trigger effects Infections mean needing steroids Needing medical help after trigger	Seeing repeated patterns of infections triggering asthma leads to expectation that an infection will lead to worsening asthma and need for medical help, including steroid prescription; the trigger effect is observed, and the repeated consequences confirm that infections are asthma triggers

COVID-19 infection was described as an asthma trigger for some participants. However, as COVID-19 discussions presented several inter-relating axial codes, and as

beliefs and experiences with COVID-19 were intertwined with all other sub-categories and the core category, COVID-19 findings are described separately (4.14).

Triggers that were identified with certainty also included non-environmental factors such as stress or physical exercise. However, they earned certainty as triggers through observation of attributable symptoms after exposure and recurrence, just as the infectious triggers did.

4.7.3 Exercise 'is hard, I get exhausted easily'

Exercise was mentioned by all participants as a trigger and was often the first trigger recalled by participants:

> *"it's a bit hard to do PE because it involves a lot of physical, like you have to run a lot, so I find that a bit hard…I get exhausted very easily and I get out of breath" (12(b)-year-old)*

Some level of exercise was possible for participants, but limitations and planning for medication needs were evident:

> *"I can still do sport but sometimes it affects whether I do long periods of sport, then I need to use my inhaler" (15(a)-year-old)*

All noted use of their reliever inhaler before or during exercise, for example:

> *"So, like if I take like two puffs on my salbutamol before I start, I'll be ok. But like if I don't, I think I would have a minor asthma attack during the activity so like if we're playing oh .. badminton things like that" (15(d)-year-old)*

Others also commented that less exertive exercise was problematic, including walking or climbing stairs, and reflected that this was a sign of deteriorating asthma control:

> *"we've been beginning to think that it feels like it's not under control again, since like ***'s started high school but again that's just walking.. it might be cold in the morning or.. ***'s saying walking around high school's really hard ***'s having to use the inhaler so" (Mother of 11-year-old)*

The 11-year-old (from the same dyad) commented on the combination of changes in temperature and additional walking around a larger school site after moving to secondary school:

> *"I think it's both but mostly when you're walking about" (11-year-old)*

However, as the subsequent sub-category will demonstrate (4.8.1.2) some participants were exposed to pets they were sensitised to at home, which upon interpretation, may be contributing to sub-optimal baseline control. This was not something that families appreciated could be happening and may also be influenced by their acceptance of ongoing symptoms due the episodic nature and perceived severity of asthma and

acceptance of the level of control. Box 1 (below) highlights an example of analytic memoing involved in reaching these interpretations.

These quotations (above), also illustrate the challenges families encounter when attempting to identify and distinguish possible asthma triggers, and how the main trigger is often identified as what is seen or felt immediately before symptoms are noticed. The possible effect of frequent exposures at home (such as pets) were not considered as contributing to underlying asthma control, upon questioning.

Box 1: Analytic note: Memo showing theoretical sensitivity and analytic decisions
Whilst qualitative findings cannot infer causality, it is noteworthy that these (struggling to walk/climb stairs) were also the participants who remained exposed to pets they are sensitised to at home. Participants did not appear to consider a potential link between ongoing symptoms with limited exertion and exposures that were not there are the time. However, it is also possible that these ongoing symptoms are particular to severe asthma, but these ongoing symptoms were also accepted and seemed normalised, particularly when compared to times where asthma symptoms were more frequent or severe (shown in section 4.10.2).

One family noted their observation that prolonged breaks from usual exercise routines (for example during COVID-19 lockdowns where group activities were cancelled), meant a deterioration in asthma. However, while this CYP and mother noticed that exercise triggers asthma, they also noted that asthma control had improved with regular exercise:

> *"the more *** [did the sport] it were as though *** body kind of got used to it and it, it helped actually a lot with *** asthma, did the [sport]. Then obviously when COVID came about, and *** wasn't doing that [sport] exercise *** started to get bad again with exercise" (Mother of 13(a)-year-old)*

The perception that sport held promise as protective and parents encouraged continuation of sporting activity, was also mentioned by one other parent:

> *"Occasionally [uses recue inhaler] because *** swims on a [week-day] night, which we're quite keen for *** to carry on with obviously for the asthma, occasionally *** 'll sort of use it [rescue inhaler] when ****'s swimming depending on what they've been doing" (Mother of 13(c)-year-old)*

Exercise was observed as a trigger by all because the connection between exercise and symptoms was clear to participants and relief was provided by taking breaks and using

rescue medication, providing feedback that exercise had triggered and necessitated active self-management.

4.7.4 Compounding stressors

Three families (all with 15-year-olds with asthma) mentioned stress or anxiety as a trigger but as this was not evident across all participants it was not developed as an axial code. However, stress is included in this findings section as it exemplifies the category 'seeing is believing' and aligns with the theoretical model (Chapter 5).

CYP and mothers described stress and anxiety as a trigger with subsequent observable effects on asthma, which were in turn relieved once the source of stress was alleviated:

> *"The main things for me to notice is the weather and if ***'s worried and stressed about something like for example *** asthma were really bad when I was due to go into the hospital and I was like 'I need to cancel cos I 'can't leave *** at home like this' but I didn't and then literally *** symptoms improved the minute ***'d seen I was fine" (Mother of 15(c)-year-old)*

CYP also mentioned strategies they employed to deal with stress such as self-distraction or strategies discussed with the psychologist in the MDT:

> *"it's like I need to take my time with stuff and not just like go for it straight away .. just like calm myself down and take time" (15(b)-year- old)*

Missing school due to asthma and being worried about the unpredictability of asthma was a particular concern around school examinations. Additionally, having multiple different anxieties can compound the triggering effects:

> *"if other emotions are making it worse .. then it's (asthma symptoms/control) worse" (15(d)-year-old)*

Stress and anxiety were clearly linked to observable effects on asthma symptoms and control by these three dyads, supporting the category 'seeing is believing' and the core category (4.16) that explains that experiences give certainty to base actions upon.

4.7.5 Irritant triggers

Other non-allergic triggers families were certain of included indoor environmental tobacco smoke (ETS), sprays/perfumes, cleaning products (although not all participants noted the latter two), outdoor environmental smoke including ETS and smoke from bonfires were noted and these were avoided. Air temperature, weather, and humidity were also triggering factors. None believed they lived in areas with poor outdoor air quality or were concerned when asked about this. Proximity to fields with outdoor

allergens (pollens) was a concern for one family. One participant noticed a clear deterioration in asthma symptoms upon visits to London and attributed this to poorer air quality.

4.7.5.1 ETS exposure: 'cigarette smoke will trigger it'

ETS was a clear trigger for participants. Although most commented on rarely being exposed, even a short passing outdoor exposure led to immediate symptoms:

> *"Sometimes if someone's smoking and I like walk past them in street and all smoke's like yeah, that can set me off" (15(b)-year-old)*

Others reflected that smoke exposure on holiday overseas where indoor public smoking remains permitted, has noticeable effects on asthma:

> *"The only problem was the smoke wasn't it? They were smoking everywhere inside.. so we had to try and avoid that" (Mother of 13(b)-year-old)*

The 13(b)-year-old from the same dyad noted the symptoms attributed to ETS exposure and the mechanisms involved:

> *"a lot more coughing and a lot more phlegm.. (because) it's just bad for you, there are chemicals" (13(b)-year-old)*

This level of certainty that ETS is a demonstrable trigger had led to one parent and her partner's decision to quit smoking earlier in the child's life, acknowledging that a period where the child had been particularly unwell with asthma had motivated the parents to stop smoking. This further demonstrated that triggers and consequences had to be seen to be believed, to inform remediation action:

> *"we did smoke and it was actually (child's name) asthma that stopped us from smoking.. yeah that were fuff, gosh about 8 years ago now.. I think when *** been, had a bad time and we thought 'it's time to stop'" (Mother of 13(a)-year-old)*

Linkages between categories and sub-categories are important in GT and a short memo abstract in box 2 explains this:

Box 2: Memo extract - interlinkage of categories and sub-categories
The above quotations show that severity of asthma symptoms are also important in nudging parents to act or change behaviour in response to asthma triggers. A further sub-category (The nature of severe asthma 'suddenly it comes again a bit like a wave" section 4.9) discusses the variable nature of asthma and the nature of severe asthma in CYP, which is conceptually linked to decisions to remediate exposures in the home.

Other mother and CYP dyads noted that fathers smoked. However, no fathers were recruited or interviewed, despite attempts at snowball sampling to include them. In these cases, one father smoked outside but the exposure outdoors exacerbated the CYP's asthma:

> *"So, *** dad wouldn't smoke in the house, but he would think it was ok to smoke near *** outside. We had phases where every time *** came back from *** dad's *** was ill, so much so I got the consultant to write a letter for me. I think *** dad thought I was just being over-protective cos he was like 'well we're outside in the fresh air it's not like I smoke right into *** face' but like I definitely noticed a difference with that" (Mother of 15(c)-year-old)*

The young person from this dyadic interview noted the observable difference ETS exposure makes and the improvements once exposures were reduced:

> *"yeah but that did seem to do something like for example if I didn't go out with him and I just stayed in the house, so I wouldn't be out there where he was smoking, I wouldn't come back as like ill or anything.." (15(c)-year-old)*

A coding example for this extract is shown in Table 9.

Table 9: Example coding processes involved for the above excerpt

Excerpt from 15(c)-year-old	**Open codes**	**Example axial codes (synthesizing/integrating open codes to show relationships)**	**Processes observed (part of selective coding- or theorising)**
"yeah but that (ETS exposure) *did seem to do something like for example if I didn't go out with him and I just stayed in the house so I wouldn't be out there where he was smoking I wouldn't come back as like ill or anything.."*	ETS exposure outdoors Exposure does something Staying inside away from ETS meant not being ill afterwards	Outdoor ETS exposure triggers Non-exposure means improved asthma	The CYP noted exposure and outcome correlation and confirmed this by noting non-exposure led to better outcomes: the trigger was seen and felt, and the improvement was observable on removal of exposure

In another dyad, a CYP described their father's smoking but was immediately contradicted by his mother during the interview, who explained that the CYP's father previously smoked but had switched to e-cigarettes, shown in the next extract from a dyadic interview with a mother and 13(c)-year-old:

> *Mother: "going outside [aggravates asthma] in general doesn't it mate? Obviously the pollen or the cold.. smoke does make you wheezy when you're quite close to it"*
>
> *CYP: especially when dad's doing it*
>
> *Mother: (louder) your dad dun' smoke anymore*
>
> *CYP: yes he does, I smell cigarettes on him and some in his pocket as well*
>
> *Mother: (laughs) … what an awful son um but yeah going outside in general, pollen does affect him quite badly especially grass pollen"*

The topic was changed to pollen but a few moments later, the same mother elaborated:

> *Mother: no, no, dad used to [smoke] when you were younger didn't he but then he would always smoke outside but he wouldn't sort of smoke in the house, he never has done uhh but now he's swapped to an e cig hasn't he and that's gradually disappearing anyway"*

When asked about exposure to other's e-cigarette vapour the question was not directly answered by either participant:

> *Mother: "yeah, I mean* (CYP'S name) *really against smoking anyway (CYP's name) hates it don't yer you're always telling us how a how bad for yer smoking is, aren't ya?*
>
> *CYP: yes"*

The contradictory accounts and possible question evasion in this dyadic interview were considered in memos (for example, Appendix 11).

In summary, all participants either described little ETS exposure, except unavoidable exposure outdoors, or described changes in family members smoking due to the CYP's asthma being triggered by ETS. This demonstrates their avoidance was based on beliefs that ETS is a notable asthma trigger with observable consequences.

4.7.6 Cold or humidity: 'I can't breathe'

Participants gave clear accounts that air temperature (in/outdoor), weather, and humidity levels affected asthma.

> *"erm it's like for weather when it gets really cold I start wheezing more and like if it comes like something the symptoms start off with that and then it starts getting like closing my throat and I need to go to hospital and the*

wheeze isn't going away and I can't like breathe and, I think the weather is one of the most triggering things, like especially since just in the UK cos it's unpredictable at times so.." (15(d)-year-old)

Table 10 shows examples of coding stages for the above excerpt:

Table 10: Coding example

Excerpt from 15(d)-year-old's transcript	**Open codes**	**Axial codes**	**Processes observed (part of selective coding)**
'erm it's like for weather when it gets really cold I start wheezing more and like if it comes like something the symptoms start off with that and then it starts getting like closing my throat and I need to go to hospital and the wheeze isn't going away and I can't like breathe and, I think the weather is one of the most triggering things like especially since just in the UK cos it's unpredictable at times so'	Triggering weather Cold (air) triggers Wheezing when cold Wheeze comes first 'Closing my throat' next Needing hospital Persistent wheeze 'I can't breathe' Weather as most triggering thing Unpredictable UK weather	Weather triggers Progressing symptoms after trigger Needing medical help after trigger	Feeling cold air then experiencing progressing symptoms and needing medical help- feeds into the category – the trigger must be seen/felt to be viewed as a trigger and the outcomes of needing help confirm this as a trigger.

Cold air was mentioned as a trigger by all and some mentioned measures to reduce effects on asthma:

Mother of 13(c)-year-old male

*"I think the cold is the most for *** when *** goes outside, ***'s got quite used to now, like I say, covering *** mouth and *** nose with either a scarf*

or a mask, like you were using a scarf round your mouth and nose way before we had masks weren't you?" (Mother of 13(c)-year-old)

In support of this, those who travelled overseas had noticed improvements in hotter, drier climates:

*"we used to always go somewhere hot in the winter, but we haven't for a while have we cos of COVID, but *** used to be amazing when we were, as soon as we got off that plane, ***'d be absolutely fantastic but then it was like when we came back it was like a big shock, so *** be quite ill when we got back cos of the cold" (Mother of 13(b)-year-old)*

Participants reflected on the importance of keeping an ambient temperature at home as heat, cold or transitioning from one extreme to another could trigger asthma symptoms:

"It mostly like triggers off in heat, so like if I go from a hot place and then go somewhere really cold, like it triggers it off and then I'd need to take my inhaler… mostly in like summer and winter" (11-year-old)

Some noted that dehumidification helped, but none connected humidity with increased HDM allergen prevalence, upon being asked about this.

One mother noted how she eventually learned that humidity induced wheeze and so made changes in the home:

*"I used to dry like my clothes on a hanger like around the house, sometimes put up clothes to the heater and I didn't know that was triggering (CYP's name) asthma as well because *** would wheeze very often and I didn't know that was one of the reasons so we changed that and we bought a tumble dryer.. so, I don't dry clothes around the house because it causes humidity" (Mother of 12(b)-year-old)*

The same mother went on to describe purchasing three de-humidifiers, in response to damp in the house, and attempting to balance the indoor temperature:

*"yeah I've got three of them (de-humidifiers) … I have to keep my house in a kind of warm but not hot either because if it's too hot it's not even good for (CYP's name), *** will also struggle to breathe if it's too hot it just needs to be warm enough" (Mother of 12(b)-year-old)*

One other family noted they used dehumidification, but neither connected humidity with increased HDM allergen prevalence. Although humidity and damp/mould are also known triggers, as discussed in 1.3.

4.7.7 Pollen: 'summer's my worst'

All CYP participants were sensitised to at least one type of pollen and experienced noticeable allergic symptoms such as rhinitis, epiphora, and ocular oedema/discomfort on exposures, particularly on occasions where anti-allergy medications were forgotten.

Although few commented on the direct effects of pollen exposure on asthma, some avoided exposure due to generalised symptoms.

Some observed that outdoor allergens had a more perceptible severe effects on asthma and these were totally avoided where possible:

> *"Well, we have a rabbit that lives outside and me daughter has everything to do with it and not us (laughs) I think the saw dust and the hay just is kryptonite to us before we even get near the rabbit" (Mother of 15(b)-year-old)*

Observable symptoms associated with pollens also led to avoidance:

> *"in't summer if *** sits on grass *** comes out in welts" (Mother of 15(b)-year-old)*

Pollen or hay fever was perceived as an asthma trigger in some, and these participants noted outdoor exposures were more easily recognisable as triggers than indoor exposures:

> *"when me and (CYP's name) have just been talking about this, this phone call (interview) we just said .. well there isn't that many things in the home that <u>we</u> think do trigger his asthma.. it all seems to be things outside.. like the weather" (Mother of 11-year-old)*

Identifying pollen as a trigger was often due to its association with the onset of wheeze when exposed. When asked what else a CYP noticed brought on wheeze, this 13-year-old noted pollen and mother agreed:

> *"going outside in general (causes wheeze) doesn't it mate? Obviously, the pollen, or the cold…but yeah going outside in general, pollen does affect *** quite badly, especially grass pollen" (Mother of 13(c)-year-old)*

Knowing this enabled the family to prepare for times when greater exposures were predicted and at 13, the CYP was starting to learn more about pollen and managing exposures:

> *"we sort of had a discussion of how we can try and help (child's name) symptoms without sort of having to cut out seeing us friends and things for *** um I mean pollen you've always known you've got hay fever haven't you from being tiny, and ***'s now sort starting to be able to identify which types of pollen are worse for *** so *** can tell rather than me saying 'no they've cut the grass you're going to be wheezy" (Mother of 13(c)-year-old)*

Only one participant mentioned measures to reduce pollen inhalation in addition to medication or staying indoors:

> *"summer's the worst but like it's all year round really but summer is my worst.. it's just like obviously keeping up with the antihistamine and things, trying like, obviously you can't stop kids like being round grass and trees and things like that, but trying to you know if ***'s been out bring *** home, shower *** like when ***'s out like I put a barrier cream and stuff underneath *** nose you know to stop pollens from getting in .. just*

*making sure like *** cleaning *** hands and wiping the eyes and things like that (Mother of 12(a)-year-old)*

In one parent-interview, a mother described the CYP as showing positive skin prick test reactions to pollen, but minimised visible symptoms and did not believe the CYP had hay-fever, perhaps due to the absence of an effect on the child's asthma:

*"you know when you start in clinic to find bits out it's not nothing where I've ever gone 'oh I think ..this is happening' I mean if *** goes out even in the summer and bits like that *** sometimes gets slightly red eyes that's it… it wouldn't ever seem to get hay fever.. *** might sneeze a couple of times that's it (Mother of 13(e)-year-old)*

However, this participant later described the effect of storms on the CYP's asthma:

*"Oh, I'll tell you what else triggers *** asthma a lot and everyone else thinks I'm absolutely doo lally but (CYP's name) is convinced and *** can feel it. *** can tell you when a storm's coming even if the weather's calm cos *** chest feels really heavy and everyone thinks ***'s absolutely off the scales but every time *** gets it right.. (Mother of 13(e)-year-old)*

On further discussion, the same mother was unaware that heat, humidity, and thunderstorms lead to increased aeroallergen (pollen) prevalence, resulting and increased reports of deteriorating asthma (Nasser and Pulimood, 2009). This was raised by the researcher during the interview, but the participant was not previously aware of the phenomena.

Recurrent observations are made and inform self-management (such as using a reliever inhaler), but the mechanisms of exposures and outcomes are not well understood. This is also shown for indoor allergens, as will be discussed in section 4.8.

4.7.8 Severe allergies: 'controlling one not to hit the other'

CYP with co-existing severe allergy (requiring adrenaline autoinjectors to be carried) noted exposure to this allergen as a high-risk trigger. Three participants had severe food allergies in addition to the allergic sensitisation requirements for inclusion in the study, and one has a parent (also a participant) who has severe asthma and history of anaphylaxis. Having seen prior reactions there was certainty avoidance was necessary and fear of consequences provided motivation.

CYP could list their allergens but often did not elaborate when asked about possible challenges of avoiding food allergens. When asked about avoiding these allergens CYP gave short replies to suggest they were unaware of any issues with avoiding these. However, in one case the CYP's parents did not participate in interviews to enable

greater understanding of whether any challenges had been adapted to by parents or remained. At a conceptual analytic level, there were other instances in participants' accounts that suggested CYP were often either protected from knowing about environmental remediations put in place by parents or were unaware as parents began remediations when their child was far younger; it may be possible that CYP are less aware of the challenges in adapting to food allergies that have been present for CYP since they were very young, particularly in families who avoid eating out due to food allergy concerns.

Other parents discussed challenges, and these were interspersed with fears that led to avoidance of social events or eating out:

> *"the peanut allergy it takes over *** life because *** tries to avoid everything *** tries to avoid eating out …we've only ever had one accident and that were last easter, *** got bought an easter basket and in that basket was um you know nougat….I check everything, (CYP's name) normally says 'Mum check this' we just thought it were chewy sweets ..um just panicking basically we got sent to hospital yeah they just kept *** in for observation and things" (Mother of 12(a) year old)*

Fears and protective procedures were echoed by another dyad with a child with food allergies, who also described gradually re-introducing the child's allergenic food back into her own diet, with great care and planning to avoid cross-contamination:

> *"so I cook the other food first that doesn't include it [the allergen] then I finish with everything before I deal with the [allergen] ..and try to remember what I've touched and try and do a tiny deep clean in the kitchen to be honest.." (Mother of 12(b)-year-old)*

A 12-year-old commented on planning ahead and taking packed lunch to school on days where the canteen serves food containing the allergen:

> *"I mostly eat food at school but if there's* [allergens] *like on Friday, they usually serve [allergen] so on Fridays I usually bring something to eat" (12(b)-year-old)*

The mother in this dyad had an appreciation for the connection between allergen reduction and asthma control. Whilst appreciating her child's food allergy was the most severe of all, the family had also put in several HDM remediations and avoided getting pets or being in contact with others' pets. When talking of her child's poly-allergic status (including sensitisations) she explained her understanding of interlinkages between allergy and asthma:

> *"you know because something might not trigger *** asthma but it kind of affects *** allergies and then from that allergy *** asthma will be*

triggered and then you have to kind of control one not to hit the other in a way" (Mother of 12(b)-year-old)

This concept was echoed in another interview with a mother of a 12-year-old with multiple sensitisations and severe nut allergy. Having described a severe peanut allergy, allergy to animals, pollen and HDM this mother commented:

"so, it's like keeping on top of the allergies as well and making sure there's like no flare ups and stuff" (Mother of 12(b)-year-old)

The concept of controlling allergens to maximise asthma control was not mentioned in families with a child with sensitisation only. It may be hypothesised that this appreciation comes from experiences with other allergens and discussions in allergy clinics (which all three with severe allergies attended) may reinforce these concepts and subsequent strategy uptake. The sub-sample of those with severe allergy in addition to sensitisation to environmental allergens is small, and so these are tentative theorisations. The concept of controlling allergens to minimise risk to asthma control was also noted by parents who had asthma and allergies themselves, suggesting family history and experiences may also be important in understanding allergens and making remediation decisions:

"I'm anaphylactic to bees and peanuts" (Mother of 15(b)-year-old)

Later, the CYP described avoiding nuts due to the mother's allergy:

"I just avoid (nuts) *for my Mum that's all" (15(b)-years-old)*

The same CYP (15(b) years) described their own poly-sensitised status after listing allergens, as being "*allergic to life*".

Further, this family also made multiple remediations and placed restrictions at home but attempted to balance the CYP's social life outside of the house with these measures. Home-based measures had become accepted and normalised, as will be discussed (4.13).

In summary, those with family history and therefore additional experience, and those with CYP with co-existing severe allergies described themselves as cautious regarding trigger and allergen avoidance and employed multiple remediations that they were aware of.

4.8 Allergic sensitisation to indoor allergens: a hidden trigger?

In contrast to triggers that participants were certain of and those with additional severe allergies, participants with only allergic sensitisation did not describe indoor allergens as triggers. Allergic sensitisation was discussed with uncertainty, which was a stark contrast to discussion of irritant triggers or non-environmental triggers, such as exercise. Whilst participants were aware of their allergic sensitisation status, and in some cases, categorised these as mild or severe, across all but one participant, none perceived a link between exposures and symptoms. Therefore, most did not view indoor aeroallergens as triggers in the same way as other irritant triggers. The next sub-section will be sub-divided into findings related to HDM and domestic pet allergen to show this.

4.8.1.1 Is it HDM or dust? Hidden vs observable mechanisms

Participants were aware of their/their child's sensitisation to HDM and listed this when asked about allergies or reactions on skin prick/blood testing results. When asked about their perceptions of HDM as a potential asthma trigger, many reverted to discussing dust as a trigger, as the pattern between exposure and consequent symptoms was observable for dust.

When asked about HDM there was far less certainty and the pro-inflammatory mechanisms underlying how HDM allergen exposure can be problematic for those with sensitisation were not understood, since upon questioning, participants could not describe mechanisms, for example:

> *CYP: "um I'm not sure (looks at Mother) (13(c) years)*
> *Mother: I think the dust definitely irritates it…" (Mother of 13(c)-year-old)*

This was supported in all other interviews (with one exception discussed below), in which participants were more easily able to understand how dust, a visible irritant could trigger asthma, but were unable to understand the mechanisms underlying HDM as an allergic trigger: this was also shown in one CYP's illustration (Figure 5).

Figure 5: CYP pre-interview drawing showing dust as an asthma trigger

These discussions highlight the limited understanding about the role of HDM exposure in asthma control. The exception to this was one mother who participated alone. The child had experienced severe HDM allergy including generalised symptoms such as facial rashes on waking. Having taken multiple remediation methods, symptoms had not improved, and the CYP had subsequently undergone successful immunotherapy:

> *"*** just finished some immunotherapy to try and what's the word for *** to become immune to the allergy that's ***'s got, the dust mite allergy? So that did work wonders, I mean it's not completely gone but it's a lot more manageable now" (Mother of 12(a)-year-old)*

Although this may appear as a negative case, it substantiates the concept that was developed as seeing is believing; due to the severity of HDM allergy in this case, the mother appreciated the connection to asthma outcomes. In contrast, as many participants were unable to appreciate a link between exposures and outcomes, it became apparent it was unlikely they would appreciate the exposure as a potential trigger.

A degree of certainty regarding the role of HDM sensitisation in asthma developed for some who had taken up HDM remediations and believed that these had a positive impact on asthma control. Others remained uncertain as they were unable to observe changes in symptoms or signs after HDM remediation uptake. Yet they maintained the

remediation methods since these had become commonplace and accepted into usual cleaning and home maintenance regimes (as will be explored in 4.13). Participants' own assessment of remediation outcomes appeared to confirm or alter their perceptions through observations about HDM remediations and their role in asthma family management.

4.8.1.2 Pet allergen: 'I don't ever feel a difference'

Pet sensitisation informed decisions to avoid pet acquisition in seven families. Four participants continued to keep pets they were sensitised to in at least one family home they lived in part of the time. A remaining family did not describe any preference for acquiring a family pet. Only one family intentionally re-homed a cat in response to advice. Another family's cat moved with an older sibling, rather than as a planned remediation to remove cat allergen. This parent reported there were no observable effects on asthma either with cat exposure or after subsequent cat removal and moving family home themselves.

Of those (n=4) who kept pets they are sensitised to, all denied seeing a connection between the pet exposure and asthma symptoms or control. In one case, the pet was at the second caregiver's home and the CYP was exposed at weekends.

The beliefs and understanding behind pet-keeping decisions conflict scientific evidence, which for example suggests that completely hypoallergenic dogs do not exist (Portnoy *et al.,* 2012) or that continued exposures minimise risks, as shown in the next quotation:

> *"I didn't think that *** would be allergic to dogs cos we'd had dogs all *** life really…..like I'm allergic to dogs but not my own… I think it means you get used to 'em maybe" (Mother of 13(a)-year-old)*

However, the repeated pattern in the data was that families did not see an observable connection between exposure and worsened asthma outcomes. A further axial code 'acceptable remediations' also reflected that some remediations were deemed unacceptable (such as pet re-homing), where the effect of pet exposures was not visible or felt by CYP. This led to the conceptualisation of allergic sensitisation being a hidden or lesser-known trigger and led the researcher to adapt interview questions (through theoretical sampling) to explore whether the word trigger is relevant to discussions of indoor allergens (this is discussed in section 4.8.5). This was shown by

participants stating that they planned to base their pet-keeping decisions on whether they observe the effect of exposure on asthma. In the following extract, the dyad were asked what they thought they would do if the child's asthma seemed to worsen when at home with pets:

> *"erm I don't know… erm I'm not sure" (13(d)-year-old)*
>
> *"I think it depend like. If we can't see it's making it worse ..then I think we'd just carry on .." (Mother of 13(d)-year-old)*

The context of this was that the CYP reported sub-optimally controlled asthma, with regular attacks that required rescue inhaler use. Moreover, the amount of rescue inhaler used was difficult to determine in the interview. This acceptance of ongoing asthma symptoms (and allergic symptoms described as sneezing, rhinitis, sore eyes) despite preventor medication use appeared to contrast accounts that suggested the family did not link pet exposures to asthma symptoms. Conceptually, triggers were perceived across the dataset as exposures that evoked a relatively fast change in asthma. However, for animals present in the home, such continuous exposure was not viewed as a trigger or as risky to asthma, as symptoms did not appear to fluctuate on exposure in those who kept pets.

Other participants who were pet-exposed part of the time at a second parent's home concurred that they did not appreciate a difference in asthma symptoms at this time or in the days following exposure. They also acknowledged that there was a chance it affected their asthma unknowingly:

> *"I never feel a difference (after dog exposures over weekends) but if… it, it <u>might</u>" (11 years-old)*

Discussions of the use of the word trigger revealed that sensitisation and exposure to allergens shown as reactive on skin prick test were not viewed as triggers:

> *"not for me…I just don't think they make a difference .. well cats anyway and now I don't have a cat at home either" (15(c)-years-old)*

Similarly, parents gave examples suggesting triggers/allergens with clearly visible outcomes were prioritised over environmental allergens. The following quotation was in answer to being asked about advice parents would suggest for others with asthma and allergen sensitivities:

> *"um I think first things first would be to take an allergy seriously cos I think a lot of people think 'oh it's just an allergy' I mean (child's name) sister's got various food allergies which is an absolute nightmare and because she's*

allergic to milk they think because it's not peanuts it's, it dun't matter, she'll get a bit of a rash but she dun't, same with sort of pollen and things 'oh it's a bit of hay fever' but it's not just a little bit of hay fever it can affect so much more than that, that would be the first thing I'd say and then obviously going down the depending on what the allergies are obviously but if it's like dust and things reminding them sort of about freezing soft teddies in beds .." (Mother of 13(c)-year-old)

However, the same family kept a dog the child was sensitised to, which could be argued as in conflict with advice suggested in the quotation above. It may be that allergens should be discussed as a separate entity to asthma triggers (if they are not already in clinics), since participant perceptions differ for each. Some commented that if observations changed, beliefs and actions may be altered in response.

4.8.2 Planning for changes in observations

Some parent-carers indicated they would re-assess pet-keeping if asthma appeared to deteriorate. However, in one case a CYP refused this idea. In another family the CYP was already making remediations to minimise some effects of ongoing exposures (itchy skin) but refused that the animals may also contribute to sub-optimal asthma control. Similarly, mothers wanted to see an effect on asthma to be convinced and felt that teenagers were of an age where they could decide this:

*"it doesn't (co-sleeping with dog) seem to affect *** asthma, I think if we got to a stage where it was starting to cause problems, we'd have to think again but I think ***'s now got to a stage where *** can sort of make that decision for ***self that it's not bothering *** asthma so ***'s happy with it" (Mother of 13(c)-year-old)*

However, when the CYP was asked in the dyadic interview if they would change their mind about having the dog in bed if asthma was to worsen, the CYP replied "*no*" emphatically, to which their mother seemed surprised. The CYP (13(c)-years) also could not explain reasons for having the dog present all night, although the mother suspected it was to help keep warm and for comfort, to which the CYP replied, "*yeah maybe.*"

These accounts often came with what appeared as contradictory explanations that altered over the course of the interviews. As with all participants, analysis included several memos and constant comparisons. For this dyad, careful conceptual analysis was required: on the surface it may have been easy to suggest that responsibility was now devolved to the CYP (13(c)-years) for making decisions about the dog exposure.

Furthermore, this seems at odds with the CYP's mother's explanations of the need for others to take allergies seriously (shown on page 128). However, when looking across the interview transcript and again across the entire dataset, it is evident that this mother has used an example where there is a clear exposure and visible outcome/symptom/sign, and earlier accounts in the dyad revealed that participants do not perceive any symptoms they are able to correlate with dog exposure. This was also discussed with regards to low/sub-optimal understanding of the potential synergistic effects of multiple exposures; for example, when this dyad (particularly the CYP-13c) was asked if he/she would continue to sleep alongside the dog if she/he was aware his/her asthma was bad to due to a virus such as a cold. The chance that this could worsen asthma was not anticipated, and the CYP remained determined not to change this arrangement.

Another CYP and mother initially stated their own pet exposures did not lead to any symptoms (asthma or otherwise):

> *"I don't think it does get affected by my pets but it's only really a problem with other peoples' pets like my auntie's that I go to, like with her dog but I'm not sure why …I've always been a bit itchy but that's it" (13(d) years)*

Gradually this participant elaborated throughout the interview and later described generalised allergic symptoms (ocular oedema, sneezing, rash, rhinitis) in response to pets at home and an acceptance of these alongside some remediations:

> *"erm if I wash my hands it helps and if that doesn't help I normally get in the shower so I wash everything off.." (13(d)-years-old)*

Remediations such as handwashing and showering where hand washing did not suffice, were used to relieve symptoms. These gradual elaborations in the interview may have been a sign of developing trust with the researcher or may have reflected genuine realisations that sometimes the young person is experiencing symptoms due to pet exposures at home.

It was challenging to establish what advice had been given to the family about pet-keeping, with the 13(d)-year-old replying *"erm.. I don't know..."* However, the CYP and mother noted that they felt they would continue keeping pets whilst they could not see an effect on the teenager's asthma for themselves:

> *"I think it depends like. If we can't see it's making it worse.. then I think we'd just carry on .." (Mother of 13(d)-year-old)*

In the same dyadic interview, participants mentioned the CYP had never been hospitalised or had emergency care for asthma: this contrasted all other participants. When examining the interconnections between categories and sub-categories, in subsequent sections it should become evident that symptoms and severity are important in informing family remediation decisions. It is hypothesised that although this participant described some allergic symptoms, some ongoing symptoms and sub-optimal asthma control, the family had not been motivated by severe attacks (unlike other families), which may explain why this family undertook the fewest remediations in the sample.

The absence of symptoms attributable to pet exposures in those that kept pets was conflicted by reports that the CYP showed reaction to other people's pets but not their own. This led to health beliefs that some animals of the same species were perhaps more allergenic than others (which is possible) or that there was a degree of acclimatisation to one's own pets, and misconceptions that a lifetime of living with dogs meant it was unlikely CYP would be 'allergic'.

> *"yeah wi' dogs, I didn't think that he would be allergic cos we've had a dog.. all *** life really.. but like I'm allergic to dogs but not my own.. I think it means you get used to 'em maybe" (Mother of 13(a)-years)*

This participant used her and the CYP's reaction to cats as a comparator:

> *"*** kind of had like the same reactions as me, like you know the sore eyes and things like that… cos we don't get the same for dogs as cats, like with the eyes and things. I think having dogs we've got used to them" (Mother of 13(a)-year-old)*

Participants with pets were also asked about whether they perceived a difference to their/child's asthma when they spent time away elsewhere. However, some took their dogs on holiday with them, for example, when caravanning:

> *"Yeah, we do actually have a caravan and I mean *** does get a bit more chesty there" (mother of 13(a)-year-old)*

When asked why this might be, this mother replied:

> *"I don't know if it's because it's quite cold or.."*

The following extract is from a subsequent interview with the CYP from the same family:

> *Int: …"when you go away in or to your caravan I think Mum said sometimes you're a bit more chesty then… can you think why that might be?*
>
> *CYP: not really…*

Int: no ok… and do you normally.. do your dogs normally go with you?

CYP: yeah" (13(a) years)

This suggested the family had not considered or discussed the dog's proximity overnight as a factor that may affect asthma symptoms or control. There was a reluctance in discussing whether pets spent time in children's bedrooms in all but one participant, who had raised this voluntarily (13c who co-sleeps with dog). In this case, this gradually became apparent to the family when asked if dogs were allowed into the CYP's bedroom:

CYP: "not really

Int: I'm the same I've got cats (laughs) and they love my bedroom but I try not to let them in cos they leave loads of fur everywhere!..... and there's no right or wrong answers for this, I know pets sneak in

CYP: yeah sometimes" (CYP 13(a)-year-old)

In other interviews dogs came into children's bedrooms and were visible on camera during the interviews. Those keeping pets represented a small sub-set within the sample but showed the category of seeing is believing held. The next sub-section will discuss domestic furry animal exposure experiences in those choosing not to keep pets, the processes involved in making this decision, and how it also demonstrates that the category holds for the full sample, but according to different experiences.

4.8.3 'Kryptonite': perceptions of pet allergen amongst non-pet-keepers

Perceptions in those who had chosen never to own pets were starkly different to those who kept pets they were sensitised to. Never pet-owners identified experiences with symptoms on, or soon after pet exposures. This largely led to avoidance or in cases where close family members (living elsewhere) had pets, led to preventative measures to limit expected symptoms:

"me partner's Mum's got two cats they're like kryptonite to both me and (CYP's name*) .. if we go up, you know, we've double dosed us antihistamines, we stay an hour, we come home strip off and straight in wash aren't they?" (Mother of 15(b)-year-old)*

One CYP drew what they believed were their asthma triggers prior to interview and these were the triggers that were deemed riskiest and were avoided (including pollen, dust, cats, and cold air); shown in Figure 6.

Figure 6: CYP optional pre-interview drawing showing cats as a trigger

Another parent who participated without her child recalled a reaction to a passing dog which determined future avoidance and decisions to keep the home pet-free, despite preferences for owning a dog:

> *"I knew *** had an allergy to dogs because we was on the bus one time and there were two dogs sat on the opposite side and we were just getting off the bus and the dog had swiped passed (CYP's name) and we got home, which was just round the corner and *** couldn't open *** eyes.. I were that panicky so yeah, he couldn't open *** eyes it were just like two big balls" (Mother of 12(a)-year-old).*

However, this participant denied any observable effect by dog exposure on the CYP's asthma. Yet these symptoms were enough to deter dog keeping despite the CYP expressing they would like a dog at home and the CYP's mother believing this was a preference for companionship. Similar examples were given by other participants who chose not to acquire pets.

The participant sample was somewhat heterogeneous (for example, some kept pets and some avoided animals altogether). However, family accounts of the levels of certainty (based on what was seen or felt) they reached to inform their decisions about exposures and remediations undertaken, and how they perceived they may respond to changes, reflected that they developed their own level of certainty and made responses or planned responses in line with these. Where uncertainty of cause and effect was perceived, pet exposures remained unchanged. Across these cases

there was also an element of handing over responsibility to the teenagers to decide whether pet exposures were tolerable or problematic.

The uncertainty around indoor allergens mechanistic effect on asthma interlinks with the concept that the seeing is believing category holds; indoor allergens may not lead to demonstrable allergic symptoms in all who are sensitised, but it is biologically possible that they may affect asthma control, and the participant uncertainty on this is outlined in the next-sub-section.

4.8.4 'I'm not too sure' how allergens affect asthma

Participants stated they did not know or were unsure how allergens might affect asthma or asthma control.

> *Int: "I wonder did you understand how house dust mites might be a problem for your asthma?*
>
> *CYP: I don't know but they said (at hospital) they are… I'm not too sure really" (13(d)-years-old)*

This may suggest mechanistic understanding of allergic sensitisation, exposure, and potential consequences for asthma control were not well understood by participants. This was echoed in parents' accounts. HDM would be listed as a known reaction on skin prick testing and some remediations were in place for all participants, yet none were sure how HDM affected asthma:

> *"I think I know quite a lot that helps me control my asthma…I think it (HDM) gets in the air … um I'm not sure on any more about it.. just making it harder to breathe really" (male, 15(a) years)*

It is possible that uncertainty about allergen exposures and how they affect asthma control may stall remediation uptake.

There was a discernible difference between responses about HDM and responses about pets; although HDM cannot be seen, and most did not see a visible link between exposure and asthma symptoms, some HDM remediations were still undertaken despite personal uncertainty about the mechanisms behind HDM effects on asthma. During axial coding these were deemed 'acceptable remediations' as they were often one-off installations or purchases (such as de-humidifiers, mattress protectors) or they involved acceptable levels of change to cleaning regimes, which gradually became normalised and accepted, despite some uncertainty over their effectiveness for asthma outcomes: For example, humidity was frequently mentioned as a trigger but

when asked why this might be, none aware that humidity increased HDM allergen presence.

On commenting that the family had purchased a dehumidifier a parent was asked why they thought this was helpful as part of HDM remediation methods undertaken, they responded:

> *"erm I'm not too sure really" (Mother of 13(a)-year-old)*

Similarly, when asked why they thought the child's asthma improved when in a hot but not humid climate (on holidays), the mother responded:

> *"I don't have a clue, I don't know if it might be the air's nicer in a different country, I don't know" (Mother of 13(a)-year-old)*

On discussion of HDM and remediations, often families reverted to discussing dust, as a visible trigger:

> *Mother of 13(b)-year-old:*
>
> *Mother: I think it's just easier to keep it dust free really..*
>
> *Int: Ok and do you think the dust is a problem or the dust mite allergy?*
>
> *Mother: um I think dust definitely when you're somewhere dusty it's worse, but I don't know…"*

Interview probes were used to uncover perceptions about possible synergistic effects of triggers and allergen exposures (including examples such as having a cold plus exposure to allergens may mean asthma control is worse than if only exposed to one of these), which appeared unappreciated by families, since this was not clearly observable:

> *"erm.. yeah, I think so but you can't really see that for sure can you?" (Mother of 13(d)-year-old)*

Participants were able to describe effects of allergens such as pollen by describing the symptoms they had on exposure (described in 4.7.7). Participants did not describe the idea of avoiding breathing in other indoor aeroallergens (animal dander or HDM) in the same way when questioned, which may suggest they did not consider indoor allergens in the same way as pollens and likely reflects that they saw an effect of pollen soon after exposure, which they were unable to see or feel for indoor aeroallergens.

Most families relied on avoidance of the outdoor environment at certain times of year, and anti-allergy medication. Only one described multiple measures to reduce pollen

exposures (4.7.7). This situation exemplifies the importance of background knowledge for research theoretical sensitivity: see box 3 below:

Box 3: Analytic memo-theoretical sensitivity (defined in 3.3.4):
Participants who had non-asthmatic allergic symptoms (sneezing, ocular symptoms, rhinitis) but denied any effect on asthma were looking for symptoms that other triggers brought on such as wheeze, uncontrollable coughing, restricted breathing and in the absence of these asthma symptoms on exposure to the allergen source (e.g., dog) participants did not believe their asthma was affected by allergens. Through theoretical sensitivity, the researcher realised that this presented lack of awareness/ unawareness of the concept of one airway (Busquet, Vignola, and Demoly, 2005); the likelihood that if exposures that affect the upper airways, there may also be affects further down the airways. Only one parent described regular pollen remediation methods to avoid inhalation. This may be an area that could be addressed with educational interventions.

4.8.5 Re-framing asthma triggers

Over the course of the interviews, it appeared that the word 'trigger(s)' may not be suitable to discuss allergens with families. The role of HDM and pet exposures in asthma management had to be explained by clinicians to those who were sensitised rather than diagnosed allergic, and as such the word trigger seemed less applicable to allergens as interviews proceeded. Early interviews showed that triggers seen/felt were easily recognised and this recurred in all interviews.

> *"when I'm in the changing room and [they] like spray deodorant and stuff… I wheeze and I cough, and my asthma gets like my chest is tight… (CYP 13(a)-years-old)*

In contrast, when asked about allergens, CYP answers are exemplified by: *"I'm not sure really…"*

Questions evolved (theoretical sampling) to allow tailoring according to the developing theory, and constant comparison was used to refine the theory and understand its applicability. These issues were reflected upon in memos, as exemplified in box 4 below:

Box 4: Memo extract: **theoretical sensitivity & theoretical sampling through constant comparison**

After ten participants emotional/psychological triggers were mentioned for the first time. This made me re-consider the word 'trigger'. Triggers seem often talked about for psychological conditions, for example seeing or hearing something that reminded someone of a traumatic experience may re-kick psychological symptoms. Even the word trigger (defined as something that causes something to start, or part of a gun causing it to fire), conjures ideas of a quick, apparent cause and effect. Very general knowledge like this is an example of theoretical sensitivity at a basic level, but it also came through in participants accounts of asthma triggers they recalled without hesitation. It is also likely that the word trigger has a similar meaning to participants generally too. Participants had been describing triggers as those things that they could see had a clearly perceptible causal link to changes to their asthma symptoms, with either a quick onset after exposure or where other potential causes were ruled out by their absence. This quickly perceptible link between exposure and outcome seemed similar to general psychological triggers.

Considering the likely continual presence of some level of allergen in the homes of those without evidence-based measures to limit HDM exposure or those with a pet they are sensitised to in the home, the exposures are ongoing in comparison to commonly described asthma triggers (e.g., PE once or twice a week, passing cigarette smoke outside, exposures to sprays or perfumes; or infectious triggers, or moving from warm to cold air). As interviews went on, it seemed important to see whether the word triggers was the best word to use when talking about indoor allergen exposures. Altering interview questions at the later stages of an interview (after a general picture was built up of the participant's triggers, thus avoiding researcher unduly affecting the direction of the interview as much as possible, before establishing participants' beliefs first), enabled confirmation of this evolving concept and re-affirming the category that asthma triggers must be seen/felt to be believed. Conlon *et al.,* (2020) discuss iterations in interview questions as a form of theoretical sampling, alongside constant comparison back through previous transcripts, once a potentially new concept appears in later interviews. These are central analytic techniques in GT and may limit the need to recruit further participants, which also could be deemed unethical, where it is not necessary (Francis *et al.,* 2010).

This consideration (that allergens are not perceived as triggers by some) may have clinical implications for how triggers and allergens are explained/ discussed (and recorded in asthma action plans or patient copies of letters/reports). It also seems important to address the misconceptions that may be part of barriers to strategy uptake.

"Waving the red flag" (Corbin and Strauss, 1998, pp.94-95): In addition to considering the use of the word triggers, I noticed at times participants would initially describe asthma control as good at the time of the interview but later say they 'sometimes' had symptoms. This led me to probe further on what was meant by sometimes, and how severe were these symptoms? This was important in understanding that severity and symptom perceptions were often described depending on comparisons to times when symptoms/control was much worse, rather than expecting to be symptom free or well-controlled.

4.8.6 Summary: category seeing is believing

In summary, this category shows that families with a sensitised child do not consider indoor aeroallergens in the same way as other allergens (e.g., pollen/foods) or irritant triggers. This is based upon learning through experiences and observations over time. However, misunderstanding or lack of knowledge of the mechanisms of allergic sensitisation and interconnections with asthma were apparent. Those with co-existing severe allergies described themselves as more cautious about all allergens they were aware of sensitivity to. Subsequent sections of the findings chapter will outline findings that are important in families' decision making about allergen and trigger remediations. The inter-relation of this category and sub-categories will be discussed and in Chapter 5 with the theoretical model and its development are described.

Additional sub-categories

The following sections represent sub-categories pertaining to both the core category and first category described (seeing is believing). The core category will be fully explained in Chapter 5, alongside the theoretical model, but it is about responding to shifts in personal certainty about observations and necessary remediations.

4.9 The nature of severe asthma "*suddenly it comes again a bit like a wave"*

The variability or episodic nature and severity of asthma recurred in interview discussions. The variability and repeated need for additional medications (such as oral steroids) hospitalisations, school absences, and their unpredictability left families

somewhere between feeling the need to control as much as is possible but resigned to the idea that attacks also appear somewhat random and at times, less preventable.

Despite being aware of triggers, participants reflected on the unpredictability of worsening asthma and at times being unable to retrospectively identify whether there was a trigger:

> *"Sometimes I just get it randomly, like my asthma flares up randomly" (15(a) years-old)*

This uncertainty was echoed in mothers' responses:

> *"it's just I don't think I've ever pieced anything to it, other than yeah definitely the weather and… it's so hard sometimes.. yeah, the sports and exercise…you see it's hard when you're not a hundred percent sure what actually triggers asthma off" (Mother of 11-year-old)*

Asthma attacks remained somewhat unpredictable, even where multiple indoor environmental remediations were in place:

> *"it's a bit like a wave is *** asthma, it'll be fine and then it'll change" (Mother of 15(c)-year-old)*

There were times for families when there was no observable trigger and unpredictability prevailed:

> *"you know, *** asthma gets like triggered even without those things. It can start anytime and anywhere so we don't know when" (Mother of 15(d)-year-old)*

Reacting quickly to deteriorating asthma control was also learned over time by participants, for example:

> *"If like you're feeling something's off don't think it's nothing… one time I can remember I started coughing but I didn't do anything, I didn't think it was anything serious but then like a few minutes later I couldn't breathe properly… I was able to take my inhaler and like a few puffs later I felt better but I should have probably done it sooner" (12(b)-year-old)*

Parents also noted learning when and how quickly to respond to changes in asthma and potential attacks needing medical attention:

> *"when I found out *** was asthmatic because I was even told off at the hospital cos I took *** a bit late and they told me it takes only a minute and I should I should not wait when (CYP's name) starts wheezing quite often um and struggles to breathe, the oxygen levels will drop very quick so I have to be quick also in taking *** to be assessed by a professional so.." (Mother of 12(b)-year-old)*

This quotation shows how this mother learned quickly from the child's first ever accident and emergency visit, that knowing when and how quickly to respond was vital. As parental confidence grew over time and with experience of attacks, they reacted quickly but sometimes felt dismissed by emergency care staff:

> *"when (CYP's name) was younger and *** went into hospital to A&E got set up 'oh *** fine' and everything else 'no *** not fine' and then we come home and then within 2 hours we've ended up in RESUS with consultants apologising to us…" (Mother of 13(e)-year-old)*

There was recognition by this parent that they and their child had become the most familiar with managing the CYP's asthma and at times they felt this was under-appreciated by health care professionals, which is discussed in a further sub-category: communication: 4.12.

4.9.1 Accepting ongoing symptoms

Ongoing asthma symptoms were normalised in the sample and appeared accepted as part of the asthma diagnosis, so long as hospitalisations, acute attacks and associated additional medications were minimised. For example, CYP frequently explained asthma was well-controlled at the time of interview but on further discussion, would describe ongoing symptoms, which they accepted as the norm:

> *"Yeah, sometimes I wake up with like coughing and sometimes it's hard to breathe, but if I take my inhalers, it settles down." (15(a)-year-old)*

Allergic symptoms were also accepted, in those with pets at home to which they were sensitised:

> *Mother: "you sneeze a lot, don't you? (Mother of 13(d)-year-old)*
>
> *13(d)-year-old: yeah, and my eyes get swollen and yeah"*

On discussion, these symptoms did not cause concern or alter perceptions about pet-keeping. The apparent acceptance and normalisation of ongoing symptoms may reflect the chronic nature and the severity of asthma in the CYP sample. However, it is proposed that acceptance and normalisation may explain behaviours such as allowing ongoing exposures despite advice that remediations may improve asthma control.

4.9.2 Learning to understand asthma severity

Parents' understanding of asthma severity developed over time, and in turn, so did their certainty about the need for urgent medical attention during periods of deteriorating asthma control. Asthma severity was explained by participants as

variable dependent on the current perceived symptom severity and comparison to previous experiences, exemplified in the following extract:

> *"I'd personally say it's moderate it's not severe but if you see now, we've only had 6 weeks where it's controlled but it makes a huge difference to my answer… yeah, I mean before they changed the inhaler in (approx. 2 months ago) *** had 6 lots of (oral) steroids within 5 months and was using the blue inhaler 6 or 7 times a day" (Mother of 15(c)-year-old)*

On asking how participants would describe their/their child's asthma, there could be a conceptual disconnect between descriptions of past experiences and how participants would classify asthma severity for some:

> *"I'd say bad.. not severe but definitely not like when you'd just be under your doctors (general practitioner/GP)" (Mother of 13(e)-year-old)*

Prior to this, the same participant in the next extract had described how her child was asked to shield during the early COVID-19 pandemic and previous experiences of multiple hospitalisations for asthma that suggest severe asthma:

> *"in the past I'd class it as quite severe we've done RESUS and PUMA paediatric urgent medical beds quite a few times… and the hospital admissions are . oh god you're talking . probably within the hundreds.. but not for a long time so I don't reckon there's been much for sort of the last.. 2 or 3 years at least" (Mother of 13(e)-year-old)*

Perceived severity is dependent on recent events, control, and comparison to previous episodes, and this fluidity of perceived severity was also appreciated by some.

Parents noted that they had previously been unaware of their child's asthma severity prior to receiving a letter instructing them to shield in the early COVID-19 pandemic. The realisation that their child should be considered vulnerable lead to fear and a new recognition of the severity of their asthma:

> *"so when COVID came I had the letter then that my child had to be self-isolated, like you know be away from the outside at the very beginning when everybody was so afraid of COVID and nobody knew what it was uh that's when I found out that (CYP's name) is considered severe condition I didn't know it was that severe but I believe it was a bit of a shock but it's been controlled" (Mother of12(b)-year-old)*

Some teenagers were more aware of their asthma severity themselves through discussions with clinicians:

> *"[it's] severe.. I've been told" (15(d)-year-old)*

This was further supported by the CYP's reasons for not pursuing pet ownership having admitted loving the idea of having a pet, but due to asthma severity and known sensitisation to domestic animals this was not pursued, supporting the interlinking of categories and sub-categories within the developing theoretical model:

> *"I just don't know if it's going to make my asthma really bad… like my asthma is like bad enough already so I don't want anything else to make it worse really" (15(d)-year-old)*

In contrast, another teenage (13d) participant who kept pets and was sensitised, denied these affected asthma, despite describing other allergic symptoms after exposures and describing sub-optimally controlled asthma. In this case, the CYP described never having been admitted to hospital, which may set apart and explain the differences in risk aversion and perceived risk of exposures.

However, CYP's understanding of their asthma severity was not universal, and some parents were surprised when CYP did not know whether their asthma was severe or not: When asked how (he/she) would describe how bad (his/her) asthma was the (15(c)-year-old) spoke quietly to their mother (inaudible to the interviewer) and the mother replied:

> *"what do you mean you don't know?" (Mother of 15(c)-year-old)*

This sub-section also highlights interlinkages with a later sub-category on communication (4.12), whereby family communication may stall and not reflect that the CYP's understanding and perceptions may evolve over time since diagnosis.

The issues surrounding severity indicate there are gaps in families' understanding of asthma and allergy and it may be hypothesised that their decisions could be better informed if these gaps were sensitively addressed, as fear and anxiety may also accompany understanding asthma severity.

The severity of allergy was clear to those who had been prescribed adrenaline autoinjectors: these CYP and their parents identified their allergy and consequences of (food) exposures as severe, without hesitation. In contrast, allergic sensitisation was discussed on a continuum whereby participants would compare the severity of each allergy or each skin prick test reaction and reflect on how this informed remediation uptake: whilst CYP could recall what they were shown to be sensitive to on skin prick

tests, parents could recall the severity of each positive result more clearly than CYP, as most described allergen testing occurring two or more years ago.

Conversely, some CYP disbelieved they were allergen sensitised because they were not exposed and therefore did not see symptoms:

> *"***'s allergic to cats as well I think.. we don't have cats *** says **'s not (laughs) but ** is… you're never around them that's why… um a bit of dust mite was in there I think" (Mother of 13(b)-year-old)*

The degree of sensitisation observed in the wheal reaction size on skin prick testing was commented on without prompting by other parents:

> *"***had some allergy tests done and **'s got a really, really severe dust allergy..it were like off the scale for the dust one.. *** did score like for cats and dogs like very low" (Mother of 13(a)-year-old)*

The same mother described multiple HDM remediation methods recently (within the last year) put in place at home. However, the family kept dogs, as discussed in detail previously:

> *"***'s highly allergic to dust it was dust and cats" (Mother of 13(a- year-old)*

Later, the same mother also mentioned allergy testing reaction to dogs:

> *"I mean ***'s also allergic to dogs and we have a dog" (Mother of 13(a)-year-old).*

Here, the family recalled the allergens which produced the greatest response on testing but did not believe there were potential problems with keeping dogs to which the child was sensitised; the degree of reaction on testing may offer an explanation for this, alongside not observing an effect of dog exposure on asthma. Descriptions of allergies were sometimes quantified by parents:

> *"Yeah, they did lots of skin prick tests and obviously dust mite's really high along with like peanuts and um animals" (Mother of 12(a)-year-old)*

The severity of recalled skin prick test reactions was linked to remediation uptake for some, particularly for HDM. In the absence of clear observable pet-induced symptoms, this was not the case for pet-keeping decisions.

4.9.3 Self-classifying asthma attacks

Some CYP had had less to say regarding overall asthma severity but would classify their asthma attacks as mild or serious. A 15(a)-year-old reported having asthma attacks every few months and went on to say:

> *"but they're not like severe attacks, they're just… it's like quite mild..I usually take steroids and then tell my GP and then he usually checks it.. checks up"*

Others elaborated:

> *"well like if I get it back under control ..like if it's minor I don't need to go to the hospital or anything" (15(d) years-old)*

At times, this classification was connected to perceived risks; for example, if an asthma trigger exposure was believed responsible for a subsequent attack that was manageable, this would be seen as lower risk. Conversely, if exposures were seen as contributing to attacks requiring urgent medical attention, hospitalisation, or symptoms/sub-optimal control, these were then avoided, where possible, due to these experiences. Some CYP discussed their perceptions of the controllability of some triggers, and these are explored under section 4.11.4.

4.10 Learning not to be 'complacent when they're feeling well': the importance of medication adherence

The open nature of the interview questions allowed participants to discuss aspects of asthma that were not originally anticipated (by the researcher) as closely related to triggers or allergen avoidance. Within the interview conversations participants talked about medications and adherence. Families described noticing differences in asthma control, symptoms, attack frequency, and overall quality of life associated with medication. Their certainty in these accounts was reflected in their confidence in seeing observable changes that they were unable to attribute to anything other than medications.

All participants reflected that adherence to daily preventor inhalers had improved over the years, and that this brought a sense of realisation of the importance of preventative medication, as once adherence improved, families were able to note associated improvements in asthma control.

"a while ago..years ago, it used to be a big problem, like forgetting and stuff, but now that we're on top of it, all the time now, it got, it's gone really well" (11-year-old)

The participant's mother reflected that improved adherence came from repeated visits to the MDT and repeated communication of the need for preventor medications and the later realisation that earlier improved adherence would have been helpful.

*"When we went to Leeds and we were speaking to them we spoke about how important the preventor inhale is, whereas if *** was going to *** dad's for example, *** just has the blue inhaler 'oh well as long as ***'s got the blue inhaler and not whatever colour inhaler'…so, just learning from them (Leeds asthma clinic) and since we've been so strict with it, we never miss it and we've seen a massive improvement as well.. we should have been doing this from day one" (Mother of 11-year-old)*

Parents could clearly tie improvements in asthma control over time, to improved medication adherence:

*"a few years (ago) you know it was just awful and … constantly on steroids.. erm 999 calls and .. it wasn't the best… I think again it's better now because ***'s on the inhalers but if we were to drop them inhalers it would be bad again" (Mother of 11-year-old)*

In support of this, others noted that deterioration of asthma control drove the initial improvement in adherence, which was followed by the recognition that adherence reduced the regularity of serious attacks:

"I don't have to go and get admitted in the hospital as much now because I take medication regularly…. um I think going to the hospital and things got worse with my asthma, so I had to start taking it more" (15(a)-year-old)

Although the route to learning the necessity of preventor medication differed slightly in each participant, all described gradual development of certainty that they needed to adhere to medication to reduce attacks and the need for oral steroids and/or regular rescue inhaler use:

*"*** can be a bit naughty with medication as well… so *** needs to make sure *** takes his Seretide every day because that is the one that will prevent *** to use the salbutamol" (Mother of 12(b)-year-old)*

However, this family were the first to note a preference for salbutamol avoidance, (as this was one of the later interviews this could not be followed up extensively) and as such presents as something of an outlier. Others reflected that sub-optimal asthma control meant they frequently used rescue medication:

*"So, ***'s on a combination inhaler, the first one didn't work, and *** had a reaction to that, so ***'s been put on another one, and it were better than *** was, but it was still sort of using his salbutamol every other day then but ***'s better now" (using the salbutamol less) (Mother of 13(e)-year-old)*

Interlinkage with (family) perceived severity at the time also affected perceptions of medication and medication changes. For example, this mother (of 13e) noted that her child's preventor inhaler was changed and she could not understand why, when everything had been perceived as well controlled by the family:

*"I just don't really see the point in changing (inhaler) if you're happy it's working it's maintaining .. it was just literally *** hadn't needed steroids hadn't been in hospital and bits like that" (Mother of 13(e)-year-old)*

Reflecting on experiences they would share with others when asked what was important to maintain the best possible level of asthma control all mentioned medications:

"um…. My medicines… I'd tell them to take their medicines all the time" (13(a)-year-old)

Parents also emphasised the need to educate CYP about the importance of medication adherence:

"make sure you educate them like it's so important to take the preventor inhaler and try and learn them not to become complacent when they're feeling well" (Mother of 15(c)-year-old)

Participants who had changed preventor inhaler type quickly noticed effects and reflected upon these, where new inhalers had positive perceived outcomes:

"I would say the inhaler yeah.. I would say it's improved" (15(c)-year-old)

Appreciation for the importance of carrying recue inhalers was also evident across the participants when asked about advice they would give to someone else their age with asthma:

"probably just like carry your inhaler everywhere you go and then like if anything happens just like straight away call your parents" (13(b)-year-old)

Changes in asthma control were attributed to inhaler type/brand by participants, who reflected on seeing a clear change in response to switching inhalers:

"The only time I've noticed a good difference is when they changed inhalers 6 weeks ago" (Mother of 15(c)-year-old)

Families also noted that dosages made observable differences in asthma control:

*"I was just going to say that I think again that it's, it's better now because ***'s on the inhalers but if we were to drop them inhalers… it would be bad again" (Mother of 11-year-old)*

11-year-old (same dyad): "we kept dropping um cos doctors were telling us and as soon as we dropped it one more down it got worse"

One participant was prescribed prophylactic antibiotics and this family reflected on the notable difference in asthma control, reduced symptoms, and improved quality of life. These comments reflected the families' certainty that the changes were seen in direct response to the reduction in infections that had been triggering or contributing to the CYP's frequent asthma attacks and sub-optimal control, improvements which had not been seen for other interventions used:

"the antibiotics, it seems to have made a massive difference it's the only actual intervention that seems to have worked" (Mother of 13(b)-year-old)

The outcomes of this appeared weighed against the improvement following a history of regular attacks requiring hospitalisation:

Mother (of 13(b): "it used (hospitalisation) to happen all the time didn't it before the antibiotics but since the antibiotics I don't remember the last time you've had one (serious attack) do you?"

CYP: "No" (13(b)-year-old)

There was also awareness of the need to treat with oral steroids periodically as well as the side-effects these could be linked to:

*"because of the amount of steroids *** took ***'s now got adrenal insufficiency, yeah so *** has medicine for that" (Mother of 11-year-old)*

Certainty about infectious triggers was confirmed for families through repeated medications required after attacks:

*"Honestly if *** catches a virus or whatever's going around it sets the asthma off so 9 times out of 10, *** always gets antibiotics or steroids" (Mother of 12(a)-year-old)*

This quotation also exemplifies the connection between the sub-categories and categories, as participants discussed infectious triggers with the most certainty and confidence of all triggers. Analytically it is observable that this is reinforced by the need for additional medication following an attack that is associated with underlying infection.

4.10.1 Other medications: remembering the ones that make a difference

Although there was learned certainty across participants about the importance of adhering to inhaler regimes, there were greater variations in the processes involved in remembering to take allergy medicines such as antihistamines and montelukast or reflux medications. Participants who appreciated an improvement in asthma with other medications noted that they remembered to take them:

> *"It's (asthma at night-time) a lot better since um Leeds started *** on lansoprazole… you do remember your montelukast every night don't yer?' … 'yeah, that's made a big difference" (Mother of 13(c)-year-old)*

The subtleties noted in previous sections for inhaler dosages, also applied to other medications, for example, montelukast variations were noted to have impact:

> *"***'s on montelukast as well like we've tried weaning *** of that but *** just had a trigger …. and were coughing, and *** chest started, so *** had to be put back on that and ***'s just had a recent appointment and everything like inhaler wise and tablets have all stayed the same" (Mother of 12(a)-year-old)*

However, all those taking or with a history of having taken montelukast had experienced side effects and one parent stressed the importance of being educated in this:

> *"Also understanding the medication because when (CYP's name) was prescribed erm the chewing tablets montelukast, I paid no attention to that might be the reason that (CYP's name) was having a lot of nightmares" (mother of 12(b)-year-old)*

Another parent reported severe night terrors as an allergy to montelukast:

> *"yeah ***'s allergic to montelukast *** had night terrors ..quite intense ones." (Mother of 13(e)-year-old)*

Some participants reflected upon uncertainties about the effectiveness of medication, and the role of such uncertainty in motivations to remember to take these medicines. A 15-year-old commented on forgetting to take cetirizine and (his/her) mother elaborated on her beliefs about why this is, explaining the CYP did not feel that the medication had any noticeable effects:

> *"it is a battle that I'm fighting at the moment (laughs) every time I ask it's like 'no' erm but it's strange, I feel like it's because *** asthma's controlled at the moment that..***'s likely to forget it?..... no erm to be fair when *** has taken it for a while I've not noticed the difference the only time I've noticed a good difference is when they changed inhalers 6 weeks ago… which is probably one of the reasons ***'s not taking it (cetirizine) to be fair*

*because subconsciously *** doesn't think it does much" (Mother of 15(c)-year-old)*

In contrast those that noticed an improvement with medications noted good adherence, as aforementioned:

"You do remember your montelukast every night don't yer?.. that's made a big difference " (Mother of 13(c)-year-old)

The level of certainty that these medications were effective in aiding asthma control came from experiences when medications were forgotten, but this was in response to outdoor allergens:

"Well, when I'm outside I like if I haven't taken any of the cetirizine or montelukast it helps erm I start it starts off like sneezing and then it's just like my chest gets tighter and like more phlegm builds up' (15(d)-year-old)

However, even in those who described themselves as particularly risk averse, parents would reduce dosages of antihistamines due to general concerns about the number of medications taken, but this often meant giving a further half dose later to counter returning symptoms:

*"sometimes I do give a break like sometimes during the weekend I give *** a break or just do half instead of giving full dose I just do half when ***'s at home yeah because there's a lot of medication in *** system well, we still give *** half of it and if *** starts telling me that ***'s a bit itchy or something then I give the other half" (Mother of 12(b) years-old)*

Medication concerns were evident generally and families compared episodes where additional medications were needed, as a point of reference for how severe the situation was.

4.10.2 "It's nothing compared to"

Just as participants descriptions of asthma severity were often fluid and based upon comparisons to times when asthma control was at its best or worst, the success of medication changes, new therapies or concerns about medication side-effects were referred to as a comparison to other times. One participant's child had undergone immunotherapy for HDM, and this mother reflected on the observable improvement following therapy:

*"***'s just finished some immunotherapy … so that did work wonders I mean it's not completely uh gone but it's a lot more manageable now" (Mother of 12(a)-year-old)*

Others noted that whilst they were aware that too many medications were undesirable, any reduction in oral steroid frequency was valued:

> *"*** probably has too much steroids for my liking or too many lots of antibiotics but it's nothing compared to the whole of this like from Christmas like usually from *** birthday (in autumn) to March (CYP's name) is in and out of hospital or on antibiotics or on steroids, so the fact that ***'s probably had 3 courses is not that terrible for you is it?" (Mother of 15(b)-year-old)*

In contrast, as will be discussed in section 4.13, there is less certainty about outcomes of other environmental remediation methods on asthma control. Here, the interlinkage of the sub-categories to the core category (4.16) were evident; certainties about medication adherence and patient-reported medication effectiveness were dependent upon being able to see and feel the associated change. As the theory will show, remediations without perceptible impacts may not be undertaken or continued, unless they have been easily accepted into normal cleaning routines or require minimal upkeep (such as anti-mite mattress protectors or air filters/purifiers). These influences will be discussed as motivators, facilitators, and barriers in the following sections.

4.11 Motivators, facilitators & barriers of indoor environmental remediation uptake

To be sure that the motivators and barriers of remediation uptake were grounded in participants' accounts, participants were asked if they were able to recall what influenced their decision and action to put these in place or not. Further analyses supported this, as interlinkages amongst categories and sub-categories explain processes involved in deciding about and initiating remediations are evident in the theory.

Parent quotations dominate this section, as due to the timing of strategy uptake, the majority of CYP could not fully recall when or (in detail) why measures were put in place and in some cases were unaware of HDM remediations. There were two exceptions, the first was a 15-year-old who believed their air purifier had been provided by the NHS many years ago:

> *"I have a **** (brand name) machine, it's like an air filter that's above my bed and I turn it on every night before I go to sleep. It cleans the air, I think*

.. I think it's around 10 years now (since installation), NHS paid for it" (15(a)-year-old)

This participant was the only interviewee to mention having a funded device, but the CYP was not able to be sure whether this was provided as part of a research project or not and the parents did not participate in the study.

The second was a 15(d)-year-old, who had clearly described risk aversion due to the severity of asthma. This participant noted that clinical advice had been sufficient to encourage the family to put anti-HDM measures in place and avoid animals:

When asked what influenced these decisions the 15(d)-year-old replied: "*I think it was advice we were given from the doctors.*"

Motivators included both medical advice and equipment provision, but as subsequent sections will demonstrate, other families took longer to implement remediations, where these were not provided or externally funded.

4.11.1 Motivation to improve outcomes

Participants recalled periods of multiple severe attacks preceding their decisions to try HDM remediations. This was often years after families had first been given skin prick test results. Time is considered as part of the theoretical model development in Chapter 5. The following quotation reflects this parent's description of these measures as a 'last resort' more than two years after skin prick testing was conducted:

*"we got rid of all of *** carpets, curtains, the light shades, and we wet dust, like we don't use any products at all, and all of the bed sheets and everything are anti-allergy ones… we did 'em (the remediations) all at once, that were actually this year when *** were in hospital all that time…*** were in and out, yeah we did it then because we thought of everything we could do to help and nothing were working at the time and so that were like us last resort" (Mother of 13(a)-year-old)*

The above quotation accumulates many features of the analyses and reflects the model (Chapter 5) and its intervening factors: an acceptable, personal level of certainty about the need to try remediations came from the absence of any other treatments working and the absence of any other visible triggers. The severity of the CYP's asthma at that time was apparent due to the need for recurrent hospitalisation. Remediation was deemed a last resort having tried all other treatments that were offered, and good preventor medication adherence was reported. Time elapsed since skin prick testing and initial advice given reflected an opportunity to observe these interlinked factors

and develop enough certainty that little else was helping at that time, and the condition was severe enough to try anything that may help. This shows that developing enough certainty is fluid and that the certainty that something will work does not have to be complete, but rather is driven by a combination of factors: moreover, this exemplifies the core category described in Chapter 5.

Similarly, a mother of a 13(b)-year-old reported the main reason for trying to reduce HDM exposure was persistent asthma symptoms:

> *"um well *** was just really poorly all the time, and *** wasn't getting any better, so we just thought it's worth a try" (Mother of 13(b)-year-old)*

Another dyad described family discussions about remediations following receiving skin prick test results (approximately 3 years prior). This family had implemented some HDM reduction methods but decided to keep the family dog to which the CYP was sensititised. They discussed balancing avoiding cats with being able to socialise, ensuring preventative and rescue medications were and accessible and used, and learning to identify outdoor environmental triggers, such as pollen. The decision to keep the dog and let the dog sleep in the CYP's bedroom was discussed with an apparent acceptance that it was inevitable that the CYP would continue with this, and that it was the CYP's decision, whilst it was not seen to affect asthma. Throughout this interview there seemed to be some defiance in the CYP's answers and interactions with the mother. These contextual issues are discussed in the appended memo (Appendix 11), since the dog also came into the room during the video-interview and the CYP would pick up the dog and rub his/her face on it, whilst looking at the camera:

> *Mother: "I mean when we had allergy testing done, we'd only had our dog about 6 months then there's been sort of no difference .. before us having a dog in the house and….. when you first sort of had the skin prick test done um we spent a lot of time sort of talking about what we can do to help it and ……um dogs we had a discussion obviously about the dog .. um and about sleeping in bed with the dog (short laugh) but I don't think that's ever going to change, is it? (Mother of 13(c)-year-old)*
>
> *CYP: no, every day and I always will (13(c)-year-old)*
>
> *Mother: and as I say it doesn't seem to affect *** asthma I think if we got to a stage where it was starting to cause *** problems we'd have to think again and things, but I think ***'s now got to the age where *** can sort of make that decision ..that it's not bothering the asthma so ***'s happy with it" (Mother of 13(c)-year-old)*

This account represents a pathway to decision-making about which remediations to employ based upon the families' certainty, developed over time, and about which remediations were both acceptable to family life and could be implemented, and which were viewed as unacceptable due to lack of apparent evidence that they caused a problem for asthma. Example coding for an excerpt from this dyadic interview is shown in Table 11.

Table 11: Coding example

Excerpt from Mother of 13(c)-year-old (as above)	**Open codes**	**Axial codes**	**Processes observed (part of selective coding)**
*"*** sort of getting to know that there's different types um dogs we had a discussion obviously about the dog .. um and about sleeping in bed with ***(short laugh) but I don't think that's ever going to change, is it?.....* *and as I say it doesn't seem to affect *** asthma I think if we got to a stage where it was starting to cause *** problems we'd have to think again and things but I think ***'s now got to the age where *** can sort of make that decision for ***self that it's not bothering the asthma so ***'s happy with it"*	Different types of dog Discussing dog Discussing sleeping with dog Parent accepting CYP decision to sleep with dog Dog doesn't seem to affect asthma If saw dog caused problems would think again CYP age means now able to make decisions	Family discussions. [Links to section on communication 4.12] CYP making exposure decisions - parental acceptance Not seeing /feeling a difference on exposure Planned response to shift in outcomes Parents allowing transition to	Family discussions have led this mother to believe that the CYP is adamant about continuing to allow the dog to sleep in his room and Mother seems to accept this due to neither of them seeing observable changes in asthma since getting a dog (links to seeing is believing category). However, Mother describes that should the observable outcomes change, she would review this (links to the core category- responding to shifting certainty)

	Being happy to continue as dog doesn't bother asthma	CYP decision-making Not seeing means not believing means continued exposures	Tentative concept: The CYP's reply refuted this idea of adapting, suggesting this was an area for potential conflict in the future and conceptually, this tension may mean CYP do not fully describe/disclose symptoms.

4.11.2 Family history & experience as motivators

In other cases, participants who had a family history or parent-participants with their own experiences of asthma and allergies or sensitisation, described how this influenced the uptake of measures for their own children:

> *"to be fair Grace I'm that bad of an asthmatic it were all cos of me anyway…. so I've always been told to avoid house dust mite and every animal under the sun, trees and grass and even the, you know when the mulch of the, you know when the flowers and everything start rotting on't road?" (Mother of 15(b)-year-old)*

The same parent also reflected upon being told she should avoid pets in her own childhood due to asthma and how she continued to avoid pet-keeping into adult life. This was further supported by the CYP's observable symptoms on occasional contact with dogs:

> *"Yeah, I think that goes off my own past trauma because when I were first diagnosed or when I first went to see a specialist (during childhood) she told me to get rid of my dog she told, oh she <u>scared</u> me, absolutely petrified me said that you know this is what's wrong with your asthma and you're not doing it" (Mother of 15(b)-year-old)*

This section shows inter-connections between the sub-categories and categories regarding fear, taking responsibility and (non-judgmental) communication with health providers (presented in 4.12). A second family with a mother with asthma also reported early uptake of HDM remediations:

> *"cos I'm quite a bad asthmatic as well I've always been quite self-conscious about just dust and things…. probably erm (remediations) since the first*

*(skin prick test) because when *** first got asthma *** started with pneumonia and then recovered and then *** was diagnosed with asthma erm so I was doing all I could to change things when *** been tested cos like I knew how bad the steroids were and *** seemed to be on them all the time, so as a Mum I was already trying to get rid of risks in the house. The only thing we did get rid of after the last one (skin prick test) was *** teddies on the bed cos they told (us) *** weren't allowed 'em". (Mother of 15(c)-year-old)*

This passage shows that there was a consciousness of dust as a trigger due to the mother's own asthma, followed by additional remediations due to CYP's asthma diagnosis, as a preventative measure, due to her knowledge of the likely necessity for steroids for sub-optimally controlled asthma and concerns about steroids. This led to control of known risk factors at home, with the later insight learned through health advice regarding HDM allergen in soft toys.

The same family also discussed that presence of a cat in the home was not seen as a risk due to lack of observable effects on asthma, and perceptions about the cat's short hair. These perceptions were further supported by the family not later seeing a change when the cat moved with an older sibling, as in the extract below:

Mother: "it was quite a short haired cat, well it was my daughter's cat, so it went to live with my eldest daughter when she left

Int: Oh, I see so it naturally moved on, the cat (laughs)

(all laugh)

Int: I see ok, and I don't know if either of you can remember then and I think this is what you were saying but didn't you notice much change when the cat moved out?

Mother: no

CYP: no"

Other participants described feeling pressure from health professionals to re-home pets. For one family this led to the decision to re-home the family cat. This was described as a reluctant decision:

*"yeah we had a cat when *** was younger, but I got rid of the cat and we moved house and it didn't get any better (laughs)… no. not at all..and also it's just sometimes the way they (in clinic) speak to you, that's like you're the worst parent in the world if you kept your cat, do you know what I mean?" (Mother of 13(e)-year-old)*

Remediation decisions are informed both by observations and by clinical advice and possibly the way advice is interpreted.

Others who had very few remediations in place and continued to keep pets they were sensitised to, were reluctant to discuss the decisions beyond stating they did not see a difference to their/their child's symptoms that they could attribute to exposures. When asked about advice they had been given, it was difficult to determine whether they had been given advice about pets and they were reluctant to discuss it in the interview or that they perhaps had not fully understood any advice given.

Those with co-morbid severe allergies to foods, also described themselves as cautious with respect to asthma management and all allergens they/their child was sensitised to, and these families described early implementation of remediations soon after advice was given:

> *"I were doing everything anyway like I'm OCD mad anyway so I were constantly like damp dusting and doing all that, I clean *** room every day, I change *** bedding every couple of days, and put it on a high wash .. there was not much more I could do for *** at home that I hadn't already done…. I don't take *** near any pets, anyway we don't have any at home no family members have got any… so yeah, I've literally done everything" (mother of 12(a)-year-old)*

As mentioned, despite cautiousness, unpredictability and the nature of severe asthma meant that some needed additional measures, such as medication changes or immunotherapy to control conditions, which complicates families' interpretations of allergen remediation outcomes. However, these issues informed dynamic perceptions over time.

4.11.3 'Learning lessons' and becoming 'clued up'

Families described how they learned about asthma and its management over time (which was interpreted as an intervening condition: Figure 8). All CYP participants had a long history of asthma from pre-school age, and all talked about the experience they gained over time and through managing the condition with health professionals. Participants' accounts reflected confidence that they felt knowledgeable about and responsive to asthma.

As discussed, learning included learning about medications through instruction and experiences. Accidental/unexpected exposures to asthma triggers or allergens were subsequently viewed as points of learning to inform future decisions and precautions. These were particularly evident with food allergen exposures as discussed in 4.7.8. For

some, lessons were learned through accidental exposures to animals they/their child was sensitised to and these informed plans and remediations, as shown in the following dyadic extract:

> *"*** does [activity] group and they're doing about animals so *** went near a dog but ***'s alright around them, it's when *** touches them and then touches *** face that it all triggers and flares *** eyes and nose" (Mother of 15(b)-year-old)*
>
> *CYP (same dyad, 15(b)): "usually it's starts with my eyes being like getting red and sore and then yeah I get like it just sets off*
>
> *Mother: so like your itchy throat and tight chest that's what she needs to hear from you love*
>
> *CYP: yeah.. sometimes it can be (quite fast) but sometimes it's quite gradual"*

The importance of preventative medication was evident again for accidental exposures to cats:

> *"yeah, that were a lesson learnt I went to my friend's house and forgot to see if he had pets or not and didn't take an antihistamine or ought wi' me and I went to sleep and (laughs) cat came in and walked all over me".* (15(b)-years-old)

The Mother in the dyad explained that this led to decisions about which friends' homes the CYP could go to and those whom it was better to invite to the participant's home instead. However, both reflected that a trial-and-error approach led to these decisions, rather than restricting socialisation, as the same mother commented:

> *"we've learned to just, haven't we, give it a shot? . .I don't wrap you up really in cotton wool, do I?" (Mother of 15(b)-year-old)*

This Mother also reflected that she had learned through experiences of her own asthma and how her own mother had encouraged her to go to places but be aware of triggers and leave if these were problematic:

> *"yeah my mum brought me up with the same thing like you know if somebody's, it's easier now cos people don't smoke do they? like my Mum was always like 'try it if you're bad come home' you know.. and that's what you (CYP) kind of do don't you?" (Mother of 15(b)-year-old)*

The inter-connections between categories and sub-categories are evident in the above quotation, as this mother drew on her own experiences with asthma and her own parents' advice regarding ETS, and continues to advise an approach for her child, which does not overly restrict socialisation but encourages learning and responding to each situation.

Participants who had other family members with asthma and allergy also drew on these experiences to inform decision making about avoidance strategies:

> *"We did quite a bit of research anyway because erm my partner's Dad, he actually died of asthma quite young, um, he was a severe asthmatic and they did a lot of research on him, but they had to do that with him, they had to get rid of all the carpets and everything in the house, but um, he's quite clued up on that isn't he, your dad?" (Mother 13(b)-year-old)*

In summary, those with family history or parental experience had a greater wealth of experience to draw on to inform self-management. Those without this, also learned through experience over time.

4.11.4 Perceived controllability of asthma triggers

Participants noted that some triggers were responsive to specific avoidance or control techniques and others required a different approach, as illustrated in the following extract:

> *"it's the same type of symptoms [when triggered by weather, stress, and dust exposures] but differently so like dust and stuff I can control it a bit more cos like the medicines help and with stress it just depends how long erm I feel that way or if like, if other emotions are making it worse" (15(d) years-old)*

Others reflected that they used strategies learned from the MDT to support them in stressful situations (for example, a parent having to stay in hospital for a procedure) where they might start to feel their asthma becoming less well controlled. Mothers reflected upon the importance of psychological support:

> *"yeah he helped you out emotionally didn't he, you know, like calming yourself down thinking about what you were feeling and it were alright to feel that way but then you know 'do you go down this path or this path?' and it gave you a lot of tools didn't it, for when you were in a stressful situation or an emotional situation.." (Mother of 15(b)-year-old)*

This highlighted the importance of a holistic approach to all types of asthma triggers, particularly evident for the older teens in the sample. Individual perceptions of the tolerability and controllability of symptoms after trigger or allergen exposures may also be important in remediation decisions.

In summary, motivators and facilitators of indoor allergen remediation were multi-factorial but within the sample, there was some sub-division: those with co-existent severe allergy (and allergy clinic attendance) and those with parents or other close

family-members with asthma and allergies described themselves as taking a cautious approach with some learning from experiences with past exposures and through fear and anxiety. However, those that were sensitised but described themselves as not allergic initially took simple remediations such as adapting cleaning and later introduced additional remediations in reaction to periods with poor asthma control with serious outcomes such as hospitalisation.

4.11.5 Barriers to implementing remediations

As mentioned, families described being influenced by the severity of asthma, desires to avoid serious attacks, hospitalisations, school absences and/or steroid use, and these alongside factors such as families' experiences with others'/or parents' own asthma and allergies, were often motivators at various points in the CYP's years since asthma diagnosis and allergy testing. Conversely, for some, these motivators came later in the CYP's lifetime with asthma (hence time being an intervening condition: Figure 8), which meant remediations were implemented in reaction to changes in asthma severity perception or perceptions of the impact on CYP and family life, rather than being viewed as a preventative measure to take earlier in the CYP's life, soon after diagnosis or allergen testing. Therefore, the seeing and believing concept could be analysed as a barrier to remediation; when there is no observable effect of exposure, and the family have not perceived the severity and potential risks and consequences of not placing remediations this is a barrier. This is an example of the flip-flop analytic technique (Strauss and Corbin, 1998; mentioned in 3.6.4.1.1).

To understand the processes families go through in making decisions about remediations and potential barriers to uptake, parents were asked about the gap between first being given advice about indoor environmental remediations and putting these in place, but families often could not recall a reason why they did not try HDM measures sooner.

As mentioned, those with family history or with children with other severe allergies, described being more risk averse than those without these factors. However, even in those describing themselves as preventative and risk averse, some were not aware of remediations that have evidence-based support, for example only five of 12 families purchased HDM proof encasings, yet this has been shown to reduce attacks, where many other frequently employed methods have not (Murray *et al.,* 2006; Custovic *et*

al., 2019). The barrier here was lack of awareness, as parents denied knowing or being told about these (although it may have been that the information was not understood or retained). Other remediations have either not been studied for effectiveness for allergen removal or have not been tested for effectiveness for children's (and adults in some cases) asthma outcomes (Custovic *et al.,* 2019) but have theoretically/biologically plausible reasoning for their implementation, particularly for younger children who may for example, sit on carpets and play with soft toys for longer periods than older CYP would be likely to. A barrier based on researcher theoretical sensitivity was that clinical advice may not have progressed to consider the aging CYP, and that provision of advice for numerous methods may be overwhelming and may lead to families self-selecting options based on their own terms, memory, or understanding of conversations with clinicians over several years. Interventions could aim to address these issues.

4.11.5.1 Hidden costs

Financial costs of heating homes may be an issue for some families and may be further driving damp and mould exposures. Furthermore, all participants noted that cold air was an observable asthma trigger they associated with symptoms.

For example, a CYP (aged 13(c) explained being "*always cold*" whilst the CYP's mother was listing HDM remediations she had placed, and this was returned to moments later:

> *CYP: "especially when I'm watching my programme it literally makes me feel like I'm frozen .. um like every time when I puff when I'm always cold it just feels like when I'm covering with my hand makes the cough like really warm but when I'm like a little bit hot or something it just makes my stomach feel like cold but sometimes it's a bit of both*
>
> *Mother: Ok..*
>
> *Int: ok and it's got so expensive putting the heating now hasn't it?*
>
> *Mother: Yeah I mean I've noticed *** really struggles with the change from hot to cold and even going from cold to hot"*

At this point, the conversation was changed by the mother in the dyad to discuss the temperature and wearing of masks (during COVID-19 restrictions) in school. Most participants changed the subject when asked about costs and the interviewer reflected upon the complexities and ethical considerations about probing on these matters in a memo extract (Appendix 11).

Very few families commented on financial costs of remediations, except one who commented on the costs of cotton bedding and concerns about potentially spiralling, unquantifiable costs of re-decorating damp areas of their rented home:

> *"yeah, the damp is still there but it comes from time to time, so we have to clean, it's mostly in the toilet and er a little bit on the window sill in the bedrooms, very little, and then we use the de humidifiers … yeah, in an old house and then and if I want to do any work on it I'm welcome to do it but I won't get any help from the owner of the house… it's covered in wallpaper you know so if I remove the wallpaper I'm afraid of what I'm gonna find underneath and then I might not have the money to cover all the costs so I'd rather just leave it you know….I was told that the best one (for HDM avoidance) was cotton, a hundred percent cotton yeah, I tried to buy cotton sometimes 100% cotton ones can be very expensive as well" (Mother of 12(b)-year-old)*

Another family purchased de-humidifiers but did not discuss the purchasing or running costs.

Families described varying access to written information regarding remediation advice, with most commenting that this came from discussions in clinics or referral to the Asthma + Lung UK information webpage, which one parent reflected upon:

> *"no, it was just talking and said sort of if you obviously the Asthma UK website um .. but not everybody can get on that " (Mother of 13(c)-year-old)*

In summary, whilst costs were mentioned by some, the dyadic nature of the interviews presented an ethical challenge regarding decisions to probe on financial costs and decisions about preventative measures that require parents to pay out of pocket. Similarly, not all families have internet access to read further information on allergen/trigger remediations. It is likely that the same challenges could apply in a clinical setting where parents may feel uncomfortable discussing costs in clinic in front of children.

4.11.5.2 Emotional attachments to pets

The sub-set of participants keeping pets they were sensitised to is small (n=4), and one was exposed to dogs at weekends only. However, to understand these decisions participants were asked about whether attachment to pets influenced pet-keeping decisions. CYP seemed to find this difficult to articulate but conceptually, the acceptance of ongoing symptoms and reluctance to change pet-keeping habits suggest emotional attachment. For example, one 13-year-old explained they did not know

why they liked to co-sleep with the dog. The mother suggested this could be emotionally comforting:

> *"Comfort yeah you like to snuggle up to her don't you?" (Mother of 13(c)-year-old)*

There are other potential explanations, such as warmth which were discussed in a memo (Appendix 11).

Although emotional attachment is a likely barrier to families considering pet-rehoming, the emotional value of pet-keeping is also important to families. Although this was also challenging for participants to articulate, for example:

> *"…erm I don't know really, I just like being with them I spose" (13(d)-year-old).*

Whilst families were clearly attached to their pets and often replaced them over the years since asthma diagnosis, CYP found it challenging to articulate the emotional attachment during interviews.

4.12 Communication: a conceptual barrier & facilitator

Communication was discussed in interviews and most families described discussions about exposures at home amongst the family. Most also described positive interactions with health professionals regarding exposures. Furthermore, families valued access to a MDT who enabled them to learn to manage each aspect of their asthma:

> *"Leeds were phenomenal especially (names psychologist) you know the fact that they could go, especially (CYP's name) who's quite an emotional asthmatic, could go and say to (psychologist) do you know this is how I'm feeling and (psychologist) would go 'do you know? what about this?' and he'd make you think about it, and do you know I think that is the more . approachable way of a child being more involved in their own, you know, health and wellbeing?" (Mother of 15(b)-year-old)*

However, as mentioned, some participants felt they were judged adversely for their pet-keeping decisions. Conversely some participants viewed clinic interactions as balanced discussions rather than provision of instructions about remediations:

> *"you know they didn't say we <u>had</u> to do this, but she said like it can be a lot better to have laminate, you know things like that, so yeah we did follow their advice" (Mother of 13(a)-year-old)*

For one mother, this contrasted her own prior experience as a young person with asthma and she reflected upon the positive changes in communication between paediatric patients and clinicians over the years and the importance of discussion rather than instruction. Moreover, this participant also reflected that some patients may not respond to advice if the health professional-patient relationship is sub-optimal:

> *"Yeah, I think you have two different types of people don't you? You have people that are asthmatic that just go see their asthma doctor to be told one thing and do opposite or you have the relationship that I have with my asthma doctor or (CYP's name) has with *** where you can bash the ideas back and forward and be like 'this isn't working, what can we do?' .. I find that way it's more helpful to be like on the same page as your doctor, than it is to be 'oh like he's telling me to lose weight or he's telling me to do this" (Mother of 15(b)-year-old)*

For families who had received a home visit from their asthma nurse, these were described as helpful. Although in some cases, the nurse reported that the family already had everything in place that was recommend:

> *"it (home visit) was quite helpful, I think we were pretty much doing everything anyway if you know what I mean, but she was quite informative yeah" (Mother of 13(b)-year-old)*

However, other families reported not being offered home visits or declining these. In some cases, this may have related to COVID-19 restrictions and staffing limitations (as discussed in 4.14.4), in others this related to parental anxiety about home visits:

> *"Now, I've got some um anxieties about people coming into the home… we had social services in, (previously) and so since then I'm very uh anxious and I sort have to work up to that and then obviously everything's happened COVID…" (Mother of 13(c)-year-old)*

Anxiety was mentioned by other participants, but this had not deterred their acceptance of a home visit:

> *"We had a home visit from somebody at Leeds… yeah, it was very nerve racking, it's like ah no, what are they gonna find?" (Mother of 13(b)-year-old)*

It was also clear that initial misconceptions about HDM had been sensitively corrected by health professionals. However, there may be some misconceptions that home-visits may be to inspect cleanliness if parents initially misinterpret skin prick test reactions mentioning dust:

*"when the result came up just how allergic *** was to dust I kind of panicked and I were like, oh my god does that mean like us house is really dusty and things like that and you know they were like, no, no, not at all <u>but</u> there is like steps that you can take, like if *** does have a carpet, you know and they didn't say we <u>had</u> to do this" (Mother of 13(a)-year-old)*

Other points of information provision were reflected upon, and one participant noted that GP provision would be useful as they are often a first point of contact:

"GPs could help a little bit more in terms of finding out because they're the first people to know about your health really" (Mother of 12(b)-year-old)

The same parent also commented on earlier referral to aid faster diagnosis of asthma:

*"you know send *** to the hospital for proper check-up, or give me a professional in asthma to check *** and do all sorts of investigations… so I didn't know (about asthma) until I was in A and E" (Mother of 12(b)-year-old)*

Some of these issues may sit outside the scope of the current research aims and question, but communication is clearly important in influencing avoidance uptake at home and families valued being involved in discussions.

4.12.1 Being listened to as unique, experienced individuals

Families stressed the importance of feeling listened to by health professionals, both as CYP with asthma and parents, particularly in acute situations:

*"There was one situation in hospital where *** literally screamed the ward down crying and shaking because people weren't listening, cos *** thought *** were gonna die" (Mother of 13(e)-year-old)*

The same parent described times where she also felt she should have been listened to and had needed to 'fight' for the situation to be taken seriously:

*"when (CYP's name) was younger and we went into hospital to A&E got set up 'oh ***'s fine' and everything else '<u>no</u> ***'s not fine' and then ***'s come home and then within 2 hours we've ended up in RESUS with consultants apologising to us and stuff like that it just .. have confidence in knowing your child no matter what the doctors tell you, you and your child know them better than the doctors and sometimes it's hard but you do have to fight for what you need sometimes . and make sure that you do fight for it" (Mother of 13(e)-year-old)*

Parents also acknowledged that each person's experience of asthma is unique and what works for one family may not for another. For example, when describing what advice she would give other families making similar decisions about allergen avoidance a Mother answered:

"I think everybody is different, aren't they?" (Mother of 13(d)-year-old)

This was echoed in other interviews and parents reflected that they are advised each case is unique but at times did not consistently feel they were treated as such. Mothers noted that they respected asthma nurses who challenged their views and decisions, where this was for CYP's health and where they also listened to families' views:

> *"yeah (nurse's name) was an absolute diamond! We had our ups and downs, you know, when you can tell but she always listened to my point, and she were someone who would challenge me but for (CYP's name) sake and she always listened" (Mother 13(e)-year-old)*

Conversely, those who felt they had not had concerns listened to or medication alterations explained to them struggled to accept changes:

> *"apparently it's like 'oh well it's better for them to be on one inhaler' well if ***'s stood there doing it (CYP's name) doesn't mind the extra 30 seconds it takes to do the other one .. and *** didn't want to change but no one could actually give me a valid reason of why we had to change … and now we have changed it's just like 'well you can't go back no we'll try something different we'll try' and it's like um but ***'s not as well as *** was . so you know just bits like that, so for me it's . no one could actually give me a reason" (Mother of 13(e)-year-old)*

Although, this participant had some outlier characteristics, in that others reported they had found a preventor inhaler that they were confident in, provided they maintained their adherence in remembering to use it as scheduled. This participant had lost confidence when symptoms had been controlled on a previous inhaler regime but was perceived to have deteriorated once they had changed regime. The boundaries of this concept are limited in that whilst all appreciated the importance of adhering to inhaled medications after years of learning and advice, their certainty and trust in the medication can be altered if there is limited understanding of reasons for medication changes; again, participants believe what they see or feel. The same may be hypothesised for allergen or trigger remediations, if the reasons remediations are suggested are not understood, this is likely to affect uptake, particularly if there is an acceptance of ongoing symptoms.

4.12.2 Family discussions & decision-making

Sometimes within family discussions were described but then contradicted by what was said in the interview, suggesting that perhaps these conversations had taken place

some time ago and as CYP had grown older they had developed somewhat contrasting ideas, evident in parental surprise at what CYP stated during interviews. This is shown in quotations presented under previous sub-categories and represents the interlinkage of sub-categories. Conceptually, it is possible that poorer communication may be a barrier to families fully understanding CYP's asthma triggers and therefore knowing what is important to remediate. Access to written information was also discussed. When asked about their asthma action plans, families indicated they had a plan but rarely referred to it, for example in a Mother and 11-year-old dyad:

CYP: "we did, didn't we, from Leeds?

Mother: yeah, we've got 'em, ..somewhere"

However, participants described the necessary procedures when experiencing an attack and so appeared well versed and experienced in dealing with these. Here, it may be possible that time and experience reduced their feeling of need for the plan. However, it is also possible that they may benefit from discussing and updating plans.

One parent commented that the asthma action plan was too stringent or insufficiently personalised:

> *"*** gets frustrated sometimes, so if *** followed that asthma plan *** should be in hospital and ***'s just like 'oh this is ridiculous' I mean like if we followed that asthma plan (CYP's name) should still be in hospital nearly every two weeks. Sometimes I think they just need to understand that kids are different and sometimes they need to adapt a bit more to kids" (Mother of 13(e)-year-old)*

This mother also commented on incorporating family-management into busy family lives and the importance of recognising the need for personalised management, which was also described by other participants generally. Some reflected on the value of written information, and importance of keeping copies of letters to refer to:

> *"here in Leeds, I had the information sending back to me.. like what I've said to the doctor like if I haven't had the need to use that and blah blah blah….. so it is very important to have those written and for you to have it, you know, you make your own record at home your own folder, like record on your child, it's really important because we parents we also forget things" (mother of 12(b)-year-old)*

Equally, information provision may also be overwhelming and in times of confusion, parents can seek inappropriate interventions for themselves:

> *"and then when you get all the information at once you feel like a bit crazy and you start looking for all sorts of things like might help, I even had*

nebulisers for myself which I could never use because I couldn't get the medication to put in the nebuliser so (laughs)" (Mother of 12(b)-year-old)

The above quotation also highlights parents may seek their own unsupported interventions when overwhelmed by information and anxiety, perhaps suggesting communication needs a sensitive approach. This also demonstrated the learning involved in family management of asthma.

4.12.3 School communication

Participants also commented on interactions with schools. Whilst the focus of the current study is management of asthma triggers and allergens in family homes, this provided contextual clues about the CYP's asthma control and experiences with triggers elsewhere, alongside multi-disciplinary liaison and communication needed to manage CYP's asthma. Families described varied experiences regarding how helpful school staff were in aiding asthma self-management, which in turn affected parental confidence in staff's ability to support their child in times of need:

*"schools can be really like lazy when it comes to asthma.. we've had it in primary and in high school… it don't seem that there's much urgency you know, I don't know if not taking it seriously is the right word or not, but yeah we've had quite a lot of you know, if ***'s come out of hospital and we've said 'right, *** needs an inhaler every 3 hours' ***'s come home and *** hadn't had it <u>once</u>, so *** does end up having quite a bit of time off actually, when ***'s been in hospital, because I'm very reluctant to send *** back" (Mother of 13(a)- year-old)*

Here, it is evident that experiences with school affect parents' confidence to the extent that CYP's return to school is delayed. There were clear differences between different schools. Families learnt through experiences with how school staff managed challenges regarding management of their child's condition, and these shaped their perceptions, affected their anxiety and confidence in sending children to school, and led to parents' selection of what to share with children. These issues were further exacerbated by co-existing food allergy:

*"school's been very good, ***'s only just started high school this year so like I'm just still getting to know the school cos like they're not very like strict on nut policy like the old school was, so that causes <u>me</u> a lot of anxiety but (CYP's name) doesn't know this side of it, that they're not that strict on it, cos we wouldn't get *** to school if *** knew" (Mother of 12(a)-year-old)*

CYP also reported needing support in avoiding common environmental triggers in schools:

*"when we're in the changing room, when *** spray deodorant and stuff and sometimes they don't really get told off for it and so it annoys me .. I wheeze and I cough, and my asthma gets like, my chest gets tight." (13(a)-year-old)*

Asthma nurse liaison and education provision in schools was regarded as invaluable in those who had experienced this:

"she (asthma nurse) did school training, you know not just for (CYP's name), but cos of the way that they were treating me, she went in and did training, you know for first aiders in school, and it were perfect" (Mother of 13(e)-year-old)

However, in some schools, problems continued despite liaison:

"(Childs name's) asthma nurse has spoken to school a few times, yeah, they'll even go in, will the asthma nurses, and speak to school and tell 'em what they need to do, even help 'em, but a lot of the time, they're still the same unfortunately" (Mother of 13(a)-year-old)

Communication with schools and interventions to improve awareness and skills in aiding CYP's self-management are important for the CYP's health, safeguarding, and emotional wellbeing, and for parental reassurance.

4.13 Perceptions and experiences of indoor environmental remediation outcomes

There was variation in the perception of the effectiveness or impact on asthma symptoms that HDM remediation and additional/altered cleaning strategies had (such cleaning strategies may also remove pet allergens in the case of those who kept pets they were sensitised to). The perceived outcomes of remediations may also influence their continuation and uptake of future remediations. Thus, these may be interpreted as barriers or enablers, depending on outcome perceptions.

Some participants believed they saw an improvement in asthma following remediations, but others found it challenging to identify exactly how they felt the remediations improved his asthma:

"yeah I can tell when I'm somewhere else that the things Mum does (carpet removal, freezing soft toys and additional cleaning)*, well we do, make it better..I'm not really sure how to, to describe it.." (15(b) years-old)*

Others were quite uncertain about the effects of HDM remediations and gave their own descriptions of how they assessed the differences. This may suggest there is a range of outcomes families use to decide whether remediations are helpful. These

may in turn relate to symptom severity, regularity, and impact on daily lives. For example, one CYP participant described beliefs that associated improved controllability of night symptoms with the presence of an air purifier in the bedroom:

> *"I think that sleeping at night is better (since air purifier installed), because I would usually wake up..sometimes* (*since air purifier installed*) I *wake up with like coughing and sometimes it's hard to breathe, but if I take my inhalers, it settles down now" (15(a) years-old)*

Similarly, a 13(a)-year-old described changes in symptom frequency since multiple HDM remediations were undertaken:

> *"it's like I've stopped wheezing and stuff…"*

There are exceptions and some CYP were less certain about remediation outcomes after additional cleaning, washing bedding more frequently and introducing anti-mite bedding:

> *"…. I don't feel a difference.. again.. but it probably did" (11-year-old)*

There were also variations in the timing for putting strategies in place. This reflected the families' reason for taking the decision to put these measures in place at a particular point in time. Despite there being some natural heterogeneity in the timing of uptake and the exact strategies undertaken (shown in Table 7) these remediations were accepted into usual cleaning routines and were continued whether or not there was certainty about their effectiveness.

Parents tended to focus on avoiding hospitalisation as their measure of remediation effectiveness (as discussed under motivators): A mother of a 13-year-old described that she observed changes in asthma following the introduction of multiple HDM remediations by comparing hospitalisations pre and post remediations:

> *"yeah, I definitely think it has [remediations made a difference], I mean *** hasn't been in hospital since we've done that" (Mother of 13(a)-year-old)*

However, regardless of certainty about outcomes, participants indicated they continued these measures, being aware they may help, and these were coded axially as acceptable remediations, for example in the case of a different 13-year-olds mother's comments:

> *"We didn't really notice much of a difference no, but we just thought well you know we'll keep going with it and hopefully it'll do something" (Mother of 13(b)-year-old)*

Those undertaking remediations for many years described their habitual continuation and normalisation of adapted cleaning routines:

> *"yeah as funny as it is, I think they've grown up in a world where nebulisers and allergies and windows shut are um you know beds pulled back and hoovered and all that's kind of normal?..yeah you don't realise you do it until like somebody points it out and you think oh yeah, yeah they don't do that (laughs)" (Mother of 15(b)-year-old)*

In other families CYP were less aware of remediations as these are parent-led:

> *"erm ***'s looking all puzzled now (CYP laughs) cos *** probably doesn't know well *** probably has very little to do with it, but *** has erm anti-allergy bedding, doesn't have a carpet in *** room, *** doesn't have any teddies….so there's a lot of stuff that I do to prevent things but I think it's I've been doing them for that many years that *** probably doesn't realise" (Mother of 15(c)-year-old)*

Families' observations were also complicated by other changes in management occurring, such as the introduction of prophylactic antibiotics, which led to observable improvements. In turn, where there had been improvements in asthma overall, families were perhaps less inclined to maintain some significant remediations; for example, the same CYP (13(b) years) moved bedrooms and was in a bedroom with a carpet again, where these had previously been removed. More recently asthma was well-controlled, and the participants described less urgency in considering carpet removal, particularly since asthma control had not altered since moving back to a room with carpet.

Participants' own assessment of remediation outcomes appeared to confirm or alter their perceptions about HDM exposures and remediations and their role in asthma self/family management.

4.13.1 Pet-keeping changes and observations

As mentioned, most families had either never owned a pet in the CYP's lifetime (n=7) or continued to keep pets, as discussed (n=4), and only two families experienced asthma pre-and post-pet (cat) re-homing. However, both noted there were no observable differences with pet presence or removal, which may then be a barrier to continuing pet avoidance in the future.

4.13.2 Openness to the idea of other remediations or interventions

As discussed in previous sections, those with pets wished to continue to keep pets whilst they were not able to observe a causal link to asthma control or deterioration. However, during interviews participants were asked for their opinions on future interventions such as information provision, or air quality monitoring interventions.

Some CYP felt they were knowledgeable enough already, and others suggested written information directed at them might be helpful:

> *"I'd use pictures" (13(c)-year-old)*
>
> *"You like, like comic book style sort of information don't you, where it reads a bit like a story" (other of 13(c)-year-old)*

On asking some participants about the idea of digitally monitoring indoor air quality to provide feedback for targeted control measures, participants seemed unsure about this idea and gave short answers. This may suggest the idea is too conceptual to describe as an intervention without further information or prototype examples.

4.14 The COVID-19 effect

Given that the interviews took place during the pandemic, all families discussed experiences with or related to COVID-19. This section both contextualises the other qualitative findings and was developed as a sub-category since it explains behaviours and links to the core category, because as certainty developed, participants altered their behaviours related to COVID-19 and asthma. The stay-home restrictions imposed in England gave a unique opportunity for families to observe their children under such restrictions and this illuminated the role of some asthma triggers to participants. For some, the fears and risks perceived, particularly in the early pandemic, were a motivator to improve self-management adherence.

All but one CYP had been asked to shield during the early pandemic. The one exception was advised not to shield due to other (neurological and behavioural) conditions. However, the CYP's mother had selected to shield anyway, due to concerns about previous infections:

> *"Well, I did have a letter saying that *** didn't have to (shield) but obviously *** was off school anyway and isolating and I just protected *** anyway for my own self cos I know if there's anything *** catches it, so I protected *** myself anyway" (Mother of 12(a)-year-old)*

For others, receipt of a letter to request their child to shield was the first time they felt they were aware of their child's asthma severity and potential vulnerability, and this led to re-conceptualisation of their child's asthma severity (showing inter-connections with sub-category 4.9).

> *"so when COVID came, I had the letter then that my child had to be self-isolated ..uh that's when I found out that (CYP's name) is considered severe condition, I didn't know it was that severe but ..it was a bit of a shock… when COVID kind of started and just before they decided to close down school so I was a bit afraid already to send (CYP's name) because I had received that letter from NHS saying that my child has been considered one of the vulnerable …I didn't know *** asthma was to be considered severe only found out when I received that letter from NHS" (Mother of 12(b)-year-old)*

This was shown in several interviews and related to initial fear of COVID-19 and the uncertainty surrounding it. Some participants noted that they altered self/family-management in response to concerns:

> *"yeah *** was on the shielding, at the start of it, it were quite scary, and I like made sure that we remembered everything every day, there were no forgetting inhalers or anything like that, you know if *** caught it, (it could) make *** really poorly, we were quite worried, but now we're a bit more laid back with, because it's just, you have to live your life don't you" (Mother of 13(a)-year-old)*

Others reflected concerns about CYP returning to school after shielding, lockdown and subsequent re-opening of schools. This was particularly so for those with a parent who was still being advised to shield:

> *"yeah we'd just been told that *** <u>had</u> to go back to school.. so even though I was supposed to still shield I was supposed to just still send (CYP's name) back" (Mother of 15(b)-year-old)*

Following the return to school the entire family contracted COVID-19. All families had experienced a re-assessment of asthma severity or approach to asthma self-management during the early pandemic.

4.14.1 COVID-19 as an asthma trigger

COVID-19 infection was seen as an asthma trigger for some. One mother described her child's ongoing wheeze since having COVID-19, but some uncertainty over whether COVID-19 was the reason, or other factors such as usual winter deterioration in asthma control, and how the absence of other changes meant a natural process of elimination led to the belief that COVID-19 had most likely led to ongoing wheeze:

*"it's (asthma control) been better than it was then…November last year was tricky because we all had COVID and since then *** has been more wheezy on and off.. whether that's down to the COVID or that's just because it's winter I'm not sort of sure, um not enough for me to sort of need to ring the GP or anybody to think *** needs steroids…. nothing else has changed" (Mother of 13(c)-year-old)*

In describing recent attacks or periods of sub-optimal asthma control, some described COVID-19 infection as an asthma trigger:

*"the only bad episode that ***'s had recently was back in October time when *** caught COVID… that set it off pretty bad and it were steroids and antibiotics and *** just had a continuous cough for weeks that *** couldn't shake off" (Mother of 12(a)-year-old)*

Prior to contracting COVID-19, this mother could not recall the CYP's last attack and also recalled that following COVID-19, use of the CYP's rescue inhaler had increased:

*"I know *** never took his inhalers before October, you know the blue one" (Mother of 12(a)-year-old)*

Some CYP described very recent experiences with COVID-19 and how the rescue inhaler "*helped a bit*" with symptoms:

"so I struggled to breathe a lot and I started coughing mostly at night . and my chest was hurting, like around where my heart is, it started hurting there a lot" (12(b)-year-old)

When asked if participants thought that having COVID-19 triggered their asthma, many described symptoms that could be asthma-related or may also be symptoms of COVID-19:

"Yeah, but much worse the first time than the second…. like my chest would be like. Simply wheezing more and getting out of breath easier . and coughing more as well" (15(c)-year-old)

Additionally, when probing to refine how participants conceptualised use of the word trigger, the same participant used COVID-19 as an example:

"erm I spose like COVID where it made me wheeze and that" (15(c)-year-old)

COVID-19 was not universally seen as an asthma trigger across all participants, with some describing mild symptoms and no apparent effect on asthma. However, in the theory development, participants' beliefs about and experiences with COVID-19 reflected the core category or were tied to the core category (5.1.1) because experiences with COVID-19 also reflected shifts in certainty about asthma, its management, and associated fears or concerns**.**

4.14.2 Asthma and COVID-19 vaccine uptake decision-making

Families mentioned indecision regarding vaccine uptake decisions. Although some either struggled to explain their concerns or did not wish to disclose these in interviews:

> *"it's just we're a bit er, undecided about vaccinating (child's name) we're not sure whether to vaccinate *** or not ..yet" (Mother of 13(a)- year-old)*

When asked if there were particular issues making the decision challenging, this mother struggled to identify one, or perhaps did not wish to discuss it further:

> *"it's difficult, I'm not sure really… I think it's hard enough for us as adults, you know, having to do it for us children as well.. not an easy one" (Mother of 13(a)-year-old)*

Again, opinions regarding vaccination varied throughout the sample, and others were keen to vaccinate and questioned the apparent paradox of CYP being asked to shield but not being offered early vaccination:

> *"what I found really confusing is *** was asked to shield but when I was trying to get *** to be one of the first to have the vaccine I was told *** wasn't eligible.. very confusing but yeah, ***'s had the first one and ***'ll be having another one once it's due" (Mother of 15(c)- year-old)*

Additionally, decisions about vaccines were complicated by contracting COVID-19 when vaccinations were due, and discussions with health professional enabled decision making:

> *"because I saw what it was doing to *** body, and I spoke to Dr **** (paediatric respiratory consultant) and she explained the risks and the benefits so I went down the middle cos the risks there's a slight risk of heart inflammation which was worse by the day and it goes to like 0.01% to the, and that's the reason why they wait 90 days and so I just felt like the benefit from the vaccine . would outweigh the risks. Especially cos we were going on a plane" (Mother of 15(c)-year-old)*

4.14.3 Asthma control during lockdown

Despite these variations in opinion across the sample, the theory appeared to hold true for the COVID-19 sub-category, in explaining that families attempted to develop a level of certainty they were comfortable with, that informed their decision on how they managed asthma in the pandemic and how they reached vaccination uptake decisions. Like allergen and asthma trigger remediation decisions, these decisions were informed by medical communication, both by being asked to shield and by

discussions about vaccinations with professionals, by fear and initial uncertainty about a new virus and its impact for CYP's asthma, and by experience with other viruses and their effects on asthma. Furthermore, the re-opening of schools and society presented new fears and uncertainties around what would happen on re-introducing children to schools where there were few or no precautions in place. These discussions also allowed families to reflect on their perceptions and experiences of asthma control during lockdown. This in turn confirmed their views that reduced or absent socialising and non-exposure to illness led to improvements in asthma symptoms:

> *"and again what's on my mind is.. with COVID and us having to stay in and then with no one really going out anyway… am I only seeing a difference in *** because of that and then now we've gone back to normal, is *** gonna start to be not as well as *** has been?" (Mother of 11-year-old)*

Younger CYP, recalled their asthma was reasonably controlled during lockdown, but did not appear to have considered or be able to retrospectively reason why this might have been, usually providing short answers indicating they did not know. This was also an area for contemplation for the researcher, particularly early in the pandemic, where surveillance data suggested a reduction in asthma attacks during lockdown (discussed in Chapter 6).

Parents considered the coincident reduction in exposures to other illnesses and the impact of this on their children's asthma as the driver for improved asthma control at that time:

> *"Infection triggers *** asthma a lot and so because *** was shielding, *** wasn't mixing with anybody so there was no colds or anything going round so that helped" (Mother of 13(b)-year-old)*

Those who had undergone changes in asthma medications during the pandemic reflected that it was difficult to determine whether medication improved asthma control or the reduction in exposures to infection:

> *"it's been quite stable for the last 2 years we haven't really gone anywhere or done anything so it's all a bit difficult to tell if it's the medication that's changed, helped the asthma control, or just sort of staying at home" (Mother of 13(C)-year-old)*

For those who had not needed medication changes, there was agreement that reduced exposure to illness was the main factor in improved asthma control during government mandated social restrictions:

"Yeah, it were perfect (child's asthma during COVID lockdown) yep, no colds, no viruses, no nothing, no cough, no tight chest, nothing" (Mother of 13(e)-year-old)

This sub-category is also closely linked to perceptible triggers such as viral infection (under seeing is believing: 4.7.2) and the experience used by participants in distinguishing asthma and COVID-19.

4.14.4 COVID-19 and delays in access to care

As mentioned (3.4.3), families had adapted to remote consultations with the MDT during the early COVID-19 pandemic. Additionally, COVID-19 disrupted access to some services, which included allergy interventions, for example:

*"but they were trying to see for (CYP's name) to kind of go to the hospital to stay at least a day for them to try (food allergen) on (CYP's name) and monitor *** but then COVID came and that was taken out of possible things to do and then that wasn't mentioned again, so I don't know" (Mother of 12(b)-year-old)*

Some families had not had home visits and mentioned that these were discussed pre-pandemic, but it had not been possible to conduct these.

"no they mentioned it a while ago but then we had COVID starting, and I don't know now.." (Mother of 13(d)-year-old)

In summary, as one mother commented, COVID-19 *"has changed not just the world but people have changed too so it's been hard, it's been hard"* and the many challenges regarding changing access to services and health-related decision making during the COVID-19 pandemic were reiterated across participants.

4.15 Qualitative findings summary

This chapter has explained the qualitative findings according to a category and sub-categories by providing exemplar quotations, codes, and memo extracts.

The qualitative findings have shown that a range of influences affect family management decisions and contribute towards influencing the uptake of trigger and allergen avoidance strategies. Influences include a complexly related number of factors comprising, changing contexts, such as the COVID-19 pandemic; family understanding of asthma, severity and chronicity, allergens, sensitisation and their connection to asthma and its management, which all contribute to health beliefs, such as not conceptualising allergens in the same way as other triggers; the evolving

learning surrounding asthma and self-management over time and through experience; the importance of support and communication from healthcare providers and ongoing intra-family communication.

The next sub-section will introduce the core category which marks the beginning of a greater level of conceptual abstraction by linking categories and sub-categories and explaining the phenomenon under research (Strauss and Corbin, 1998).

4.16 Introduction to the core category: Responding to shifting certainties

The core category was named responding to shifting certainties to reflect the adaptable, iterative nature of family decision making about asthma trigger and allergen remediations undertaken to attempt avoidance. This involves learning from experiences and responding to the variable nature of asthma, and the challenges of severe or sub-optimally controlled asthma and co-morbidities, within the context of family-life. Shifts in certainty also occurred in response to new information or recurrent information provision by clinical staff. Furthermore, the COVID-19 pandemic changed participants' perceptions about CYP's vulnerability and understanding of asthma severity. This is exemplified in a mother's quotation which shows remediations were employed many years after initial allergy testing results and advice were given, but in response to deteriorating asthma and in the absence of other explanations for deterioration:

> *"we got rid of all of *** carpets, curtains, the light shades, and we wet dust, like we don't use any products at all, and ***'s got um, all of *** bed sheets and everything are anti-allergy ones… we did 'em (the remediations) all at once, that were actually this year when *** were really, when *** were in hospital all that time…*** were in and out, yeah we did it then because we thought of everything we could do for *** to help *** and nothing were working at the time and so that were like us last resort, and *** got like I think it's a de humidifier and a dust mite plug in.. in *** room"* (Mother of 13(a)-year-old)

The theoretical model and core category will be described in greater detail with explanation of how it was conceptualised, in the next chapter.

Chapter 5 The theory: Responding to shifting certainties

This chapter will further describe the theoretical model developed with the qualitative interview data through iterative GT analyses, and the development of the core category.

5.1 The theoretical model

Whilst the theoretical model represents an abstraction it also explains a clinically important behavioural phenomenon, that is, how beliefs are informed by experiences and understanding (or misunderstanding) of various aspects of asthma and co-existing conditions. Figure 7 is a diagrammatic representation of the theoretical model.

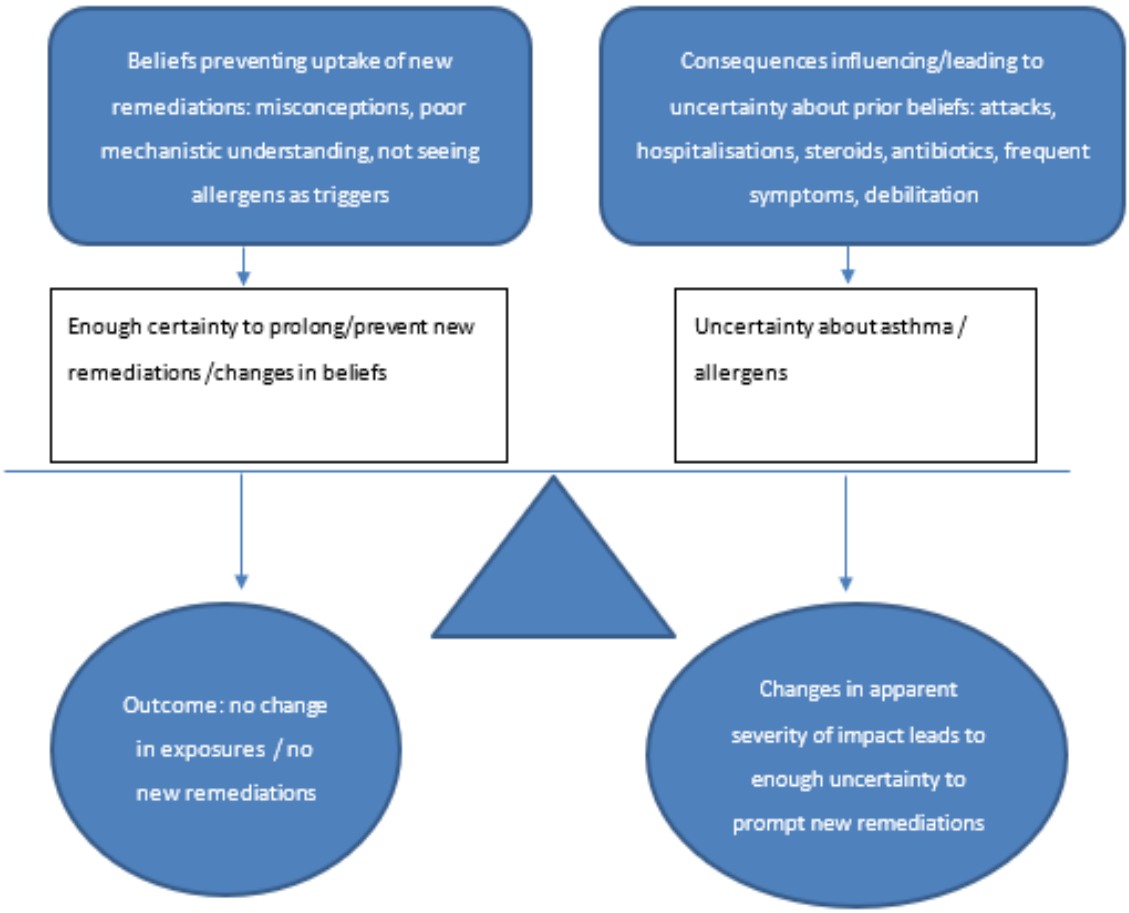

Figure 7: The theoretical model

The blue line in Figure 7 represents a balance and sliding scale of certainty about self-management; a change in symptoms or outcomes that cannot be explained may tip this balance sufficiently to prompt families to believe that allergens may need

consideration and remediation. Where there are no changes in exposure outcomes or perceived severity, and symptoms are tolerated or accepted as normal, any existing remediations that have already been normalised into family routines (e.g., adapted, or increased cleaning) will remain, but no new remediations are likely to be undertaken unless additional education (e.g., home visits, repeated clinical advice) and/or severity and outcome perceptions alter through experiences. This also applies to medication adherence, as families discussed improved adherence over time, through repeated clinical explanations and experiences prompting behaviour change (better adherence).

5.1.1 Core category explanation

Responding to shifting certainties represents an explanation of beliefs and behaviours surrounding asthma and family-management decisions about asthma triggers and allergen exposures. The theoretical model shows that categories are interlinked. Two concepts are central to this theoretical model; first, that asthma triggers must be seen or felt to be perceived as triggers and that this involves learning through experience, advice, and information provision over time. Second, that multiple factors feed into this learning and remediation uptake decisions (shown by the sub-categories). The model ties these concepts together under one overarching core category.

The theory explains that asthma is a variable condition, and this brings uncertainty about when control may deteriorate. Families look for a level of personally acceptable certainty to inform decision-making regarding their management. Over time, families developed certainty that inhaled medication adherence (4.10) is important and this provided certainty that they were able to control this element of self/family management through developing routines and structure to ensure CYP remembered to take preventor inhalers. Families also developed certainty about irritant asthma trigger exposure and outdoor allergen exposures and how these led to symptoms (4.7.1-4.7.7). The degree of symptom acceptability depended on perceived severity and discomfort related to those symptoms, and this led to personal certainties about which triggers to avoid, remediate, or tolerate limited exposures to. However, participants were far less certain about concepts regarding how indoor allergens affected asthma and they were largely unable to perceive a direct effect between exposure to HDM allergen and asthma control or symptoms (4.8). This uncertainty is

conceptually (or abstractedly) related to the delayed uptake of most HDM remediations (4.11).

Advice from clinicians led to initial uptake of acceptable remediations, such as adapted and frequent cleaning regimes, because families could be certain that dust was a clear irritant trigger. However, the remediations for HDM allergen exposures such as humidity control, mite-proof bedding/mattress encasings and air filtration, which may arguably require some understanding of the mechanisms of HDM allergen to understand the potential these measures hold for improving asthma control, were less frequently used by families with a sensitised CYP, as an early intervention. This example shows the close interlinkage to the additional category, 'seeing is believing' (4.7.1); if families cannot appreciate HDM allergen in the same way they appreciate other asthma triggers (i.e., there is uncertainty), they are less likely to remediate unless motivated by episodes of poor control, severe attacks, hospitalisations, oral steroids, and school absences, or in some cases motivated by similar personal or family experiences or personal cautiousness to avoid these consequences.

The picture was similar for pet-keeping decisions (4.8.1.2). Families' decisions were driven by the certainty they had reached about exposures and outcomes. Where participants saw no or limited evidence of symptoms perceived as related to pet exposures, they continued to keep pets. However, on probing, some admitted generalised allergic symptoms (e.g., itching, sneezing) but denied there was a link between pet exposures and ongoing sub-optimally controlled asthma; as a result, these participants tolerated allergic symptoms and attempted to remediate in other ways (e.g., hand washing). There was one exception, who re-homed a cat purely in response to repeated medical advice to do so. In those who opted never to have pets, this decision was due to certainty developed through previous experiences with exposures and subsequent symptoms or related to fears about risks due to their asthma severity and unpredictable control.

Severity and variability were also concepts that participants learned through experiences and developed certainty about through health professional interactions and through receipt of COVID-19 shielding advice (4.14). Learning that CYP's asthma was severe enough for them to be considered vulnerable (when they had not previously understood this), led to shifts in their certainty about their condition and

associated risks for those not already managing asthma optimally at the stage. This led to shifts in their response to this information, for example, tightening prevention inhaler regimes and making informed decisions about COVID-19 vaccination by considering risks and benefits.

This apparent fluidity in decision-making in response to observations and experiences may indicate opportunities for interventions to change beliefs and potentially behaviours. Interventions to increase understanding of the mechanisms involved in allergen exposures in CYP with asthma, and altering perceptions about what might count as an asthma trigger to include indoor aeroallergens, may influence future behaviours; this will be discussed in Chapter 6.

5.2 Reaching the core category

5.2.1 Axial coding paradigm use

The use of coding paradigms, which are diagrammatic representations of analytic relationships (Corbin and Strauss, 2008) was useful in considering the factors involved in the processes families go through in reaching decisions about what triggers asthma, what to remediate, and which methods to select. Figure 8 shows an example axial coding paradigm developed during analyses. Other diagrams were developed throughout, but this example shows the contextual issues affecting decisions including the intervening and causal conditions, and consequences of action/inaction, from later analytic stages. These informed core category development (alongside other techniques described) by using Strauss' and Corbin's (1998) suggestions to explore data according to possible contextual factors, marking the start of conceptualisation of the processes involved in the phenomena.

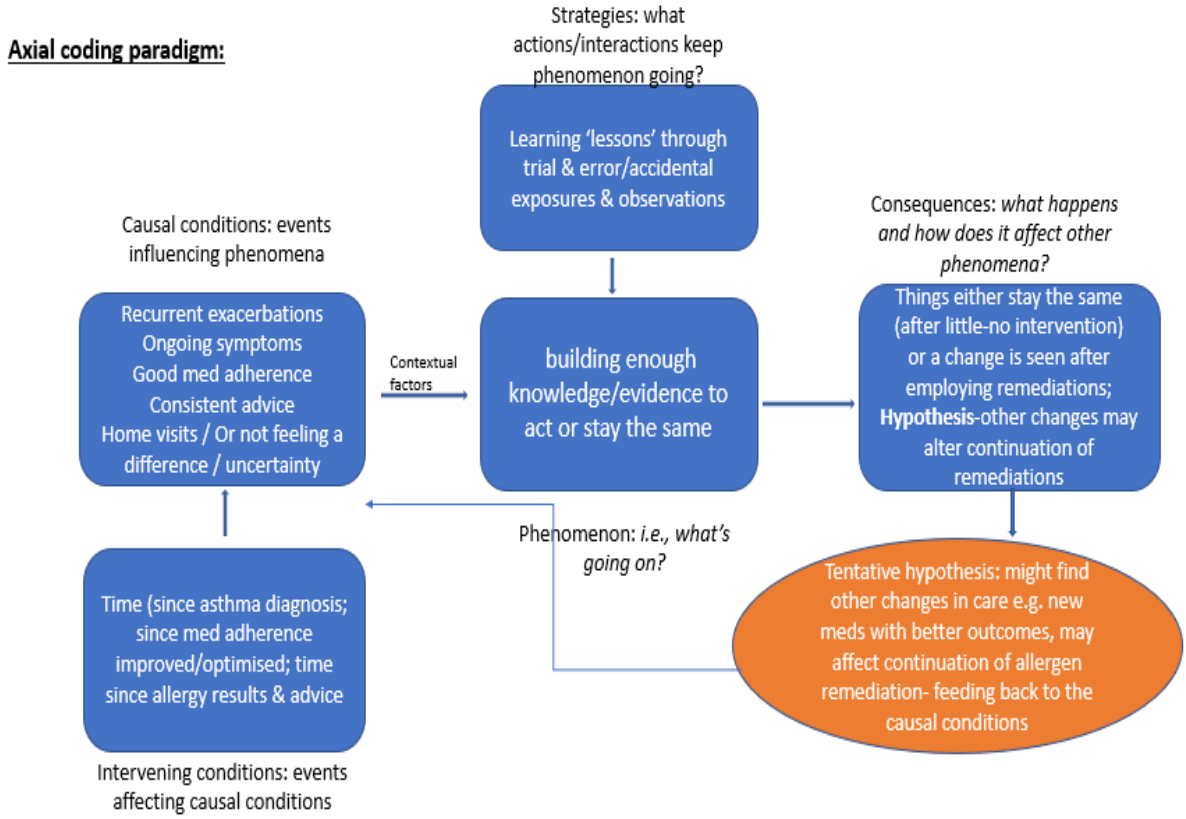

Figure 8: Axial coding paradigm

The axial coding paradigm shows the influencing conditions participants described as pertinent in decision-making. The central phenomenon at the stage of the analysis where the paradigm was used (working towards building the theory), was the concept of building enough experience to enable decisions to continue with the current level of remediations employed (or not employed in some homes) or using experiences and knowledge gathered to inform change through remediation uptake. Surrounding the phenomenon were the conditions affecting the phenomenon (the events, e.g., hospitalisations) and time elapsed (an intervening condition) to allow for knowledge and experience to build to inform decision-making. The consequences of the events also inform the phenomenon, for example, if a severe attack occurs, the evidence balance is tipped toward families being inclined to remediate exposures further. Tentative hypotheses were made from some participants who described discontinuation of some allergen remediations following improvements they attributed to new medications, suggesting a possible feedback loop, whereby larger, more costly remediations maybe discontinued if there are improvements attributable to other management changes.

5.2.2 Reaching the core category: memoing

Corbin and Strauss' (1998) GT techniques encourage interlinking of concepts and categories by asking, what must be true for this phenomenon to occur? This consideration was vital in determining what was included in the model and which findings were grouped under sub-categories and which became categories. Considering this, the core category describes how participants alter their beliefs or openness to altering them as they make new observations, receive new information, and as the severity of asthma appears to fluctuate. In turn, this openness to altering their level of certainty about these issues means they potentially alter their ideas of what remediations, and self-management tools are acceptable to implement. An example memo regarding decisions about categories and sub-categories is shown in the box below:

Memo example for deciding categories/sub-categories, theoretical sampling via question adaption, and constant comparison:

Memo: Is the role of COVID going to be a category or sub-category? (04/05/2022)

Previously, I had thought of this (COVID-19) as another potential trigger, as it is a viral illness (a pre-conceived idea before data collection started). However, it links to the severity concept as well and links to medication advice adherence in some cases. I had also thought of it as something that they (participants) developed more/a reasonable amount of certainty about to base their decisions on (including exposure risks; vaccination decisions; impact on adherence/plans to control asthma as well as possible for those who felt they could improve on that / some were already doing as much as possible when the pandemic started and felt the only change was in the levels of exposures to illness during shielding which all commented on). Again, it might fall under causal or intervening conditions that stated not all conditions in the paradigm will necessarily be categories (Strauss and Corbin, 1998) and so I don't want to force it into becoming a category or sub-category, but it does seem to link to all other ideas / concepts in the data; which meant it fits the sub-category criteria.

Fear and risk aversion is coming across more in recent transcripts (or I'm only just really noticing it's recurrence): On the 17th transcript I have named the tentative axial code '**fear and / leads to risk aversion**'-

Plan: I need to go back and re-check across data for this too. This again might link to severity which all probably feeds into developing enough certainty to base decisions on.

Theoretical sampling via question adaptation – plan (me to revisit Foley *et al.,* 2021 reference)

Do I need to continue to ask whether the severity / better knowledge / understanding about asthma severity is important in informing family decisions? I need to look back across data again for this.

Am I getting bogged down in asking the right questions, when actually the answers are already in that transcript without me specifically asking - I suspect the answers are there, and my analysis is starting to connect those issues now.

5.3 Tentative typologies

During analysis, sub-divisions amongst participant pathways to remediation uptake became apparent. These could be considered as typologies or sub-sets within the sample. These three sub-divisions related to whether 1. CYP participants had family members with asthma and/or allergies (particularly mothers or other close relatives); and/or 2. CYP had severe asthma and severe co-existing food allergies; or 3. CYP had allergic sensitisation and severe asthma only. Whilst the analysis techniques were not specifically selected to study participant typologies, these sub-sets had different approaches to overall remediation uptake due to their differing experiences. It could be tentatively proposed that families of sensitised children without family experience of asthma or other allergies are the group that are most likely to need and potentially benefit from early educational interventions, as they have more uncertainty about the role of allergic sensitisation and remediations. It may also be hypothesised that those with co-existing severe allergies take a generally more cautious approach to asthma control and allergen avoidance, which is driven by fear and motivated by maintaining asthma control and may further be supported by additional contact with allergists.

This could be supported by further research using specific typology approaches. However, samples of over 30 participants are recommended for typology research (Stapley *et al.,* 2022); as such, this is presented as a tentative finding alongside the theoretical model, which may usefully inform future targeted interventions.

5.4 Chapter conclusion

This model theorises that family experience, receipt of repeated clinical discussions, and information provision can adjust certainty about what exposures necessitate

control measures to minimise symptoms and consequences. This certainty can be shifted by new experiences, showing fluidity in these decisions. This fluidity could present an opportunities for interventions to encourage earlier uptake of evidence-based remediation measures. Potentially relevant BCT and methods will be discussed with the wider study findings and theory, alongside current literature in the next chapter.

Chapter 6 Discussion

6.1 Introduction & unique contribution

The aim of this study was to develop a substantive theory to explain beliefs and processes involved in asthma trigger avoidance decisions and behaviours. In response to the research questions and aims (3.2) the current study is the first to explain family understanding and beliefs about asthma triggers and indoor allergens, and family decisions and actions to remediate exposures. This was conducted in response to clinical observations and gaps identified by the scoping review outlined in Chapter 2, to better inform future interventions to increase remediation uptake.

The theory explains that families develop a personally acceptable level of certainty about asthma and asthma triggers which informs their avoidance decisions and actions. The personal level of certainty is informed by learning over time through repeated exposures and outcome observations, and ongoing experiences with the variable nature of asthma. The development of certainty about the importance of preventor inhaler adherence also occurred over time (supporting this theoretical concept). However, a great deal of uncertainty remains regarding indoor aeroallergens and the mechanisms by which these can affect asthma amongst the participant sample. There is also uncertainty about which remediation methods to select and in some cases, their effectiveness. The theory also suggests that because learning is ongoing, certainty about avoidance decision-making is dynamic and responses change accordingly as experiences provide new information, which alters perceptions and can support information provided by health professionals. This suggests that families may be responsive to interventions that alter perceptions about the role of indoor allergens.

6.1.1 Structure of the discussion chapter

During this chapter, the study findings (Chapter 4 and Chapter 5) will be referred to as the current study or current theoretical model.

This chapter opens with brief discussion of the two categories and sub-categories which include findings related to how triggers are conceptualised and explanations for current perceptions of triggers and allergens. Discussion of medication adherence, the nature of asthma and its control and the communication involved in supported self-

management, alongside current literature follows. These are included in the discussion chapter since these findings ground the current substantive theory and add to evidence discussed in Chapter 2. The chapter will then discuss the substantive theory alongside extant theory and literature on the role of uncertainty in asthma and asthma management.

The next section will discuss current interventions described by participants and mapping of potentially suitable BCT and approaches for future interventions. The strengths and weaknesses of the current study and theory will be discussed and learnings from the application of GT methodology described. The chapter concludes with a summary and recommendations for further research and practice.

6.2 Discussion of the qualitative findings that ground the theory

6.2.1 The categories

The theoretical model encompasses two categories, first, seeing is believing, which explains that families use observations and experiences with triggers and exposure outcomes to aid avoidance decision making. Second, the core category, responding to shifting certainties, supports that seeing triggers and their outcomes (or not seeing this) leads to personal levels of certainty about the role of each trigger but adds that this experiential learning and adaption also occurs for other elements of asthma family management. These include medication adherence, working with other agencies to manage asthma at school, understanding severity, when to seek help, and the variable nature of asthma, which is also learned over time and leads to changes in certainty levels about asthma knowledge and beliefs in response to each new experience with asthma. Contextual changes, and/or new experiences, such as experiences during the COVID-19 pandemic and with asthma and co-incident COVID-19 infection, also alter families' personal certainty about asthma and how to manage it. The differences between observable and therefore believable triggers and perceptions about indoor allergens were evident in the findings, and these will be discussed next, in 6.2.2 and 6.2.3.

6.2.2 Identifying and Conceptualising asthma triggers and allergens: sub-category- 'allergic sensitisation to indoor allergens – the hidden trigger'

The current study has identified that indoor allergens are not consistently conceptualised as asthma triggers amongst CYP with sensitisation to indoor allergens or by their mothers, due to lack of observable outcome effects, uncertainty about the mechanistic effects of such allergens, and uncertainty about remediations and their effectiveness. There is a paucity of literature in this area, as shown by the scoping review (Chapter 2) and by the wider literature discussed in section 6.8. The idea that indoor air quality is considered far less than outdoor air quality has been identified amongst children and parents in low-income settings in the USA. Although, this study did not select participants based upon asthma diagnoses, nor did it mention indoor allergens, the authors suggest that senses, particularly smell and visibility of air quality contaminates were important in family perceptions of air quality (Kim *et al*., 2019). In the current study, only one family mentioned indoor air quality related to a wood burning stove, which the family had since stopped using, due to it triggering the CYP's asthma. However, other contributors to indoor particulate matter were not mentioned by participants.

The under-recognition of allergens and indoor particulate matter as triggers amongst CYP and their families is likely to have implications for practice and research. For instance, under-recognition may lead to under-rating of the importance of allergic exposures in studies of HRQOL which use perceived triggers as a measure. For example, Kansen *et al*., (2019) reported that presence greater numbers of perceived triggers (all types) is associated with decreased asthma specific and generic HRQOL, and particularly non-allergic triggers were associated with reduced HRQOL. However, data on allergic sensitisation status was not collected and the design relied upon perception of triggers for analyses. The current study findings have implications for how CYP and their families should be asked about triggers and allergens and their perceived effects on asthma in research and practice.

Additionally, the current study adds that the potential for reducing asthma control by continued allergen exposures was not well understood, in contrast to other triggers which were visible, or had effects that were felt by participants, allowing correlations to be made through experience. This is in line with a previous American study with

CYP in which the author suggested that although CYP could list triggers they did not understand the link between trigger exposures and deteriorating symptoms (Simon, 2013). However, Simon (2013) did not refer to allergens or allergic triggers and included both CYP with asthma and CYP who did not have asthma (but had knowledge through family members' asthma) nor was allergic status or asthma severity (of those with asthma) determined. The current study therefore adds that in CYP with severe asthma and allergic sensitisation, the connection between allergen exposures and asthma outcomes remains sub-optimally understood by CYP and their mothers.

6.2.3 Indoor aeroallergens: other possible explanations for low perceptions as triggers

The current study is the first known to explore beliefs and behaviours surrounding indoor aeroallergens in CYP with severe asthma and allergic sensitisation and their parents. As such, there is little evidence to discuss. Only two articles included in the scoping review mentioned HDM minimally and neither referred to CYP's sensitisation status (Jan *et al*., 2014; Mammen *et al.*, 2018).

There are relevant scientific explanations for why HDM exposure may not produce the fast associated asthma symptoms that participants recognise with other triggers. Wilson and Platts-Mills (2018) present three convincing arguments for CYP with asthma and HDM sensitisation presenting to clinicians without reporting discernible allergic symptoms: 1. HDM allergen particles are too large to enter the airways (particularly lower airways) in vast quantities. 2. Additionally, HDM allergen does not remain airborne for long periods after being disturbed (usually up to 20 minutes). Wilson and Platts-Mills (2018) explain that bronchial inflammation related to HDM exposure occurs through chronic exposures. 3. T cells and innate immune cells mediate the inflammatory response as opposed to an IgE response, leading Wilson and Platts-Mills (2018, pp2) conclude;

> *"Taken together then we have the enigma of the allergen that is most strongly associated with asthma being invisible, lacking clearcut seasonality, and rarely giving rise to respiratory symptoms at the time of exposure"*

Additionally, patient history may not provide indication that HDM is problematic for the CYP (Wilson and Platts-Mills, 2018), which supports the current qualitative findings that families often prolong remediation uptake since they cannot see a correlation

between symptoms and exposures. However, HDM allergen avoidance remains advocated despite advances in asthma medications (Wilson and Platts-Mills, 2018).

Pet allergen is often considered a very different entity to HDM allergen in the literature, for numerous reasons. Firstly, small particle pet allergen (<5µm, as detected for airborne cat allergens) remains airborne for up to 14 days, with larger particles settling within two days. Secondly, different pet allergens differ in particle size, meaning that some penetrate the lower airways and lungs more easily than others (Custovic *et al*., 1998). Research from Murray *et al*., (1983) also suggests that symptoms of cat allergy are more commonly reported than with dog allergy in CYP. Authors suggested this may be due to increased proximity to cats in sensitised cat owners, compared with dogs in sensitised dog keepers. Furthermore, cat owners had more nasal symptoms and lower spirometry measures than dog owners. However, this was not statistically significant (Murray *et al.,* 1983). Whilst this research has not been replicated recently, it remains relevant as cat allergic symptoms were more commonly reported in the current qualitative study and in some, these deterred cat acquisition. However, it may not be possible to fully explain the current findings for those who did not perceive allergic symptoms or sub-optimally controlled asthma due to pet exposure using such scientific evidence, since the current study also suggests there is normalisation and acceptance of persistent symptoms, and these factors appear important in family decision making. Additionally, whilst families do not feel certain that symptoms are wholly attributable to pets, families in the current sample suggested they will continue to keep pets. HDM remediations were undertaken in response to unexplained repeated severe attacks, and it could be hypothesised that families may reconsider pet-keeping in similar situations, or that deteriorating asthma presents an opportunity to review these decisions with families in clinic.

6.3 Discussion of asthma trigger findings

The current study supports the findings of previous literature suggesting commonly perceived and identified triggers amongst CYP include exercise, weather, colds, and influenza (Vernon *et al.,* 2012; Kansen *et al*., 2019; BTS/SIGN, 2019; GINA, 2019), and adds that these are conceptualised as triggers due to their symptom inducement being easily felt, seen and attributable to the exposure. Moreover, these findings contributed to the development of categories and sub-categories and presented the

contrast between trigger and allergen conceptualisation. Since the study took place during the COVID-19 pandemic, there are unique contributions to knowledge regarding asthma and COVID-19.

6.3.1.1 Infection as an asthma trigger & the COVID-19 effect

Co-existing infection, particularly viral infection is a well-documented asthma trigger across the literature (Vernon *et al.,* 2012; Janssens and Harver, 2015; Kansen *et al*., 2019) including systematic reviews of children's and family asthma perceptions and self-management descriptions (Fawcett *et al*., 2019). A further systematic review of barriers and facilitators for effective self-management reported families' difficulties in differentiating colds and asthma symptoms (Miles *et al*., 2017). The current study also highlighted a newly emergent virus (COVID-19) as an asthma trigger for some, and this area was previously underexplored. Whilst asthma was not triggered by COVID-19 in all current CYP participants, comparisons across the sample are complicated by the timing of contracting COVID-19 and each CYP's vaccination status at that time, as well as COVID-19 severity, and overall asthma control at the time of COVID-19 infection.

Furthermore, the current study adds new findings on family perceptions of COVID-19 infection in CYPs with severe asthma, and the varied impact on family management and decision making.

Evidence suggests rates of paediatric asthma-related hospital attendances and related parental telephone inquiries reduced during UK lockdowns (Chavasse, 2020), and there were reductions in asthma attack rates across age-groups, according to English primary care data (Shah *et al.,* 2021). An online survey of clinicians caring for children with asthma across twenty-seven countries reported improvements in asthma that surpassed clinicians' expectations (Papadopoulos *et al.,* 2020). This is supported by a systematic review and meta-analysis comparing paediatric asthma control pre-pandemic and during the pandemic, which showed improvements in asthma control tests (Yang *et al*., 2022). There is scant evidence to present family beliefs or explanations of reasons for this. Parents of children with mild-moderate asthma in China reported increased medication adherence and reduced exposure to outdoor triggers and respiratory infections as reasons for improved asthma symptoms (Jia *et al.,* 2021). Although a few families in the current study reported increasing adherence to self-management tasks in response to the pandemic, others described being

adherent prior to this. This may reflect that all had severe asthma in contrast with the children of parent-participants in the study reported by Jia *et al.,* (2021). Furthermore, there may be important cultural and contextual differences. Other factors may have contributed to improved control, such as improved outdoor air quality (The Air Quality expert group, 2020). The current study adds the valuable perspectives of CYP and parents in the UK, who believed that reduced exposures to viruses and illness in general was protective and resulted in improved asthma control during lockdowns. Moreover, Jia *et al.,* (2021) did not report indoor trigger/allergen exposure discussion with participants. Whilst exposures to indoor triggers may have increased during lockdowns, a proposed explanation may be that without the synergistic effects of regular infections that CYP encounter through school and social exposures outside of lockdowns, asthma control experiences were often improved during lockdowns, despite some ongoing indoor trigger or allergen exposures in the sample described in Chapter 4.

6.3.2 Summary of unique contribution to asthma trigger knowledge

Asthma triggers are conceptualised as such if families can appreciate an exposure-outcome relationship. This appreciation leads to planning for exposures, remediation, or avoidance in the case of irritants such as ETS, or exercise and outdoor exposures. Indoor aeroallergens are not consistently appreciated as triggers and as such are often remediated when asthma control deteriorates, and deterioration cannot be explained by other factors such as medication changes or other appreciable trigger exposures. The importance of experiential learning in self-management decision making has not previously been discussed with reference to indoor allergens. Further discussion of sub-categories will follow and highlight additional influences on remediation uptake.

6.4 Barriers and motivators for remediation uptake

The current qualitative study participants described discussions with health professionals, tailored advice, and some had experienced home visits. These are some of the benefits of attending a multi-disciplinary clinic. Yet, not all participants were aware of the remediation methods with the greatest evidence for associated asthma outcome improvements, such as HDM proof bedding (Custovic *et al.,* 2019). However, the scoping review (Chapter 2) highlighted evidence to suggest information provision

alone is not sufficient (Finkelstein *et al*., 2002), and that in some settings, provision is lacking (Biksey *et al*., 2011). This is somewhat supported by the current study, since some participants placed remediations in response to advice and home visits and others did not. However, this could be for numerous reasons that could not be accounted for in interviews, such as differing advice from different individuals in clinics or family health literacy. The remediations not undertaken were often ones which families denied they had been advised about (for example, HDM proof mattress protectors). Additionally, participants also reflected that they could not always retain all verbal information or access online information.

Many families described being motivated by information given in clinic and home visits only when they could either see for themselves the trigger or allergen exposures led to symptoms or when asthma control deteriorated without other explanations. Families were motivated to remediate triggers and allergens when symptoms limited the CYP's daily lives or led to increased medication use, hospitalisation, and school absences. Being motivated by necessity or changes in necessity perceptions is discussed in section 6.5 regarding medication adherence. However, the current theory suggests that this also applied as a motivator to try additional allergen and trigger remediations. There is a scarcity of literature in this area and the current theory adds new evidence.

The current study also suggests that despite information provision and signposting, participants did not understand how allergen exposures can reduce asthma control. It may be arguable that this understanding is not necessary for all since some undertook some remediations despite not fully understanding how or why they worked. However, when choosing from a range of options, a greater understanding of the mechanisms by which proposed remediations work, may be influential if interventions aim to steer families towards selecting evidence-based methods, which likely links to health literacy. Considering the importance of health literacy for intervention development (Belice and Becker, 2017) and that recent definitions have advanced to include importance of the *'ability of an individual to obtain and translate knowledge and information in order to maintain and improve health in a way that is appropriate to the individual and system contexts'* (Liu *et al*., 2020, pp.7), family understanding seems key to improving evidence-based remediation uptake.

Other barriers to remediation included financial constraints, for example, for mould or damp control or purchasing suggested bedding. A systematic review showed out of pocket expenses for preventative health and condition self-management remain a barrier to uptake in high-income European countries, including the UK (Rezayatmand *et al.,* 2013). Further research is needed to investigate the cost-effectiveness of provision of allergen remediation interventions.

An objective of the current study was to explore health beliefs informing current behaviour. Due to the apparent under-recognition of indoor aeroallergens as a trigger, which is in turn due to not seeing the exposure outcome relationship as is evident for other types of trigger, some beliefs were based on misconceptions. The current study revealed that some participants believed that they or their child had become accustomed to the pet they lived with. These families described how others' pets sometimes triggered symptoms, but not their own pets. Whilst it is possible that some animals may produce more allergen than others, there is no such thing as a completely hypoallergenic pet (Portnoy *et al*., 2012), nor is there any clear evidence to suggest that ongoing exposure produces tolerance to allergens (ASCIA, 2019). It is possible that ongoing acceptance of symptoms or even downplaying of symptoms by CYP may be a factor in families not perceiving an effect from pet exposure (this is discussed further in 6.6). It is also possible that exposure-outcome patterns are somewhat masked when families have always had a pet in the home.

Emotional gain from pet-keeping appeared likely to influence families' decisions in the current study, alongside factors discussed. The current qualitative study contributes a conceptual idea that emotional attachment in CYP and their families will outweigh the possibility that their asthma may improve if pets were re-homed, because of a combination of misconceptions surrounding pet allergy, and apparent lack of visible association between exposures and outcomes. Families can also feel judged about pet-keeping choices and in the few that choose to re-home pets against their preferences, due to feeling judged, there may be a risk that if asthma is not perceived to improve after re-homing a pet, clinician reliability for future advice may be questioned by families, and there may be mistrust. These issues complicate supporting self-management decisions about pet-keeping but addressing myths and misconceptions (such as believing their own pets cannot cause a problem) by

enhancing education to alter beliefs and providing evidence-based advice should continue and be updated as necessary (Clark and Valerio, 2003).

These are important concepts to consider since pet-keeping has increased during the COVID-19 pandemic. An estimated 62% of UK households keep a pet (an 18% increase compared with 2019-20), with 34% keeping dogs and 28% keeping cats. The same survey reported that happiness and companionship were the commonest reasons for pet-keeping (Statista, 2022). One family in the study was uncertain whether they had undergone allergy testing for a pet hamster they had recently acquired. It is suggested that the possibility of new pets should be regularly discussed with patients (as it may already be in some settings) as testing may be required in advance to inform family decisions.

In summary, the categories outlined in Chapter 4 explain that triggers are conceptualised as such when there is a clear outcome-exposure pattern, and this pattern is not frequently recognised for indoor aeroallergens. In the absence of recognition families take some limited remediations until motivated by periods of poorer asthma outcomes which leads to a change in the certainty of their beliefs about indoor aeroallergens, whereby they are motivated to consider remediations. Interventions are needed to motivate preventative rather than reactive uptake. However, experiential learning also appears important in influencing behaviours, in addition to medical advice, and this has been noted for medicinal asthma self-management and pet-keeping decisions based on trial-and-error approaches in CYP and their parents (Callery *et al.,* 2003). This has been discussed in the literature for asthma and other chronic conditions; Leventhal *et al*., (2016) present a common-sense model of self-regulation highlighting the influences on self-management behaviour, which includes the importance of individual perceptions of threat informed by experiences. This was shown in the sub-categories of the current study which will be discussed in the next sub-sections for allergen and trigger remediation, whereas Leventhal *et als'*., (2016) discussion pertains to medication adherence.

6.5 Learning not to be complacent when they're feeling well: the importance of medication adherence

The current qualitative findings suggest CYP and mothers gradually learnt the importance of preventor medication adherence. Participants explained this was influenced by recurrent discussions with clinicians and through experiences with recurrent attacks, hospitalisations, and need for additional medications, often associated with side-effects. Some participants also acknowledged wishing they had adhered sooner. This also resulted from seeing that periods of adherence had led to improvements in asthma and is tied closely to the concept in the category seeing is believing and the core category, responding to shifting certainties. Improved preventor medication adherence meant less rescue inhaler use and this was identified as a positive by some participants. However, others were reluctant to discuss the frequency of rescue inhaler use (particularly those exposed to pets at home), which conceptually may be linked to their knowledge that frequent rescue inhaler use should be minimised. Whilst there appears to be a lack of other evidence to support this concept, excessive use of rescue inhaler is discouraged by clinicians (Levy *et al.,* 2014).

There is a large evidence base regarding asthma medication adherence for CYP, which is somewhat beyond the scope for discussion of the current study aims and objectives. However, some of the current study findings echo those of a framework developed and applied to explain non-adherence. The necessity-concerns framework, initially developed using adult data, is described as '*an extended self-regulatory model, which includes treatment beliefs as well as illness perceptions"*. The framework proposes that necessity beliefs ("*patient*" belief about the need for treatment) and concerns about the treatment influence adherence (Horne and Weinman, 2002, pp29). The current qualitative study appears supportive of the framework, since participants described gradually altering perceptions about need and balancing concerns about side-effects against this and against perceived side effects of additional medicines they might need if non-adherence led to severe outcomes. It is noteworthy that adherence discussions often resulted from open questions which may be viewed as credible support for the framework. What is added by the current study for this group of older CYP with severe asthma, is that this was learnt over time and through personal experience. Participants also mentioned strategies they had learnt to prompt

preventor inhaler use (e.g., leaving with toothbrush/next to bed), which supports recommendations for multi-faceted interventions to improve adherence (Mosnaim *et al.,* 2016).

The necessity-concerns framework can be applied to many other conditions (in adults) and adherence to other medications (Horne *et al.*, 2013). However, application to allergy medication has not previously been made.

Qualitative findings (section 4.10.1) suggest that the necessity concerns framework may also apply to allergy medications for the current sample. Further research in this area may be needed to expand on these findings and their potential application.

6.5.1 Other medication findings

Anti-allergy medications and add-on-therapies (e.g., montelukast) were prescribed for all participants in the current study. As discussed, there was variable adherence to these, somewhat in keeping with the necessity concerns framework (Horne and Weinman, 2002). CYP who were sensitised and remained exposed to indoor allergens (i.e., with low remediation uptake) included those who adhered to montelukast. A plausible hypothesis could be that montelukast and antihistamines such as cetirizine (reportedly prescribed for all participants), alongside inhaler use, may mask any perceptible relationship between exposure and asthma outcomes; resulting in the category- seeing is believing and core category. These medications are also likely to reduce co-existing allergic sensitisation symptoms (BTS/SIGN, 2019), and medications may be considered a convenient alternative to implementing multiple environmental remediations or lifestyle alterations, although there is no clear evidence to support this. As discussed, not seeing related outcomes meant disbelieving (and low certainty) and sometimes, low allergen remediation uptake. A future research question could investigate whether cues to avoidance are masked by medication such as montelukast, or polypharmacy. However, these medications remain important as they reduce symptoms and aid asthma control and are prescribed according to evidence-based guidelines.

A reliance on medicinal approaches to asthma and allergic conditions has previously been acknowledged by Morrow-Brown (2012) (who was at the forefront of allergy research, including allergen testing):

> *"While appreciating the benefits inhaled steroids have given to patients world-wide, he regrets that this development has enabled any doctor to treat asthma or rhinitis effectively without even thinking about the possible allergic causes"*

Whilst the current study makes clear that clinicians do provide allergen control advice in the local MDT, the notion that polypharmacy may mask cues to allergen avoidance echoes Morrow-Browns (2012) thoughts, but by considering the possible effect on patient and parent perceptions, rather than clinical approaches.

6.6 The nature of asthma: 'suddenly it comes again like a wave'

Some of the current study findings support existing literature regarding asthma severity perceptions and beliefs in CYP and parents. For example, Prout *et al.,* (1999), described parents and CYP as considering asthma by comparison to others' asthma severity. Most knew another person with more severe asthma and perceived others' associated risk from asthma as higher than their own. Others made comparisons to other family members with different chronic conditions. Additionally, some participants reported not being advised about asthma severity (Prout, *et al.,* 1999). This appears relevant in 2021-2022, as some of the current sample described being previously unaware of asthma severity (prior to COVID-19 shielding advice) and in some cases CYP remained uncertain about the severity of their condition during their interview. Participants also compared asthma or allergy across family members in the current study. International data from multi-centre studies (including the UK) suggest parents underestimate severity and overestimate asthma control (Carroll *et al*., 2012). These issues were raised in the analyses of the current qualitative data as participants would describe ongoing symptoms but often report that asthma control was reasonably good at the time of interviews and reported previously not appreciating the severity of their/their child's asthma, until being asked to shield from COVID-19.

It is also possible that there is a disconnect between family and CYP perspectives of severity and control compared with clinicians, which cannot be fully explained by the current study findings, since clinicians were not included. Theoretical sensitivity enabled the researcher to question the data, for example, where families reported not understanding needing to switch to a single (once per day) preventor inhaler; a theoretical explanation may be that families underestimated severity and/or overestimated control compared with clinical opinion. This is supported by evidence

that in patients meeting definitions of clinically uncontrolled asthma, over 80% of 8000 adults (aged 18-50 years) surveyed believed their asthma was controlled (Price *et al*., 2014). Overestimation of control and underestimation of severity has been reported in a study of parents (Carroll *et al.,* 2012) but there seems to be a paucity of research conducted with CYP participants in this area.

It is also possible that the clinical aim of switching inhalers was to reduce the use of rescue inhalers, in cases of sub-optimally controlled asthma (BTS/SIGN, 2019). These complex issues present challenges for analyses by non-clinicians, who must learn some of the nuances of asthma treatment decisions and ask questions sensitively, without leaving families feeling they have been judged negatively. The interconnection between the categories and sub-categories are evident here (for example, communication, severity, seeing is believing and the core, responding to shifting certainties) and support the theoretical model.

6.7 The role of communication

The sub-category communication (4.12) supports some existing literature, including the challenges with school staff's lack of awareness or training on how to support CYP's self-management (Gabe *et al.,* 2002). Parents' low confidence in school staff's effectiveness in assisting with self-management or believing CYP as dependable/trustworthy symptom-reporters was shown in the literature (Gibson-Scipio *et a*l., 2013; Cashin *et al.,* 2008; Holley *et al*., 2018; Mansour *et al*., 2000: Laster *et al*., 2009; Shaw and Oneal., 2014; Stewart *et al.*, 2012; Martin *et al.,* 2010; Trollvik *et al*., 2011), the current study and a systematic review (Fawcett *et al*., 2019). Parent-carers in the current sample described how levels of concern led to prolonged school absences, which was reported without questioning or prompting in the current study, supporting findings in the wider literature (Fawcett *et al.,* 2019).

There have been recommendations about the importance of having onsite school nurses in supporting self-management (Mansour *et al*., 2000; Cashin *et al*., 2008; Trollvik *et al.,* 2011). However, these were studies conducted outside of the UK, and trained onsite nurses are not consistently available in UK schools. The presence of school nurses or first aiders with robust training in asthma would likely alleviate many issues for families and CYP with asthma.

6.7.1 Asthma action plans

The intended purpose of asthma action plans are to support self-management, as discussed (1.3). The families in the current study rarely used asthma action plans and some disagreed with their apparent prescriptive nature. Families felt experienced and knowledgeable after managing asthma for many years and so did not feel they needed to refer to the plan, but this (as discussed-4.12.2) may also mean that plans should be more regularly updated. A systematic review and qualitative synthesis (including six studies with CYP and four with parent-carers), reported facilitators and barriers of asthma action plan use. Parent-carers and patients reported being able to self-manage (Ring *et al.*, 2011), in agreement with the current findings. The review also included health professionals as participants and in some cases, they viewed themselves as the expert who permitted patients to self-manage. Additional overlaps with the current study and the review findings were that patients and families made their own assessment of severity and used a self-determined, needs-based assessment to determine their health-seeking pathways, rather than following the action plan (although only one family in the current study suggested they deviated from the plan). In further agreement, good bi-directional communication was viewed as vital. The ongoing adaption of action plans to reflect patient ongoing experiential knowledge was recommended (Ring *et al*., 2011). The importance of updated asthma action plans was reiterated in the national review of asthma deaths (Levy *et al.,* 2014) by noting only 33% sought medical attention at the time of their fatal asthma attack and 17% had an action plan. The emphasis on action plans for children with asthma was repeated in the independent report by the UK Healthcare Safety Investigation Branch (HSIB, 2021). The current study adds that although all participants had action plans, they are used far less frequently in this group of families of CYP with a long history of severe asthma. Further research may be necessary to understand how plans could be refined to ensure they are perceived as and remain useful for such groups.

6.7.2 Intra-family discussions

There are fewer studies that have investigated whether or how asthma is discussed within families and the implications of this for self-management. Following a qualitative study with children (aged 7-11 years) and parents, Garnett *et al.,* (2016) developed a model explaining how families dynamically share asthma decision making.

This is somewhat evident in the current study, since CYP were gradually given more responsibility to make decisions about exposures, but parents would intervene by negotiating and advocating on a CYP's behalf where they needed support, for example to prevent ETS exposure. Some parents also commented that if asthma should worsen, they would re-assess pet-keeping if the two were perceptibly linked. This seemed to represent a shift in decision-making away from CYP, who, in some cases, refuted the idea of reducing pet exposures or re-homing pets completely, regardless of variations in asthma. There appears to be a paucity of evidence explaining whether families discuss these issues and how responsibility for trigger and allergy avoidance is designated, delegated or shared. In the current study, it appeared that families had often not discussed this until the interview but that many aspects of self-management had already shifted to CYP, with oversight from parents.

It is recommended that ongoing promotion of discussion of triggers and allergens may be useful since perceptions and experiences appear to change over time and with CYP age. This may mean parent-carer understanding of CYP's beliefs and experiences may become outdated if these issues are not re-visited by families.

6.8 Discussion of the substantive theory: responding to shifting certainties

Theories about uncertainty have been proposed and applied but are either discussed related to the uncertainty of diagnosis or prognosis or general uncertainty associated with living with chronic conditions (Mishel and Braden (1988) and Mishel (1991). Stewart and Mishel's (2000) uncertainty in illness theory explains how patients and their caregivers understand the uncertainty accompanying chronic condition trajectory. Whilst this type of uncertainty was also shown in the current sample, and is evident in the unpredictability and variability of asthma (section 4.9), the shifts in response to changes in certainty in the model depicted in Chapter 5, differ from Mishel's model (1991) in other respects. For example, Mishel's updated theory (1991, pp.256) proposes that uncertainty leads to '*inference or illusion'* (illusion being the "*construction of beliefs that generally have a positive outlook",* and inference being an assessment of potential consequences of uncertainty) and either perception of opportunity or threat, and each coping strategy is undertaken in response to threat or opportunity. In the model outlined in Chapter 5, there is an adaptation or shift in

response to a change in certainty, but it is proposed that this also leads to change in beliefs through a change in experience or in the level of certainty a person has about their belief and/or outcome of their response adaptation.

Mishel's theory has shown that perpetual uncertainty leads to psychological distress among parent-carers (Stewart and Mishel, 2000). Additionally, Mishel (1991) suggests where inferences are positively viewed then uncertainty is seen as opportunistic. In contrast, where negative inferences are made, concerns are raised. In the model outlined in Chapter 5, uncertainty (about mechanisms of allergen exposure and asthma outcomes, and difficulty conceptualising allergens as triggers) first explained the low uptake of remediations. However, in the absence of other explanations for continually poor asthma control and worsening outcomes, this uncertainty motivated remediation uptake, in that sense it was taken as an opportunity. Whilst there are similarities to Mishel's theory (1991), the current theory suggests uncertainty driven by low understanding can also be barrier to behaviour change. Additionally, as some participants in the current study believed improved outcomes were attributable to remediations put in place, it can be concluded certainty levels are dynamic in the context of asthma self-management. Furthermore, Mishel's theory (1991) concentrates on the emotional effects of uncertainty in illness (Stewart and Mishel, 2000).

Extensions of Mishel and Braden's (1988) and Mishel's (1991) updated work have included a modification based upon qualitative research with families of children undergoing cystic fibrosis diagnostic testing/genetic screening. The modifications included that concepts of opportunity or danger should be considered as a 'continuum' and that uncertainty led to precautionary approaches for the entire family. Time was also noted as an important factor (Tluczek, *et al.,* 2010, pp6) and this was also discussed as an intervening condition in the current theory (5.2). The current study findings share some commonalities, as opportunity and danger perceptions appear dynamic but opportunities to remediate indoor allergens are taken in response to newly perceived danger, in the absence of other explanatory factors, when asthma outcomes deteriorate.

The current substantive theory outlined in Chapter 5, suggests that changes in certainty can affect uptake of physically protective measures and families place value

on their experiences and assessment of exposures, risks, and outcomes. Another important difference is that the current study included CYP who also described uncertainty about allergic triggers and remediation outcomes. CYP's opinions and beliefs appear largely overlooked in studies of the application of Mishel's' (1991) theory.

6.8.1 Potential use of extant theory to further develop the current theoretical model

Mishel's theory (1991) could be used to extend and add a conceptual hypothesis to the current study. Mishel (1991) suggested that uncertainty becomes more appealing when certainty clearly has a negative consequence. This may apply to the current study, for example with pet-keeping, there is participant uncertainty around whether pet exposures lead to poorer asthma outcomes, and the alternative is likely perceived as negative, since it would provide a clear signal that pet-removal was necessary.

6.8.2 Limitations of substantive theory

Substantive theories are usually contextually bound and therefore transferability may be limited (Dey, 1999). However, if sufficiently abstract, substantive grounded theories may be extended to other settings or conditions (Strauss and Corbin, 1998). It is argued that a substantive theory is useful for the purpose of the aims outlined in 3.2, (understanding the target population's beliefs and behaviours) which demonstrates methodological coherence throughout (Tracy, 2010).

6.8.3 Uncertainty themes in the literature

Uncertainty has been discussed in the paediatric asthma literature and has been reported for the pre-diagnostic stage by parents (Horner, 1997). Qualitative research explaining parent-carer beliefs have proposed that when asthma '*is in outbreak*' uncertainty increases and mothers' attention centres on the child with asthma, which can detrimentally affect relationships with other family members (Rydstrom *et al*., 2004, pp.87). Van Dellen *et al.,* (2008) reported CYP and parental uncertainty regarding asthma aetiology, consequences, and symptoms, in the Netherlands. These two studies focus on parental uncertainty, with the exception of CYP uncertainty regarding asthma aetiology (Van Dellen *et al.*, 2008). In the current study, CYP also noted uncertainty about allergens and their role in asthma and CYP may also be

influenced by parental uncertainty about the perceived importance of remediation. Others had learned to embrace some uncertainty as the CYP aged and took trial and error approaches to some exposures outside of the home, to permit a balanced social life alongside asthma management.

There is a wealth of literature regarding uncertainty in other chronic conditions. In families of children with cancer, and several other life-limiting conditions, uncertainty leads to stress. This was initially due to diagnostic uncertainty, but diagnosis led to new uncertainties around prognosis and family management (Cohen, 1993).

Stewart and Mishel (2000), synthesised the literature on studies of illness uncertainty including parent and CYP participants. Two different parental responses to managing uncertainty were identified:

1. Information seeking
2. Minimising or disregarding information which exacerbates uncertainty.

The synthesis authors described these as '*mutually exclusive'* (Stewart and Mishel, 2000, pp.310). In the current study, parents with personal experiences or experiences of other close family members with asthma and allergies, and those with CYP with an additional severe allergy described information seeking for themselves. However, others who did not have these additional experiences often sought information later, when CYP experienced elongated periods of poor asthma control with multiple negative consequences. Shifts towards greater uncertainty about what had triggered these events were analytically identified as factors that motivated allergen remediation uptake, since they had sufficient certainty to believe other triggers or causes were absent, but insufficient certainty that allergen exposures could contribute. Here, the two responses to uncertainty were not necessarily mutually exclusive, rather they were motivated by different experiences and sometimes along different time trajectories. Those continuing to adopt fewer remediation methods concentrated on the uncertainty they had about whether exposures were related to asthma outcomes and therefore whether remediations would be worth trying. Some of these participants were those who described fewer (or in one case, no) hospitalisations for asthma, and fewer regular supplementary medications, which supports the interconnection of conceptual categories in the current model (Chapter 5).

The differences between the current findings and those of Stewart and Mishel (2000) may relate to the differences in conditions (paediatric cancer) discussed for the responses to manage uncertainty. Although many conditions fluctuate for many reasons, asthma is variable in nature, which may account for the variation in certainty described and the fluidity in family responses.

The papers in Stewart and Mishel's (2000) review that included research with CYP, concentrated on the psychological outcomes of uncertainty, as did parental studies, which is a main difference between the current study and other theory and studies reporting uncertainty.

Mullins *et al*., (1997) showed correlations (after adjusting for demographics and asthma-specific variables) between illness uncertainty and higher levels of psychological distress in students with asthma (17-26 years). Stress, fear, and anxiety were noted by many participants in the current study, and these factors can also exacerbate asthma in CYP (Pateraki *et al*., 2018). Certainty or uncertainty in the current study was discussed regarding trigger and allergen beliefs and remediation uptake and perceived outcomes. Therefore, it provides new insights into the role of uncertainty in asthma self-management decisions. However, distraction techniques and 'selective attention' to risks noted for CYP studies (Stewart and Mishel, 2000, pp.310) may be relevant to asthma since increased focus on risks and consequences may highlight uncertainties and promote anxiety. Additionally, CYP's cognitive development may impact how risks are perceived and processed (Pateraki *et al.,* 2018) which may, in turn, relate to anxiety levels and impact of anxiety.

A recent meta-analysis has continued focus on uncertainty and psychological implications of illness uncertainty in parent-carers and CYP, and showed uncertainty is associated with psychological impact reported by CYP and parent-carers, and that intervention studies report uncertainty is changeable (Szulczewski *et al*., 2017).

A recent modified Glaserian GT study showed uncertainty also prevails for parents of children with serious infections. Uncertainty regarding diagnosis, symptoms, and illness trajectory were reported. Additionally, *"symbolic uncertainty (how behaviour will be viewed by others)"* was reported as a concern when seeking second opinions (Neill *et al.,* 2022, pp.11).

In summary, this sub-section suggests most related literature focusses on the psychological impacts of uncertainty in chronic conditions. The current study adds that shifts in certainty may present opportunities for behavioural interventions to promote better asthma control by explaining allergic mechanisms and presenting evidence-based methods for remediation. Uncertainty about these issues seems to initially hinder uptake and eventually lead to uptake as a last resort, except in those with experience of other severe allergies. Educational interventions to clarify issues shrouded in uncertainty for families may increase certainty that remediations are worth trying and may require further research to develop and pilot interventions. Such interventions are likely to require different approaches for CYP and parent education.

6.8.4 Clinical uncertainty

Medical uncertainty from clinicians' perspectives has been appreciated in the literature for many years. Availability of information on the internet may have complicated the role of clinicians in providing advice. Furthermore, how patients and providers interpret certainty of medical advice might affect patient and family home-management decisions (West and West, 2002). As there is currently an emphasis on shared decision making in the National Health Service (NHS England, undated), the role of certainty about efficacy of evidence-based methods for self-management is likely to be important.

Whilst this thesis focuses on CYP and parent perspectives and decision making, clinicians likely also face uncertainty about what to advise families. Although expert opinion pieces based on current evidence (Custovic *et al*., 2019) and practice parameters (Portnoy *et al.,* 2012; 2016) suggest advice for clinicians to pass to families with a CYP with asthma and allergic sensitisation, the evidence for effectiveness of remediation interventions is frequently critiqued (Custovic *et al.,* 2010), and UK guidance (BTS/SIGN, 2019) does not advocate specific advice, complicating decisions about the advice to give.

The role of certainty of CYP/parent-carers' health beliefs and their influences on physical self-management decisions does not appear to be discussed elsewhere. Therefore, the substantive theory outlined in Chapter 5 adds to knowledge. The substantive theory may also apply to other conditions or more generally to self-

management decision making. Future research could explore potential transferability and explore clinician uncertainty and/or establish a consensus among a range of clinicians regarding allergen remediation advice.

6.9 Behaviour change theory (BCT) discussion and recommendations

The findings chapter suggests there are gaps in CYP and mothers' knowledge and understanding, and opportunities for interventions to improve uptake of trigger and indoor allergen remediations. However, as earlier chapter sections discussed (1.5.3) there are several behaviour change theories and techniques and justified selection is complex. This sub-section will firstly explain the current approaches to allergen remediation advice, as described by participants in the current study and secondly, make suggestions for selection of BCTs and methods to maximise uptake of evidence based remediations.

This approach is taken since intervention guidance places importance on first explaining current behaviours (including influences on behaviours), second identifying behaviour change techniques and third, identifying connections between the behavioural influences and behaviour change techniques (Hardeman *et al*., 2005; Kok, *et al*., 2017). This section aims to explain these three steps based upon the findings (Chapter 4) and the substantive theory outlined in Chapter 5, using a taxonomy of behaviour change techniques and intervention mapping steps one and two (Kok *et al.,* 2017).

6.9.1 Step 1: Determining current behaviours and current interventions

Current behaviours related to indoor allergen remediation in families participating in the current study can be described using Kok *et al's.,* (2016) taxonomy. For example, the lack of visible association between exposure and outcome described by participants ('seeing is believing' thus the barrier is that conversely, not seeing means disbelief, or doubting) means that there is low or very delayed remediation uptake. This maps to one method known as deconditioning, in the taxonomy, which Kok *et al*., (2016, table 4, pp.9) define as:

> *"Letting people experience a lack of reinforcement or even negative outcomes of the undesired behavior"*

This appears to be what is happening; families in the current study eventually undertook or increased the number of remediations in response to repeated periods of poor asthma control and associated consequences, and the absence of other explanations for these. As the taxonomy states, this is a slow process (Kok *et al*., 2016) and has many potential disadvantages for CYP with asthma. Kok *et al.,* (2016; table 4, pp.9) also state "*It may be necessary to create a continuous lack of positive reinforcement"* where deconditioning is in place. However, it is proposed that deconditioning is not necessarily an intended intervention for the current sample, it is simply what is happening for some. It is also unlikely that clinicians would positively reinforce indoor pet-keeping for example, in sensitised CYP with asthma.

Current interventions for these families focus on tailored information provision in clinic, signposting to online information (e.g., Asthma+Lung UK) and historically included home visits from asthma nurses and recording triggers in asthma action plans. These can also be tentatively mapped to the taxonomy shown in Table 12.

Table 12: Map of current interventions (described by participants) methods used, definitions and parameters

(using Kok *et al*, 2016, taxonomy)

Interventions described by participants	**(Possible) Method***	**Definition***	**Parameters***
Information provision in clinic (verbal and copies of letters)	"Persuasive communication" Kok *et al*., (2016) cite: (Communication-Persuasion Matrix; Elaboration Likelihood Model; Diffusion of Innovations Theory; McGuire, 2012; Petty, Barden, & Wheeler, 2009; Rogers, 2003)	(table 1 of Kok et *al.*, 2016) "*Guiding individuals and environmental agents toward the adoption of an idea, attitude, or action by using arguments or other means"*	*"Messages need to be relevant and not too discrepant from the beliefs of the individual; can be stimulated by surprise and repetition. Will include arguments"*
Information provision in clinic (verbal and copies of letters)	"Individualisation (Kok *et al.*, 2016 cite: Bartholomew *et al.,* 2000)	"*Providing opportunities for learners to have personal questions answered or instructions paced according to their individual progress"* (Kok *et al*., 2016)	*"Personal communication that responds to a learner's needs"*(Kok *et al*., 2016)

Interventions described by participants	**(Possible) methods***	**Definition***	**Parameters***
Asthma action plans	This is an example of Modelling (Social Cognitive Theory; Theories of Learning; Kazdin, 2008; Kelder et al., 2015) Cited by Kok *et al.,* 2016	*"Providing an appropriate model being reinforced for the desired action"*	"*Attention, remembrance, self- efficacy and skills, reinforcement of model; identification with model, coping model instead of mastery model*"
Signposting to online information	----------	Theory may not directly apply here	----------
Home visits	An example of individualisation, as described above		

*****From Kok *et al*., (2016), table 1, pp6-7.

In addition to Table 12, it possible that clinicians utilise other methods, such as discussion of personalised risk (precaution-adoption process model, Skinner *et al*., 2015). However, this is complicated by the lack of evidence to support clinical decisions regarding this. For example, for nut allergen, skin prick test results of an 8mm wheal or greater, are predictive for clinical peanut allergy (Roberts and Lack, 2005), but no such evidence-based guidance exists for indoor aeroallergens such as HDM or pet dander. Patients can be advised based upon their history, asthma control and/or severity in addition to the size of the skin prick test wheal, where a wheal of 3mm or greater is a good predictor of a potential role of sensitisation in asthma (BTS/SIGN, 2019). However, in patients with positive but relatively smaller wheals, the benefits of allergen reduction appear undetermined in the literature.

It is proposed that many theories are relevant to current practice for providing information to families regarding risks and remediations, including many well-established BCTs.

In summary, step one: examining current behaviours and their influences has involved a scoping review of explanations of remediation uptake (Chapter 2); a qualitative study to fully explain current beliefs and behaviours and influences in CYP with severe asthma and allergic sensitisation to indoor allergens (Chapter 4); and a substantive theory to explain the phenomenon (Chapter 5). This sub-section has mapped the current interventions described by participants to promote remediation uptake to behaviour change techniques and their respective advantages and disadvantages. Steps two and three will identify further relevant BCT and methods that may address barriers highlighted by the current study findings.

6.9.2 Steps 2 & 3: identifying BCT and methods

The aim of this section is to match the current findings (particularly the influences on remediation uptake) and substantive theory described in earlier chapters to BCT and methods that could be used in future interventions to promote trigger and allergen avoidance. These can also be considered in terms of addressing the barriers to remediation uptake (outlined in Chapter 4).

The influences or target behaviours and participant knowledge gaps from the current study have been cross-referenced to an existing taxonomy of BCTs and methods (Kok

et al., 2016) and these have been tabulated as Kok *et al.,* (2016) did, to provide suggestions of BCTs for future interventions (Table 13):

Table 13: Map of apparent behavioural influences and barriers to change against suggested behaviour change theory, methods & parameters

(using *Kok *et al.,* 2016, taxonomy)

Behavioural influence	Barrier to address	Suggested method of behaviour change	Definition / suggested intervention	Parameters
'Seeing is believing': seeing an exposure triggers an outcome	The exposure – outcome relationship is not visible to families	May require a pragmatic approach, such as air quality monitoring and feedback alongside theory-based educational intervention (detailed below) and/or provision of evidence-based remediation such as mattress protectors	As suggested, a pragmatic approach such as indoor air quality monitoring. This could be coupled with information provision using BCT outlined in other sections of the table	Making the exposure-outcome relationship visible is challenging due to confounders in asthma management and outcomes, such as natural variation in asthma and other triggers such as viral infections
Sub-optimal understanding of the potential effects of allergen exposure on asthma control	Increasing understanding of the mechanisms underlying the exposure-outcome relationship	Environmental re-evaluation (transtheoretical model, Prochaska, *et al*., 2015; cited by Kok *et al*., 2016)	"*Encouraging realizing the negative impact of the unhealthy behavior and the positive impact of the healthful behavior"* (Kok *et al.,* 2016, table 5, pp10)	"*stimulation of both cognitive and affective appraisal to improve appraisal and empathy skills"* (Kok *et al.,* 2016, table 5, pp10)

Behavioural influence	Barriers to address	Suggested method of behaviour change	Definition	Parameters
As above	As above	**(alternative theories)** Self-monitoring: Theories of self-regulation (Creer *et al.,* 2015; cited by Kok *et al.,* 2016, table 7, pp12)	*"Prompting the person to keep a record of specified behaviours"* (Kok *et al.,* 2016; table 7, pp12): Could be adapted to keep a record of symptoms before and during a pragmatic intervention; if there is an improvement this would increase the visibility of the exposure-outcome relationship, thus encouraging continued uptake and possible uptake of other methods	However, Kok *et al.,* (2016, table 7, pp12) state: *"The monitoring must be of the specific behavior (that is, not of a physiological state or health outcome). The data must be interpreted and used. The reward must be reinforcing to the individual"* Here the behaviour is continued exposures, so may be very hard to apply this
Each family has adopted differing levels of remediation and/ or perceive different risks regarding environmental exposures (which may also depend on perceived asthma severity)	The barrier may be lack of perceived threat of exposure to asthma control	Tailoring (Kok *et al.,* 2016, table 1, pp4): Trans-Theoretical Model; Precaution Adoption Process Model; Protection Motivation Theory; Communication-Persuasion Matrix; Lustria, Cortese, Noar, & Glueckauf, 2009; McGuire, 2012; Weinstein, Sandman, & Blalock, 2008; Werrij, Ruiter, van `t Riet, & de Vries, 2012: Cited by Kok *et al*., 2016	*"Matching the intervention or components to previously measured characteristics of the participant"* (Kok *et al.,* 2016, table 1, pp4): the tentative typology (5.3) may apply and parental typologies (Crosland *et al.,* 2009), discussed in (section 2.2.2.4) may be relevant to future interventions	*"Tailoring variables or factors related to behavior change (such as stage) or to relevance (such as culture or socioeconomic status)"* (Kok *et al.,* 2016, table 1, pp4)

Behavioural influence	**Barriers to address**	**Suggested method of behaviour change**	**Definition**	**Parameters**
The idea that learning takes time & remediations are applied as a *'last resort'* when all other aspects of self-management are adhered to, but control remains poor, may be an area to tap into to promote earlier uptake	All above barriers may apply here	Motivational interviewing (MI) (Kok *et al.,* 2016 cite: Self-determination theory; Theories of self-regulation; Miller & Rollnick, 2012; Ng *et al*., 2012; Ryan & Deci, 2000) may apply. Or anticipated regret (Kok *et al*., 2016 cite: Theory of Planned Behavior; Reasoned Action Approach; Richard, van der Pligt, & de Vries, 1995): regret for not adhering to preventor medication was discussed in section 4.10, and the same may later apply to environmental remediations.	MI: "*Providing a collaborative, goal-oriented style of communication with particular attention to the language of change; designed to strengthen personal motivation for and commitment to a specific goal"* (Kok *et al.,* 2016, table 1, pp6). "*Anticipated regret: Stimulating people to focus on their feelings after unintended risky behavior, before any losses actually materialize"* (Kok *et al*, 2016, table 5, pp10)	MI requires a supportive and collaborative relationship between the families and health professionals (Kok, *et al*., 2016, table 1,pp6). Anticipated regret*: "Stimulation of imagery; assumes a positive intention to avoid the risky behavior."* (Kok *et al.,* 2016, table 5, pp10).

6.9.3 Intervention recommendations

The findings and theoretical model (chapters 4 and 5) suggest that perceptions and beliefs must be changed first to inform alteration of remediation behaviours. Educational interventions may inform beliefs in the sample described in Chapter 4, although, experience and direct observation are also vital in informing relevant health beliefs and have informed remediation behaviours. Therefore, it is proposed that a multi-faceted complex intervention is likely to be necessary. The use of multiple BCTs and techniques in one intervention is common (O'Cathain *et al*, 2019), and is supported by the mapping in Table 13. Care must be taken to design such interventions, as whilst single BCTs have often been tested, combinations or piecemeal combinations of theories have often not been systematically evaluated, rendering them 'a*theoretical*' (Prestwich *et al*., 2017, pp.79).

There is debate over the use of theory in interventions; interventionists who wish for a practical solution to address a problem may choose not to adopt theory but rather develop evidence-based interventions. For those wishing to understand how and why an intervention may or may not be successful or those wishing to test theory, theory-based intervention development is advocated (Prestwich *et al.,* 2017).

6.9.4 Previous interventions & theory use

As highlighted in earlier chapters (1.5.1; 1.5.2; 1.5.3) many intervention descriptions do not elucidate specific BCT or techniques clearly and evidence-based trigger interventions have been small scale studies, which limits generalisability. The current substantive theory may be a useful model to understand beliefs and behaviour and provide options for testing BCT to address beliefs that act as barriers to remediation uptake.

Interventions aiming to achieve best possible health outcomes can lead to unintended consequences (Michie and Abraham, 2004). The next subsection will discuss the potential for unintended consequences related to the suggested broad intervention aims and potential BCTs and techniques discussed.

6.9.5 Potential disadvantages of increased trigger perceptions

An argument presented in this thesis has been that improving trigger and allergen avoidance is likely to promote improved asthma control in CYP with severe asthma, particularly those exposed to allergens they are sensitised to. As outlined in Chapter 1, this is a somewhat controversial area, since meta-analyses and systematic reviews reported insufficient data to support recommending allergen avoidance measures for all with asthma and sensitisation in the UK (BTS/SIGN, 2019). As also discussed, experts in the field believe a pragmatic, individualised approach is required for CYP (Custovic *et al.,* 2019).

Additionally, self-management studies (including some discussed in chapter 2) provide evidence that supported self-management is a complex, time consuming and burdensome practice for families. CYP are also often overburdened by anxiety and fear that accompany managing a potentially life-threatening chronic condition (Pateraki *et al*., 2018), and co-morbidities in some cases. Parent-carers also describe fear and anxiety related to children's asthma (Fawcett *et al*., 2019) and severe allergies (Lagercrantz *et al*., 2017), in addition to managing daily and family lives (Horner *et al.,* 1998; Maltby *et al.,* 2003; Hughes *et al*., 2017). This sub-section will critically describe the evidence surrounding the burdens of managing triggers and allergens and will note interventions to increase understanding must also tackle any increased burden by promoting evidence based and practical solutions for busy families.

As highlighted in section 2.3.3, increased trigger awareness has been associated with reductions in QOL in CYP (Janssens and Harver, 2015). Yet, reduced QOL is also associated with exposures to a greater number of triggers (Luskin *et al*., 2014), and more severe attacks (Chipps *et al.*, 2018). Families and CYPs must be equipped with knowledge and understanding and although beyond the control of many families, be financially capable or financially supported to enable selection of evidence-based methods to reduce exposures once identified, to counter possible reduction in QOL or associated anxiety. Some behaviour change techniques rely upon exposing potential negative consequences, as suggested by theories that promote deconditioning, environmental re-evaluation, or anticipated regret (Kok *et al.*, 2016). However, as the findings chapter explains, families learnt the importance of preventor inhaler adherence and in some cases allergen remediation uptake over time, through

experience, in addition to clinical advice. As section 6.9.1 explained, such deconditioning is time consuming (Kok *et al.,* 2016) and anticipated regret may impact QOL. Moreover, methods such as deconditioning, if purposefully undertaken, could be regarded as ethically questionable. Additionally, early uptake of HDM remediation has been suggested for sensitised children, as it may be protective against asthma development. Whilst the evidence here remains debated and further research is necessary, experts promote early remediation until clear evidence is available (Zuiani and Custovic, 2020).

Evidence also shows that some indoor aeroallergens (for example, HDM: Der p1) act as irritants in addition to their allergic properties (Machado *et al*., 1996), which may alter perceptions of the importance of remediation for some.

In summary, selection of BCT and techniques to support intervention development and evaluation is complex, and the possibility of increased fear and anxiety associated with increasing trigger and allergen knowledge and perceptions should not be overlooked.

6.9.6 Interventions to reduce uncertainty

Interventions to manage uncertainty in those with chronic conditions is a developing field, focussed on psychological outcomes. Additionally, most have focussed on other conditions, particularly cancer, diabetes, cystic fibrosis, and rheumatic conditions, with fewer targeting CYP than adults or parent-carers (Szulczewski *et al.*, 2017).

The current study findings and promise shown by pilot interventions to reduce uncertainty in other conditions (Szulczewski *et al.*, 2017), may suggest future interventions to address uncertainty for CYP with asthma and their parent-carers may be beneficial for coping with uncertainty and for practical decision making about allergen avoidance.

6.10 Discussion of methodological quality of the current study

This section presents a critical evaluation of the current qualitative study and substantive theory. Critical evaluation is vital for demonstrating credibility (Charmaz and Thornberg, 2021). Many checklists and criteria have been developed to assess qualitative rigour, but these are not universally accepted and some advocate use of criteria particular to the methodology used (Creswell, 2007; Tracy, 2010). Judging

quality in qualitative research is complex and evolving, as Corbin (and Strauss 2008, pp.297) explains:

> *"Though I have been concerned with quality for some time (Corbin, 2002, 2003), I find this chapter on evaluation difficult to write. I feel paralyzed, unsure of where to begin, or what to write. As I search the literature, I find that everyone agrees evaluation is necessary but there is little consensus about what that evaluation should consist of. Are we judging for "validity" or would it be better to use terms like "rigor" (Mays & Pope, 1995), "truthfulness," or "goodness" (Emden & Sandelowski, 1999), or something called "integrity" (Watson & Girad, 2004) when referring to qualitative evaluation?"*

Tracy (2010, pp.837) described eight markers for qualitative research, which will be used as sub-headings to discuss the strengths and limitations of the current findings and theory. The markers include, topic worthiness, rich rigour, sincerity, credibility, resonance, contribution significance, ethics, and meaningful coherence. Tracy's (2010) markers were selected to guide this discussion as there appears to be a move away from the traditional use of terms such as validity and reliability in qualitative research due to quantitative connotations and origins (Charmaz and Thornberg, 2021), particularly for the variant of GT used in this thesis (Strauss and Corbin, 1998; Corbin and Strauss, 2008).

Tracy's (2010) criteria are supported by grounded theorists (Charmaz and Thornberg, 2021), who also recognise that each GT variant may emphasise differing elements of rigour. As such, Corbin and Strauss' canons (1990) and quality guidance in methodological texts (Strauss and Corbin, 1998; Corbin and Strauss, 2008) will also be referred to throughout subsequent sections.

6.10.1 Topic worthiness

Worthiness can be judged according to whether research is relevant, timely, significant, and interesting (Tracy, 2010). The scoping review provided insight into research gaps and needs for greater understanding of the target group's decision-making to inform future interventions. As discussed, these gaps were addressed by the current study and theory. Additionally, the findings support scientific evidence suggesting that indoor allergens are less likely to be appreciated (Wilson and Platts Mills, 2018: section 6.2.3) through participants' experiences and descriptions, which provides novel evidence. The study timing afforded an unanticipated opportunity to

explore participants' experiences before, during and post COVID-19 lockdowns, which also contributes to apparent research gaps about CYP with severe asthma and their self and family management of asthma during lockdowns and subsequent return to societal norms. It is argued that whilst clinicians continue to review CYP for sub-optimally controlled asthma which remains unexplained besides allergen exposures, that the findings of the current study and model can be applied in future intervention development to address low or slow uptake of allergen remediations.

The current qualitative study and substantive theory also provide novel insight into the perceptions, experiences, and decision-making processes of CYP with severe asthma and allergic sensitisation to indoor allergens and their parents. Asthma triggers are frequently referred to in the literature and asthma guidelines (BTS/SIGN, 2019; Fawcett *et al*., 2019) but research into family understanding of triggers and allergens and the effects of family understanding on remediation decisions has previously not been described. As discussed, the concept that irritant triggers and allergens are perceived differently may usefully inform interventions and should be considered for other types of research using patient-perceptions as outcome measures, which has not been highlighted previously. The inclusion of CYP participants is a strength, since the scoping review highlighted most previous research has included only parent-carer participants. Additionally, severe, or sub-optimally controlled asthma has often been overlooked or poorly defined, with many studies including parents of children with mild or moderate (sometimes self-reported) asthma. The sample demographics incidentally addressed the low number of studies with families living in more deprived areas of England (described in 2.2.2.5), since the current sample predominantly included those living in the most deprived decile (described in 4.3). Conversely, this may mean that current findings may be less transferrable to families living in more affluent areas. However, there was some spread of residence in a variety of deciles in the current sample. Adult and CYP PPI informed the study design and documents and was central to developing a lay summary (Appendix 4). The scoping review identified that PPI was not reported in included studies.

In summary, the current study adds to the evidence base, includes novel findings, contributes to evidence gaps, and has potential to inform intervention development or adaptions.

6.10.2 Rich rigour

Tracy (2010) notes the importance of rich description and evidence of sufficient data collection and analyses, but also cautions that time spent collecting or analysing data is not easily pre-specified; this is particularly so for GT (Strauss 1987) since it relies upon iterative methodology and theoretical sampling which can elongate data collection and concurrent analyses (Glaser and Strauss, 1967). Data in the current study were generated and concurrently analysed throughout, which was possible due to a slower recruitment phase than anticipated (discussed in 6.12). Iterative analyses are vital for GT (Corbin and Strauss, 1990) as discussed below.

Participant sample and context must be discussed when considering rigour (Tracy, 2010). There are limitations to consider regarding the participant sample. Qualitative studies often include fewer participants (relative to quantitative studies). Grounded theorists (and other qualitative researchers) stress data richness and theoretical saturation as opposed to pre-specifying ideal sample sizes (Morse, 1995; Morrow, 2005; Strauss and Corbin, 1998; Birks and Mills, 2015), which as Charmaz (2014) suggested, allowed more time for in-depth analysis in the current study. It is also arguable that recruiting further participants may be unethical if saturation is deemed (Francis *et al.,* 2010). During the concurrent recruitment and analyses period, signs of theoretical saturation were interpreted during analysis, and three further families were interviewed to confirm saturation and allow certainty that other theoretical insights had not been missed, by continuing induction alongside deduction and abduction. This approach avoids imposing the developing theoretical ideas on interviews and analyses too early. Later questions were developed and added to the end of the evolving topic guide, to explore whether those recruited later in the study had similar perceptions and experiences that could be explained by the developing theoretical model (as discussed in box 4, pp. 136-7). One further family was invited to participate, for a final interview discussion of the model. Unfortunately, the researcher was unable to contact them to confirm participation preferences, and no further families matched the inclusion criteria within the already extended recruitment period.

The experience with the current study sample size and saturation is supported by research that has shown that during qualitative analyses of 60 interviews, saturation

was achieved by the 12th interview (Guest *et al*., 2006). An ideal, feasible minimum sample of twelve is also suggested by other qualitative researchers (Braun and Clarke, 2013).

Theoretical sampling is a central tenet for GT (Strauss and Corbin, 1998) and this included sampling for a variety of CYP ages, ethnicities, and as described (3.4.9) sampling for fathers and further female CYP was attempted. The sample was dominated by mothers and male CYP. Attempts were made to address this using snowball sampling and by extending to public advertising specifically for fathers and female CYP. No further participants were identified via these methods. However, the two female CYP in the sample did not describe any new experiences that were specifically associated with being female. It is not possible to state that this means a larger sample of female CYP may not reveal other differences. For example, it is known that asthma is more prevalent in women than men, which is likely to be due to hormonal and immunological differences after puberty, but confounding factors are challenging to disentangle (Almqvist *et al*., 2007; Zein and Erzurum, 2015).

The predominance of male CYP can be pragmatically explained by epidemiological data. A review of the literature revealed that boys have higher prevalence of asthma and wheeze, but that data shows this begins to alter after adolescence (Almqvist *et al*., 2007). However, allergic sensitisation to indoor aeroallergens is also pertinent, since males have significantly higher rates than females (Melén *et al.,* 2020).

Fathers' participation in health research about CYP is often lower, which may be explained by ongoing preponderance of mothers as main carers in the British context. Research has shown that fathers participate less frequently as they report they are less frequently invited (Davison *et al.,* 2017). Adaptations were made to the recruitment strategy to attempt to counteract this (3.4.9). However, as mothers in the current study reported they were usually the ones to attend asthma clinics with CYP, mothers became unanticipated gatekeepers for researcher access to fathers. Mothers often explained fathers attended clinics less frequently or explained their absence due to family separation and mothers gave proxy perceptions of the low remediation uptake in separated fathers' homes. Future research could explore fathers' perceptions of asthma triggers and allergen exposures for CYP with asthma, since mothers and CYP accounts suggest fathers' understanding of these may also be limited, and increasing

fathers' knowledge may benefit CYP, if exposures at frequented family environments can be reduced.

The current study sample was made up of predominantly white British families (16 participants (76%), made up of nine mothers and seven CYP), with five belonging to other ethnicities (24%; made up of three CYPs and two mothers). This is somewhat representative of Yorkshire's population, which is includes approximately 85% white British people (UK population data, 2022). As discussed, the majority (58%) of the sample also resided in some of the most deprived areas. Representativeness is not usually an aim of qualitative research (Corbin and Strauss, 1990), and with GT, explanatory power is emphasised (Strauss and Corbin, 1998: Corbin and Strauss, 2008). However, it is important to fully describe the sample as this allows readers to assess transferability (Carminati, 2018).

Families living on low incomes were historically described as having limited asthma knowledge and understanding, but this was reportedly unfounded in one qualitative study (Simon, 2013). The current study suggests that overall, families have a wealth of knowledge and experience with asthma in general, but that addressing myths and misconceptions (altering beliefs) and expanding knowledge regarding pathophysiological mechanisms could provide a foundation for increasing remediation uptake across demographic backgrounds. Furthermore, remediation uptake did not appear more limited in those living in most deprived areas in the current study. This might suggest families prioritise financing remediations they believe are worth trying or they are motivated to try due to recurrent episodes of poor control.

Despite some limitations regarding sample demographics, theoretical sampling includes sampling within the data, via constant comparison, through re-examining previous transcripts in light of recent interviews. Theoretical sampling also includes interview question adjustment in response to discussions and emergent findings and later, in response to the emergent theory (Conlon *et al*., 2020; Foley *et al*., 2021). These were conducted throughout the study, and consistent methodological application lends support for rigour (Corbin and Strauss, 1990; Strauss and Corbin, 1998).

Whilst rigour assessment often involves assessing whether methodological procedures are followed, Corbin and Strauss (1990) stated their central tenets and criteria may be

perceived as overly prescriptive and recognise the need for flexibility, but caution that incomplete use of GT methodology may result in incorrect description of the study and lower quality theoretical outputs. Many of the points Corbin and Strauss (1990) describe for evaluative criteria were discussed in Chapter 3 and the central tenets were adhered to maximise the current study and theory quality.

6.10.3 Credibility

Tracy (2010, pp.842) discusses credibility regarding '*trustworthiness and plausibility*' and apparent truth. Credibility in GT is argued as shown through the development of explanatory concepts and conceptual connections, the identification of processes, and apparent significance of the findings (Corbin and Strauss, 1990; Strauss and Corbin, 1998). Whilst Tracy (2010) notes that member-checking or triangulation may demonstrate credibility, grounded theorists attest that credibility comes with following guidance and including the vital methodological steps (Corbin and Strauss,1990; Strauss and Corbin, 1998; Corbin and Strauss, 2008); for example, constant comparison can be used to explore meaning across the data, and theoretical sampling allowed for comparison across the data in the current study. This may be viewed as akin to member checking/responder validation or triangulation (Elliott and Lazenbatt, 2005).

Analytic techniques such as memoing are used to explore researcher reflections and ensure findings are grounded in data (Birks and Mills, 2015). There are many overlaps across Tracy's (2010) markers, for example, Engward (2013) notes that reflexivity is vital for the credibility of a GT, and reflexivity will be discussed in the next sub-section regarding sincerity.

6.10.4 Sincerity

Sincerity in qualitative research can be demonstrated through research reflexivity and transparency regarding the methods, methodology, and difficulties experienced in their application (Tracy, 2010). As discussed, challenges were experienced with recruitment, and sampling, and other challenges will be discussed in this sub-section.

GT methodology (Strauss, 1987; Corbin and Strauss 1990; Strauss and Corbin, 1998) was applied throughout. However, application of the conditional matrix was challenging for the researcher. Conditional matrices can be used to aid analyses (as discussed 3.6.3), particularly by aiding development of a storyline (Scott and Howell,

2008). Attempts were made to use a matrix (essentially a tabulation that uses questions such as*, why does this happen, when and with what consequences?* Scott and Howell 2008; Strauss and Corbin, 1998). However, as the concepts became complex and dense, condensing these into tables, without losing the complexity became challenging and did not seem to add anything to analyses. Instead, diagrams and use of axial coding paradigms (Figure 8) fulfilled the same purposes, as Strauss and Corbin (1998) suggest. The vital components of GT methodology (constant comparison, theoretical sampling, memoing, grounding in data; Corbin and Strauss, 1990) were adhered to throughout, with examples provided in Chapter 4. The writing of storylines (Corbin and Strauss 1990; Strauss and Corbin, 1998; Birks and Mills, 2015) was also employed in place of matrices, and these formed early drafts of the findings chapters. This allowed for checks to be made that categories were inter-linked, any gaps were explained, and the theory remains grounded (Birks and Mills, 2015).

Reflexivity is not well defined or explained in much of the literature (Palaganas, *et al*., 2017). Yet it is important in qualitative research to acknowledge researcher position, beliefs, identity, and preconceptions and avoid subjectivity unduly influencing any stage of the study. Reflexivity is often accounted for through journaling (Finlay, 2002). Prior to starting recruitment, notes were kept tracking thoughts and ideas that may affect decisions about the study. Memoing is important in GT and are often multi-purpose, including memos to aid planning, analytic memos, and reflexive notes (Birks and Mills, 2015). Memos were often multi-layered (as exemplified in Appendix 11) to acknowledge preconceptions that could unduly direct the findings or future data generation. Constant comparison also forces re-exploration of data through new lenses acquired from new data, ensuring findings are continually re-assessed for grounding in the data (Strauss and Corbin, 1998).

Critically, reflexivity may be perceived as researcher self-indulgence, and may in-turn steer researcher towards excessive self-focus (Finlay, 2002). To avoid excessive reflexivity, assurances that the findings and the developing theory were grounded in participants' accounts and meanings, participants' meaning was checked by repeating back to participants and asking them to confirm their meaning (Brinkmann and Kvale, 2018). There are also ethical responsibilities to avoid misrepresenting participants and

reflexivity contributes to this (Jootun *et al*., 2009), alongside verifying participant meaning during interviews, which was conducted.

In summary, transparency over the use of methods and methodology and reflexivity throughout the current study contributes to apparent sincerity, which are important components in allowing others to judge quality.

6.10.5 Resonance & evidence contribution

Potential impact and transferability are important when considering quality and Tracy (2010) terms this resonance. Discussing transferability of new findings is challenging immediately after a study is completed, but as discussed, some findings support (e.g., medicinal adherence; 6.5) extant literature that has been explored with other groups, such as adults or those with mild or moderate asthma. This might suggest that other findings may be transferrable to other age groups or asthma severities.

Grounded theorists suggest that theories are always provisional (Strauss and Corbin, 1998), and may be adapted for new contexts or alter over time. This also coheres with pragmatic roots, where Corbin and Strauss (2008) note that Mead recognised new knowledge as provisional. Additionally, theoretical concepts should only be developed into categories if they represent all participants in the sample (Strauss and Corbin, 1998), which may increase the likelihood of transferability. Negative cases should also be considered (Strauss and Corbin, 1998; Barbour, 2001), and this was exemplified through the tentative typologies suggested (5.3), including their differences and similarities, which also informed theory development.

6.10.6 Significant contribution

Tracy (2010) refers to the importance of whether a research study adds to knowledge or can guide practice or even provide empowerment. As discussed, the current study contributes to evidence gaps, and provides new theoretical knowledge grounded in participants accounts of their experiences. Behaviour change techniques and intervention suggestions are discussed related to findings and emergent theory.

The remaining markers of quality (ethics, meaningful coherence) were discussed in Chapter 3 and adhered to throughout. Although Tracy's (2010) ethics criteria has been critiqued since some *"believe ethics is an umbrella construct that threads through every aspect of qualitative work (including what seem to be technical considerations)".*

(Gordon and Patterson, 2013, pp.693) and this is in line with the current researcher's perspectives. However, Gordon and Patterson (2013) also note that they were able to usefully apply Tracy's (2010) criteria to their studies, in support of Tracy's (2010) proposed all-inclusive criteria, as it remains sufficiently flexible.

In conclusion, Tracy's (2010) criteria provided a useful tool to structure discussions of quality alongside the GT methodological guidance. GT has been critiqued and variants of the methodology have evolved over time. Those critiques that apply to decisions made during the current study will be discussed in the next sub-section.

6.11 Methodological critiques of grounded theory

All variants of GT have been critiqued to some extent, and the following discussion highlights limitations that may apply to the current study. Glaser has openly critiqued Strauss and Corbin's approach, by stating it forces the data, rather than allowing analysis to emerge (Glaser, 1992; Melia, 1996), through the use of conditional matrices and coding paradigms (Dey, 1999). As a result, Glaser argued that Strauss and Corbin's approach should be described as "*full conceptual description*" rather than GT (Glaser, 1992, pp.5). Further critiques that Strauss' (1987) and Corbin and Strauss' (1990) approach was perceived as rigid and less creative (Melia, 1996), were later addressed by Strauss and Corbin (1998) in their response, where they suggested their texts were guidance with some flexibility, particularly developed for novices and students. As discussed, for the current study, matrices were challenging to apply and seemed to add little value, although diagramming and following the axial coding paradigm technique guided examination of the data for processes and patterns beyond description alone. Strauss and Corbin (1994) explained that their variant of GT is a general methodological approach to conceptualising data, but that a GT can be developed using these techniques. Moreover, they noted that Glaser and Strauss had over-emphasised induction in early studies (Strauss and Corbin, 1994). Reichertz (2019) notes that Glaser's approach uses induction, but Strauss and Corbin utilise induction and abduction (Reichertz, 2010), "*which makes the action the data represent comprehensible and explains it. Research that takes an abductive approach makes action comprehensible by indicating the irregularities this action is based on, making its motives apparent, to an extent far beyond what the acting individuals themselves are aware of"* (Reichertz, 2019, pp.268). Since the current study aimed to develop

explanatory theory, choosing Strauss and Corbin's methodology may go some way to suggest methodological coherence.

This sub-section has summarised some arguments across GT variant proponents that may apply to the current study and theory and has argued for the use of the methodology employed. The next sub-section will discuss lessons learnt during the application of the methodology and methods selected.

6.12 Lessons learnt

6.12.1 Lessons learnt about methods

Adaption of the current study for pandemic measures afforded opportunities to try new methods and assess advantages and disadvantages. This section will explain experiences with recruitment, gatekeepers, remote, dyadic, and individual interviewing and will conclude with methodological insights gained.

6.12.1.1 Recruitment

As described in sections 3.4.3, 3.4.7 and 3.4.12, recruitment and data generation methods were adapted due to the COVID-19 pandemic. Recruitment was complicated by many clinical appointments also being remote and many clinics being cancelled. This resulted in fewer eligible participants than anticipated and elongated the recruitment period. However, slower recruitment allowed time for transcription (rather than using external transcribers), concurrent in-depth analyses and theoretical sampling, which are often seen as major challenges of GT in applied health settings (Elliott and Lazenbatt, 2005). Transcribing as soon as possible after interviews permitted early analyses and memoing alongside transcription, where larger participant numbers would likely have necessitated professional transcriber employment. This may have necessitated additional time for immersion in the data, had the sample been larger.

6.12.1.2 Gatekeeping

It is well known that research with CYP involves multi-layered gatekeeping (Brady and Graham, 2019). However, for the current study this elongated recruitment time and the data generation and analyses period, as parents also had to pass study information to their child and make time to discuss participation. Also, there were many delays

due to recurrent illness in recruited participants, which meant interviews were often postponed for long periods. Many of these issues were unavoidable since clinics used for recruitment continued to run virtually. Also, the nature of CYP's severe asthma often meant needing longer to recover from illnesses.

6.12.1.3 Remote interviewing

Most interviewees (eight of thirteen interviews: 61%) opted for telephone interviews. Most mothers commented that this was due to previous difficulties with using links to virtual options such as Microsoft Teams or Zoom. This meant that the options of using features of these software options (such as showing pictorial probes or sharing a white board to list triggers) were limited. These had been planned for participants who may have struggled to recall such experiences or who may have been uncomfortable on camera. However, those that did have virtual interviews did not need such probes.

Those who participated 'on camera' sometimes used unanticipated visual expressions, such as showing their dog and holding the dog close to their face, demonstrating that their asthma was not immediately altered upon exposure. In other cases, dogs coming into bedrooms during interviews may not necessarily have been captured in telephone interviews (although they were in one) and contributed to discussions about allowing pets into children's bedrooms. These insights are unlikely to have been captured if participants had been interviewed in a school or clinical setting.

It is possible that those who preferred telephone interviews may have declined if virtual interviews or (in-person) had been the only options, therefore offering both options likely maximised participation. Most telephone interviews worked well but a few were limited by poor connectivity at times, requiring participants to repeat some points. Fieldnotes and memoing immediately after interviews were indispensable for documenting details of both telephone and virtual interviews. Repeated calls with mothers to discuss the study and arrange participation also provided valuable insight that was followed up during interviews, for example, where a CYP had been unwell (which was common) and interviews had been re-scheduled, this provided an opportunity to build on what mothers had mentioned in previous calls and gave overall context of CYP's wellbeing and recent asthma experiences.

6.12.1.4 Dyadic and individual interviews

Most families opted for dyadic interviews, often stating that it was easier to arrange one time and date around other activities. It is possible that this was influenced by having never met the researcher in person and in most cases, prior discussion of the study was only possible with mothers.

Dyadic interviews largely worked well with participants comments reminding one another of experiences. They also afforded insight into how the dyad discussed asthma and allergy/sensitisation amongst themselves. Although, it is accepted that whilst interviews aim to capture conversations that are as natural as possible, participants knowledge that they are being researched is likely to alter how participants behave and what is said, and this can produce a filtered account or pre-used narratives (Morris, 2001). However, participants in the current study noted that their accounts were at times unfiltered, by stating they wondered if they should not comment on less positive experiences with clinical or school staff, for example.

In some dyadic interviews one participant dominated discussions, which is noted in the literature (Arksey, 1996). Attempts were made to balance this where possible (by re-directing or repeating similar questions to the less dominant participant), but just as researchers can be viewed as persons in positions of authority the same is likely true of parents (Punch, 2002). This was somewhat addressed by having some individual interviews but in most cases, parents were present in the background for these and so CYP would be aware their answers were heard by parents. It is not possible to know whether parental presence affected CYP's willingness to discuss some topics. However, discussing more controversial first-hand exposures (such as ETS or ENDs vapours) may have been avoided by CYP. Yet, the study design focussed on exposures in the home, and CYP are unlikely to smoke/vape at home with parents. As discussed in Chapter 1, first-hand smoking or vaping in CYP with asthma in the UK, is somewhat under-researched.

Individual interviews meant that participants were clear that questions were directed only to them and often meant CYP appeared more vocal than in dyadic interviews, although some CYP dominated dyadic interviews or parents encouraged them to be most vocal, as such this may relate to the parent-child relationship and personalities, or other undisclosed factors.

Dyadic interviews can complicate decisions regarding analyses, but some topics lend themselves to dyadic interviews (Eisikovits and Koren, 2010), and the current research about family management of triggers and allergens seems to align with this, due to parental influences on home environmental control. Inevitably, some perspectives were shared within dyads, and some differed in the current study. What remains unknown is whether further differences in perspectives were left unsaid due to the presence of the other respondent. This is also potentially important when asking CYP with pets if they are more symptomatic or triggered by pets. As all families wanted to keep pets, these responses could be guarded, especially in the presence of mothers.

Methodological literature on individual versus dyadic interviews often exemplifies studies with couples and some suggest interviewing separately but considering the dyad as the unit of analyses (Eisikovits and Koren, 2010). This can be considered as a means of triangulation which enhances credibility (Tracy, 2010). For the current study, dyadic interviews were analysed both as one unit and as separate accounts; for example, did participants agree or contradict one another? How was this reflected in codes and how did it contribute to the theoretical model? The same was true for individual interviews; where both a CYP and mother from the same family were interviewed separately, the same questions were asked of the data. There were some that were the sole participant from their family (one CYP and two un-related mothers). This meant that only one perspective was provided in these cases. However, GT emphasises constant comparison (Strauss and Corbin, 1998) at all levels. '*Subtext and relationship dynamics'* are also important to consider in dyadic analyses (Eisikovits and Koren, 2010, pp.1652), and as mentioned, these were of interest in the current study for context. A three-way conversation *'can reflect public and already rehearsed stories, but it also has the potential to challenge the implicit account*' reinforcing the need for researchers to attend to what is said by whom, interruptions, topic changes and researcher input (Morris, 2001, pp.564). Moreover, findings can be limited by participants' willingness to discuss topics. This can be due to participants' personal preferences over what they are willing to divulge, relate to fear of judgment, or even concerns they may be treated differently depending upon what they disclose (Randall and Phoenix, 2009). Participants were regularly reminded of their anonymity, rights to withdraw, or decline particular questions in the current study, but none did this. However, some did change the topic or seem to avoid questions at times. It is possible

these issues relate to rapport, and on revisiting all reflections in memos after interviews, conversations with some participants had felt more at ease and natural than with others. Additionally, two families had been concerned about the time the interview might take, due to other commitments and so both the researcher and participants were conscious of that during interviews, despite discussing alternatives such as to moving interviews to dates when families had more free time.

Attention to the conduct and analyses of child-parent dyadic interviews regarding medicine and health has been given far less attention in the methodological literature than adult interviews, particularly for GT studies. Insights from the current study add to evidence regarding these issues.

In summary, whilst recruitment was elongated, and gatekeepers were multi-layered, this, together with transcribing interviews, permitted time needed for data immersion, iterative analyses, and theoretical sampling. Remote interviews introduced some challenges but also provided important contextual insight into the home environment. Options of dyadic and individual interviews allowed participants choice. However, as with all parent-carer-child dyadic research, it is challenging to ascertain whether dyadic interviews or parental presence at individual interviews, consistently constrained or facilitated richer data and more or less open accounts.

6.12.2 Methodological lessons learnt

6.12.2.1 Application of theoretical sampling

Individual interviews were useful for application of the selected methodology within families; for example, data analyses from the first interview were used to allow question development for the subsequent family member interview and for filling in any gaps from the first interview, particularly historical gaps, where CYP may not be able to recall events in earlier life.

6.12.2.2 Reflection on the selection of Strauss and Corbin's (1998) and Corbin and Strauss' (1990; 2008) methodology

The selection of methodological guidance provided by Strauss and Corbin allowed for examination of the current literature to identify gaps and inform the study direction. However, other forms of GT (particularly classic or Glaserian) would have cautioned

against reading extant literature in advance (as discussed 3.3.4). This meant in the current study, eligibility was narrowed early to focus on a group identified as at risk of severe asthma outcomes, rather than starting broadly with few eligibility criteria (as many GT studies do). This may be perceived as at odds with other GT variants ethos, but Strauss and Corbin's guidance (1998) allowed this flexibility. This reduced the usually long process (Glaser and Strauss, 1967) of developing a research question whilst acquiring theoretical sensitivity throughout early analyses.

In conclusion, adoption of the methodology used suited the current study and permitted methodological coherence throughout.

6.13 Summary of recommendations for future research

There have been a limited number of studies investigating the effectiveness of the range of methods available for allergen reduction in homes of CYP with severe asthma and allergic sensitisation. As a result, UK guidance writers (e.g., BTS/SIGN, 2019) are unable to provide recommendations to clinicians to advocate particular methods. Clear guidance for which patient groups (for example, what level of IgE or skin prick test response is associated with remediation effectiveness for asthma outcomes?) are also most likely to benefit from such methods is also recommended. Further robust research in these areas could provide definitive evidence for clinicians to discuss and provide recommendations to families.

Innovative methods or techniques may be required to demonstrate the effects of allergen exposure on the airway responses to families and to improve understanding of the potential remediation can have for improving asthma symptoms and outcomes. Indoor air quality monitoring may also be a means to demonstrate healthy and unhealthy levels of allergen or indoor particulate matter to families, since these appear under-considered in most of the sample.

A range of BCTs and methods may be applicable but self-monitoring and encouragement of precaution adoption, which follow theories of self-regulation, were evident when mapped to current behavioural insights. Furthermore, self-regulation is repeatedly recommended for asthma self-management behaviour change (Clark, 2003; Horne and Weinman, 2002) and appears supported by the findings of the current study and theory.

6.14 Recommendations for practice

Future intervention developments will need to encompass emerging updates to the underlying evidence base regarding the effectiveness of remediation methods. Currently families undertake a range of methods. Whilst these are commonly recommended in clinics and have plausible likely benefits to asthma self-management, they are largely unsupported by robust evidence, (for example, carpet removal is a plausible suggestion to reduce dust reservoirs and thus reduce allergen exposures but remains untested as a means to improve asthma outcomes) (Custovic, *et al.* 2019).

Given that families with access to MDT care continue to struggle with these concepts, it is possible that families without this access (for example in cases of CYP with moderate/mild asthma) may be likely to benefit from further interventions also.

Practitioners should continue to offer advice in a supportive manner, recognising that families such as those in the current sample believe their child's asthma is unique and as families, they are experienced and able to rely upon their observations and experience to make decisions regarding CYP's exposures. More attention to asthma action plans may be required to update these in line with families growing experiences of self-management. In instances where families cannot conceptualise allergens in the same way as other more readily recognised triggers, more in depth explanation may help families to understand that an exposure may not elicit immediate symptoms in the same way as other triggers, but rather chronic exposures may contribute to overall sub-optimal control due to the underlying mechanisms involved.

6.15 Thesis conclusion

In summary, the current study and resultant theory address the gaps identified by the scoping review, by sampling CYP with severe asthma and co-existing allergic sensitisation and explaining their beliefs and behaviours about avoidance uptake. Participants resided in a predominantly socially deprived area of England, which addresses a further gap noted by the scoping review. Families are likely to benefit from further interventions to address low understanding of pathophysiology of the role of allergic sensitisation in asthma, as well as myths and misconceptions, which feed into related health beliefs and subsequently remediation uptake. The substantive theory explains the phenomenon holistically and may be transferrable to other

settings, conditions, CYP with different asthma severities, or other age groups. Methodological insights and experiences with methods will also contribute to a growing evidence base regarding research conduct during a pandemic, and the nuances involved in family research.

6.16 Reference list

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Appendix 1 Scoping review search terms

1 (child or children or childhood or adolescen* or teen or teens or teenager* or youth or youths or girl or girls or boy or boys or p?ediatric* or juvenil* or "young people" or "young person" or "young adult*" or "schoolchild*").ti.
2 (child or children or childhood or adolescen* or teen or teens or teenager* or youth or youths or girl or girls or boy or boys or p?ediatric* or juvenil* or "young people" or "young person" or "young adult*" or "schoolchild*").ab. /freq=2
3 Pediatrics/
4 young adult/
5 child
6 adolescent/
7 child/
8 or/1-7 [young people]
9 exp asthma/
10 asthma*.ti.
11 asthma.ab. /freq=2
12 or/9-11 [asthma]
13 (dust or mite*).ti.
14 (dust or mite*).ab. /freq=2
15 (animal dander or pet* or dog* or cat*).ti.
16 (animal dander or pet* or dog* or cat*).ab. /freq=2
17 Allergens/
18 (aller* or hypersensitiv* or sensiti?ation).ti.
19 (aller* or hypersensitiv* or sensiti?ation).ab. /freq=2
20 (trigger* or exacerbat*).ab. /freq=2
21 (trigger* or exacerbat*).ti.
22 or/13-21 [triggers]
23 ((barrier* or facilitator* or behavio?r*) adj5 asthma*).tw.
24 ((challenge* or constrain* or experience* or motiv* or influenc* or chang* or enab* or attitude* or perception* or perceive* or belief* or believe* or opinion* or view* or standpoint*) adj5 asthma*).tw.
25 ((incent* or factor* or limit* or demand* or driver* or driving* or facilitat* or threat*) adj5 asthma*).tw.
26 (interview* or qualitative or theme* or survey* or questionnaire* or focus group*).tw.
27 health knowledge, attitudes, practice/
28 "Attitude of Health Personnel"/
29 exp *Qualitative Research/
30 focus groups/
31 interviews as topic/
32 exp *Questionnaires/
33 family/px
34 parent/px
35 *Caregivers/px [Psychology]
36 ((attitude* or perception* or belief* or experience* or perspectiv* or knowledge or understanding) adj3 (carer* or caregiv* or care giv* or parent* or mother* or father*)).tw.
37 Attitude to Health/
38 or/23-37
39 8 and 12 and 22 and 38

Appendix 2 Scoping review findings summary table

Please note that gaps/differences in the detail in the table reflect the different reporting styles in the original articles: i.e., if aims/purposes were not reported in original articles, they are not reported here. Only findings relevant to this scoping reviews questions are noted. This table is minimally adapted from Lewis *et al.,* (forthcoming: supplementary information 3: no pagination) with the addition of statistical results for Raymond *et al.,* 2012; Shegog *et al.,* 2012; Biksey *et al.,* 2011; and Finkelstein *et al.,* 2002.

Reference	Context/country	Aim/purpose	Population	Study design
Crosland *et al,* (2009)	Northeast England, UK	Provide an exploration of parental perceptions of indoor environmental asthma risks and outline strategies taken in relation to those risks	(n=22) parents of (n=32) CYP (aged 4-16 years) with asthma (n=22 mothers and n=2 fathers)	In-depth qualitative interviews analysed using constant comparative analysis.
Holley *et al,* (2018)	Southampton & Isle of White, UK	To gain insight into barriers and facilitators for self-management, to inform an intervention	Adolescents (n=28), 16-18 years with asthma, and (n=12) parents	Semi structured qualitative interviews and focus groups were conducted and analysed using inductive thematic analysis.
Laster *et al*, (2009)	Metropolitan Atlanta, USA	Inform intervention development	(Total participants n=28) CYP aged 8-17 years, with moderate-severe, asthma and their parents/caregivers. Most (22/28: 78.6 %) were described as urban, low income, Medicaid/SCHIP-State Children's Health	Focus groups and thematically grouped description was used.

Reference	Context/country	Aim/purpose	Population	Study design
			Insurance Program receivers. 7.1% were uninsured	
Finkelstein *et al,* (2002)	USA	Assess prevalence of environmental trigger presence. Identify risk factors for trigger exposure. Determine whether parental trigger education is associated with fewer trigger exposures.	Parents of children (n=638 children) with asthma, aged 3-15 years	Cross-sectional study. Face-to-face interviews using 'close ended questions' [57, pp.259] were used to collect data. Statistical results: dog ownership was associated with lower parental education levels (Odds ratio (OR), 2.3; 95% confidence interval (CI) 1.2-4.3). household smoking was associated with low income (OR, 1.9; 95% CI 1.0-3.7) and low parental education levels (OR, 4.5; 95% CI 2.4-8.2).
Archibald *et al,* (2015)	Urban Canada	Gain insight into parents' asthma information needs	21 Parents of (n=23) CYP with asthma	Qualitative semi-structured interviews. Interpretive description guided design and analyses.
Shaw & Oneal (2014)	USA	To develop a grounded theory to guide interventions to reduce emergency visits and hospitalisations due to asthma	10 families, made up of 20 participants (n=13 parents, n=7 CYP, aged 0-18 years)	Semi-structured interviews. Grounded theory design and analyses.

Reference	Context/country	Aim/purpose	Population	Study design
Jonsson *et al,* (2017)	Sweden	Describe daily life experiences of adolescents with asthma, particularly relating to self-management.	16-18-year-olds (n=10)	Semi structured qualitative interviews analysed with systematic text condensation.
Velsor-Friedrich, *et al,* (2004)	USA (including four areas: inner-city, suburban, and rural)	Explore teens experience and behaviour related to self-management.	14-18-year-olds (n=24)	An ethnographic approach to exploratory focus groups.
Cashin *et al,* (2008)	Canada	Understand lived experience of being a father to a child with asthma	N=8 Fathers (of 7-11-year-olds with asthma)	Phenomenological, inductive design, using open interviews.
Gabe *et al,* (2002)	West London, UK	Aimed to study the meaning of asthma amongst CYP and strategies used to ameliorate asthma impact.	N=55 (11-16 years old) CYPs' data was analysed (14 parents were present in interviews, but not interviewed directly)	Semi-structured interviews were conducted. Ethnograph (software) was used for analysis.
Maltby *et al,* (2003)	Perth, Australia	To outline the meanings mothers ascribe to managing a child's asthma as part of daily life	N=15 mothers of children with asthma	A descriptive phenomenological study, using thematically analysed qualitative interviews, followed by focus groups to verify interview findings.

Reference	Context/country	Aim/purpose	Population	Study design
Horner, (1998)	USA (rural and urban)	An exploration of how families with school-aged children with asthma assimilate asthma into everyday lives	N=12 families (including n=15 CYP with asthma, aged 6-18 years old) Nine of the children were described as 'allergy positive' pp360 [27]	Qualitative interviews using grounded theory methodology.
Stewart *et al,* (2012)	4 Canadian provinces (mostly urban)	Identify young people's asthma and allergy support needs, barriers to meeting needs and resources available. Outline preferences for a support intervention	Young people (n=57) responded to questionnaires. Qualitative group interviews were conducted with (n=8) younger adolescents and parents (n=8; 6 mothers, n=2 fathers), meeting eligibility criteria of the scoping review age restrictions. Findings from young adults not meeting the inclusion criteria were not extracted.	Mixed methods, using a non-standardised questionnaire and in-depth group interviews. Thematic content analysis was performed using NVIVO and descriptive statistics were used for quantitative results. However, only the qualitative findings were relevant to the scoping review, therefore quantitative results were not extracted.
Van Dellen *et al,* (2008)	Amsterdam, Netherlands	Compare beliefs from families (with a child with asthma) of different ethnicities living in Amsterdam. These included native	CYP (n=40): Grouped (n=26) were 6-12-year-olds and (n=14) were 13-17-years old), and mothers (n=28)	Focus groups (grouped by ethnicity) were analysed using Kleinman's theoretical model (1980) [cited by 33].

Reference	Context/country	Aim/purpose	Population	Study design
		Dutch, Surinamese, Turkish and Moroccan families		
Parikh *et al,* (2018)	Washington DC, USA	To develop an understanding of the barriers and facilitators for asthma management, from parental perspectives held whilst children are in hospital for asthma care	N=10 parents of (n=12) children, all under the age of 12 years	Qualitative interviews were conducted with parents during their child's in-patient hospital stay. These were subjected to content analysis and quantitative content analysis (authors [56] cite Krippendorff, 2013).
Edgecombe *et al,* (2010)	Southampton, Portsmouth, & Isle of White, UK	To understand young people's experience of living with difficult, severe asthma, with interest in health care professional interactions and medication adherence	(N=22) young people, aged 11-18-years-old	Qualitative semi-structured interviews were analysed using the thematic approach of continual comparison.
Trollvik *et al,* (2011)	Norway (mostly rural-(n=12 of n=15 participants)	Explore children's experiences of asthma to inform the design of an asthma learning programme	Children (n=15), aged 7-10 years (All had co-existing allergies)	Semi-structured qualitative interviews combined with a meta-communication technique (children drew pictures to highlight asthma experiences and explained these to the researcher) was used. Phenomenological analysis of data was conducted.

Reference	Context/country	Aim/purpose	Population	Study design
Lakhanpaul *et al,* (2017)	London, UK	Explore and compare asthma perceptions and experiences between white British and South Asian families. This was planned to identify barriers to management to inform management and interventions that are culturally suitable	Matched (where possible) white British families (n=14 families) and British South Asian families (n=30 families)	Parents, children, and some extended family-members participated in qualitative semi-structured interviews, analysed with interpretive thematic analysis.
Raymond *et al,* (2012)	USA	Create a list of asthma management strategies adopted by parent-caregivers (by topic). Establish whether themes related to asthma severity, lung function and quality of life	Parents of children with asthma, aged 5-12 years (n=200 caregivers)	Mixed methods: qualitative interviews were analysed using open coding and line by line content analysis. Quality of life measures were used for the quantitative component and as results cannot be used to answer the scoping review questions, these were not extracted. Quantitative results: 77% avoided some indoor environmental triggers: 29% avoided ETS, 35% avoided pets, 10% avoided dust and HDM, 14% avoided keeping stuffed toys.
Yonas *et al,* (2017)	Pittsburgh, USA	To define experiences and issues in an economically underserved group with asthma. This was	Parents (n=14) and CYP (n=7) with asthma, living in the Homewood area (considered socio-	Community-based participatory research, using three concept mapping (focus group style) sessions.

Reference	Context/country	Aim/purpose	Population	Study design
		designed to inform a community-based intervention.	economically disadvantaged)	
Hughes *et al,* (2017)	Ireland	Explore young peoples' asthma in everyday life and develop a theory explaining how young people resolve concerns	N=51 young people, aged 11-16 years	Grounded theory design. Data from 18 interviews and 5 participant diaries (recorded over 2-week period) and 33 asthma consultations were analysed.
Mansour *et al,* (2000)	USA (inner city)	Explore parents' perspectives on the barriers to asthma care in an inner-city, minority group (all parents described their ethnicity as black)	N=40 parents (of n=47 children, aged 5-12 years), with asthma	Focus groups using open-ended facilitator questions. Statistical software was used to count the frequency of barriers mentioned.
Jan *et al,* (2014)	Hualien, Taiwan	Develop an understanding of family self-management experiences for children with moderate-severe asthma	Parents only (n=15) of children aged 8-12 years with asthma	Qualitative in-depth interviews were content analysed.
Martin *et al,* (2010)	Chicago, USA	Outline family self-management behaviours and beliefs	N=32 participants included	Participatory design using qualitative interviews and focus groups. Analyses

Reference	Context/country	Aim/purpose	Population	Study design
		in Midwest Puerto-Rican families with a CYP with asthma	Parents (n=13) and CYP, (n=19) aged 9-18 years old	were performed following naturalistic inquiry methods.
Biksey *et al,* (2011)	Pennsylvania, USA	Determine the extent of parents' knowledge about environmental asthma risks in homes, their behaviour, willingness to make behavioural changes, and determine any racial differences	(N=12) Parents only (of 4–8-year-olds with asthma): N=8 white families and (n=4) African American families	Mixed methods pilot study. Qualitative interview transcripts were initially coded into themes and a codebook was developed (authors [39] cite Miller & Crabtree, 1992). Transcripts were coded a second time to explore racial differences. Quantitative methods were less clearly outlined. Participants were asked about whether they knew or did not know environmental asthma risks in their homes, and their related behaviours. Statistical results: In 'white families' - greater awareness of triggers (t=2.43 p=.017) and higher uptake of avoidance strategies (t=1.98; p=.04; particularly for HDM reduction t=3.23; p=.009).
Yinusa-Nyahkoon*, et al,* (2010)	Boston (inner city), USA	Outline ecological and social barriers families experience in managing children's asthma	(N=19) African American parents of 5-12-year-olds with asthma	Semi-structured interviews using a constructivist grounded theory approach to qualitative analysis were used Follow

Reference	Context/country	Aim/purpose	Population	Study design
				up interviews were conducted 1 year later in n=11 cases).
Gibson-Scipio *et al,* (2013)	Urban Detroit, USA	Identification of asthma management goals, beliefs and issues facing carers of African American and mixed-race teenagers with asthma	(N=14) caregivers of 14–18-year-old African American or mixed race CYP with asthma	One Focus group was conducted. Content was iteratively analysed, and descriptive themes were outlined.
Gibson-Scipio *et al,* (2015)	Urban Detroit, USA	Exploration of management goals, beliefs, and behaviours of African American teenagers with asthma	(N=13) CYP aged 14–18-years-old	One focus group was conducted. A modified grounded theory approach was used.
Soo & Tan (2014)	Singapore	An exploration of carers' knowledge, understanding and perceptions of asthma and how these influenced self/family asthma management	N=14 carers (of CYP with asthma, aged 4-15 years) in 3 focus groups (included 3 ethnicities and n=13 mothers and n=1 father)	Three focus groups were conducted. Content analysis was undertaken with NVIVO software.
Mammen *et al,* (2018)	Upstate New York, USA	Develop an understanding of teenage asthma self-management and teen and carers' perspectives on the important	(N=28 participants / 14 family dyads including parents and CYPs). Teens were aged 13-17 years. Most were categorised as having moderate asthma,	Qualitative interviews with CYP and parents were conducted, and CYP voice diaries recordings were collected. Data analysis followed the 3-step process outlined by Walker and Avant [cited by 51] for theory synthesis. After initial analysis,

Reference	Context/country	Aim/purpose	Population	Study design
		aspects of self-management	but some had mild or severe asthma	priori codes from Mammen and Rhee's 2012 [cited by 51] study with clinicians and researchers, were used for comparison (transcripts were re-coded with priori concepts from the previous study. Atlas.ti and Xmind were used for analysis.
Shegog *et al,* (2012)	Urban, USA	To classify what CYP and parents believed they could attribute successful or failed asthma self-management tasks/outcomes to	(N=65) CYP (9-13 years, 63% male) and their primary carer participated. (50.7% of CYP had mild asthma, 38.5% moderate and 10.7% severe)	Participants were randomly presented with scenarios (showing both successful and poor asthma self-management) to facilitate structured interviews. Interview findings were coded by causal dimensions (internal/external; stable/unstable; controllable/uncontrollable) and correlations were calculated to explore relationships between child-parent causal dimensions per each self-management 'domain' (domains included: medication adherence, symptom monitoring and environmental trigger avoidance) [59, pp.274]. Quantitative results: Children attributed trigger avoidance success and failure to mostly internal (85.9% to 96.9%) and controllable (73% to 93.2%) and unstable (69.2-79.4%) causes. Parents believed causes of success/failure of trigger avoidance were internal (79-68.3%),

Reference	Context/country	Aim/purpose	Population	Study design
				controllable (85.5-54%) but unstable (59.7-73%).
Pradel *et al,* (2001)	USA (North Carolina)	Explore knowledge and beliefs about asthma, child's autonomy in asthma self-care, medication, and any variation in this by age	(N=32) children aged 7-12 years with moderate-severe asthma	Two interview styles were used to triangulate qualitative findings using content analysis 1. An 'ethnographic' interview where children were asked to draw the last time they were unwell and then talk about it in interview. 2. An 'asthma figurative process interview' (29; pp.201), during the same visit as interview 1, or in a 2nd visit (30 interviews) was used. The aim was for children to describe the processes involved in an asthma exacerbation. Data were coded and Stata 4 for Windows database was used to count the frequency of answers.
Prout *et al,* (1999)	North Midlands, England, UK	Explore the adaption perspective in families with cases of childhood asthma	N=9 families with a child (7-12 years) with doctor diagnosed, moderate asthma	Semi-structured interviews were conducted with parents and separately with children. The study included children's drawings to facilitate discussion and parents made a timeline of events preceding the child's last asthma exacerbation. Findings were reported per family rather than collectively or thematically. The methodology and methodological references were not

Reference	Context/country	Aim/purpose	Population	Study design
				explicitly outlined. The authors noted that the *"study reported in this paper was originally conceived of as broadly within the adaptation* *Framework"* [58, pp.142].

Appendix 3 Example CASP assessment for a study included in the scoping review

[An additional scoping review checklist (PRISMA-SCR) for the review is available in the supplementary information for the published scoping review: Lewis *et al.,* forthcoming)]

CASP Qualitative checklist (CASP, 2018) ***refer to hints online, if needed***	
1.Validity (are aims clear?)	1. *Yes*
2. Is qual methodology appropriate?	2. *Yes*
3.Is it worth continuing? (Was the research design appropriate to address the aims of the research?)	3. *Yes*
4. Was the recruitment strategy appropriate to the aims of the research?	4. *Yes, but other alternatives also appropriate*
5. Was the data collected in a way that addressed the research issue?	5. *Smaller focus groups might have been better but otherwise yes*
6. Has the relationship between researcher and participants been adequately considered?	6. *They state reflexive but no other details given*
7. Have ethical issues been taken into consideration?	7. *Seems so*
8. Was the data analysis sufficiently rigorous?	8. *Seems so*
9. Is there a clear statement of findings?	9. *Yes*
10. How valuable is the research? (will results help locally?)	10. *Adds to the evidence base re misconceptions and age for responsibility being quite arbitrary.*

	-suggestive that more work needed in school liaison given amount of time spent there

Appendix 4 Lay summaries: Summary of research study findings

Lay summary for 11–15-year-old participants:

Short study title: What families believe and do about children's asthma triggers at home

Researcher: Grace Lewis

What were the main aims of the research?

To talk to children, teens, and their parents to find out more about living with asthma, asthma triggers, and what families do about triggers.

Summary of the interview findings

Thank you for talking to me about asthma and things that trigger your asthma.

Here, I will tell you a bit about what people in your age group told me and how I will use these ideas.

Children and teenagers were able to tell me what triggers their asthma. Asthma triggers were seen as things that set off a cough or wheeze quite soon after the trigger.

By choosing not to be near that trigger again, children and young people were able to see if this helped with asthma. If it did help, these things were avoided when possible.

When we talked, children and young people told me lots of things trigger their asthma, but they were not sure if house dust mite was a trigger.

Cats and dogs were seen as triggers by some people. Sometimes cats or dogs made people's eyes sore or runny or gave them a rash. This also made them avoid these pets. Others could not see that pets triggered their asthma and so kept pets at home even if they sometimes had sore eyes or an itchy rash.

Most people told me they would carry on with the same things they do now to avoid triggers. They might think about changing this if their asthma got worse. Young people who owned pets were keen to keep their pets and were comforted by having them, even though an allergy test showed that the pet might be a problem for their asthma.

Everyone I spoke to found it hard to know how house dust mite or pets might affect their asthma or other people's asthma.

Some people I spoke to did not know all of the things that parents do to help them avoid house dust mite. This included things like having mite-proof bedding covers or washing bedding at a high temperature, for example. This was sometimes because these things were done since they were very young.

What happens now?

I am writing about this research and will share what I have found with people who work in asthma research and with doctors and nurses.

I will tell them that some things that trigger asthma are easier to spot than others. Things like house dust mite and furry pets do not always seem to be a trigger for all children, even if their allergy test shows they might be.

I will suggest that it might help families to know more about how things like house dust mite and furry pets can affect asthma in different ways to other triggers. It might also help for families to hear more about what they can do to cut down on the effects of these things at home.

Thanks again for taking the time to talk to me for this research.

……

Summary of research study findings [for parent participants: this will be emailed to participants as per their preferences]

Short study title: What families believe and do about children's asthma triggers at home

Researcher: Grace Lewis

What were the main aims of the research?

To talk to children, teens, and their parents to find out more about living with asthma, asthma triggers, and how these are avoided.

Summary of the interview findings

Thank you for taking part in the asthma trigger study interviews during the last year.

This is a short overview of what parents, children, and young people told me in interviews.

If families can see that a particular trigger making their child's asthma worse, then they try to avoid it. Families choose to avoid triggers and allergens they are sure have an effect on their child's asthma but are less likely to avoid things they cannot see have an effect. This is true where there has been a reaction on a skin prick test. This tells me that experiences with asthma and seeing what triggers it for yourselves are very important in making decisions about what to avoid.

Advice in clinic is also important but sometimes families had been worried about home visits and about being judged for triggers or allergens that are still in the home.

When it came to how to avoid or reduce allergens like house dust mites, some families had lots of things in place for this, such as freezing soft toys or removing carpets. Others had not heard of some ways to reduce house dust mites (such as mite-proof mattress protectors/ bedding or using de-humidifiers) at home and were unsure if trying these things would make a difference. For some, there were other barriers to tyring these, such as financial costs.

Families struggle with the idea of re-homing pets when they cannot see that pets have an effect on children and young peoples' asthma.

Families have a lot to remember from clinic appointments. Not everyone could remember all ways to reduce allergens at home and not everyone could access this information on the internet.

Many families told me that care for their child's asthma at school is disappointing and worries them.

Families are keen to reduce their children's need for extra medications (like oral steroids and antibiotics), regular asthma attacks and hospital stays. In some cases, families told me that they thought putting extra

things in place to reduce house dust mite at home had helped improve their child's asthma control. Others were unsure if it was these things that helped but had noticed a general improvement in asthma control over time but could not be sure whether this was due to changes made to avoid triggers or allergens.

What happens now?

I am writing up all findings in my PhD thesis and presenting this work to health professionals who work with children and young people with asthma. From the study findings I will recommend many families will benefit from the following:

1. Early, clear information for all about what allergens are, how they affect asthma and how they can be reduced
2. Early, clear advice on which house dust mite reduction methods (for example, mite-proof mattress protectors) have been shown to successfully reduce mite presence and have benefits to children's asthma
3. Discussions in clinic about re-homing family pets need be more understanding of family's feelings towards pets and the emotional benefits of pet-keeping.

Other areas for future research:

More research is needed to know which children are more likely to benefit from pets being rehomed to help doctors and nurses advise families on these difficult decisions. More research is also needed to understand which children are most likely to benefit from ways of reducing house dust mites.

Additional recommendations:

Although this study focussed on asthma triggers in children's homes, all parents had some concerns about managing asthma in schools. Further research in this area is needed to improve children's and teenager's access to medication and care during school time.

Appendix 5 Study poster

Are you 11-16 years-old

& have asthma?

If so, you and your parent/carer(s) may be able to take part in our research study looking at asthma triggers. Please scan the QR code or visit https://leeds.onlinesurveys.ac.uk/asthma-trigger-research-survey to answer a very short survey and read the study information.

Thanks for reading! Grace Lewis, PhD student, University of Leeds & Asthma UK Centre for Applied Research. **Email:** hcgml@leeds.ac.uk

Telephone: 07874 895723 or 0115 888 0791. Local supervisors in paediatric asthma clinic: Dr Duff & Dr Adams

IRAS no: **292697.** Version 2, 19/02/2021. Research Ethics Committee ref. no: **21/SW/0034**

Appendix 6 Study information sheets

School of healthcare

Young persons' information leaflet

What families believe and do about children's asthma triggers at home

Are you aged between 11 and 16, have asthma and a positive skin prick test (to animals/pets or house dust mite)? If so, I would like to speak to you and your parent(s)/carer(s). Please read on to see if you are interested.

You are being invited to take part in a research study. This information sheet describes the study and tells you what to expect if you choose to take part. First, I will tell you all about it and then you can take some time to decide and talk to family and friends about your decision. The first 3 pages tell you about the research study. The final page tells you and your parent/carer more about how we will use the information you give if you take part.

What is the study about?

We know that people with asthma find lots of things can 'trigger' their asthma. By triggers, we mean things around you that bring on your asthma or make it worse. These triggers might be things like being around animals or strong smells, for example. I hope to find out more about what you think about triggers. This research is part of my PhD project I am carrying out at the University of Leeds, School of Healthcare with Leeds Children's hospital. [Research Ethics Committee reference number: 21/SW/0034].

Why have I been chosen?

For this research, I would like to speak to people your age who have asthma that can be more difficult to control and who have had reactions to skin prick tests in clinic. I hope to speak to around 15 families who have a young person in the home that fits in with those things. I hope to do this over the next few months.

What will the project try to find out?

By the end, I hope to be able to explain to other people what you and others with asthma think about triggers and what you might do or not do about them. This can help us to change the way we explain triggers to people and help them to avoid triggers when needed.

How does the study work? What will happen if I take part?

If you agree to take part, I will talk to you about what you think about asthma triggers and what your experiences are. This type of study is just like having a chat and it is usually called an interview. You do not need to worry about not knowing what to say before we start. I will ask questions to help with this. I hope to talk to one or both of your parents/carers too. This

can be at a different time, or I can speak to you and your parent/carer together if you prefer. You can still take part even if your parent/carer does not want to take part themselves. I will need to check your parent/carer is happy for *you* to take part, if you are under 16 years old.

Should I do anything to get ready before the interview?

You do not have to do anything before the interview, but it might help you to think of things that set your asthma off or make it worse. To do this you could write a list, draw pictures, or take photos. If you do take photos, please do not include peoples' faces and ask your parent/carer's permission before taking photos at home. If you do take photos, draw a picture, or write a list, we can talk about those in the interview. If you agree, I might use some photos or pictures in research reports, but these would not include your name or anything that might show it is yours. This would be your choice. These activities are optional, and you can still take part in the interview without doing them. It is also ok if you cannot think of any triggers, you can still take part if you want to, and this will still be useful to the research.

How would it work?

We can find a time to suit you, after school or on a weekend. This research only involves talking, so we can plan to do this online or by phone. Before we can talk, I would need to ask you and one of your parents/carers to sign a form to say that you both agree to this; if you are aged 11-15 years – you and your parent/carer will need to fill in both parts of form B (if you *are* 16, only you needs to sign form A). This can be done by you and a parent/carer before we talk, and if you can, please send a photo/scan of the form by email. If not, we can talk through the form instead on the day of the interview. So that I do not have to take lots of notes I would like to record us talking. I will only do this if you agree to it and would only record us talking, not video. The length of time we talk for will vary from person to person. I will check with you if you need a break or if we are talking for too long. A rough guide would be that we might talk for 20-30 minutes but it can be less if this is too long for you on the day. If you have written a list of triggers, drawn pictures, or taken photos, you can show these on camera if we are talking online, or talk about them. These can also be sent by email to hcgml@leeds.ac.uk but only after you/your parent/carer has either sent forms A/B or we have talked through these. It is ok if you choose not to do this, we can just talk instead.

If I agree to take part, who will interview me?

My name is Grace Lewis, and I am a PhD student at the University of Leeds, and I work closely with Leeds Children's Hospital NHS Trust and Asthma

What will happen to the things I say?

I will listen to the interviews and put them into writing. A person trained to do this will help me. This person has agreed with the university of Leeds to keep this private and safe. At the same time, we will take out your name and anything that shows that it is about you or your parent/carer. Once your name and any other details about you are taken out, my supervisors (listed on the last page), will be able to see the written versions. This is so that we can agree on what we think the research tells us.

When I write my report at the end of the study, I will use some short quotes from our interview, and pictures/photos if you have agreed to this. In these reports, short quotes are used to explain what we mean clearly. Quotes (or pictures/photos) will not have names linked to them, so no one will know it is you that said those things. Photos/pictures will only be used in reports if there is no way to tell they are yours. This is why it is important not to include faces. Reports can be seen by other people who are interested in this kind of research (usually people studying or working in health or research). If you are interested, I can send you a short summary of what I find out, when the research is finished.

What happens to recordings and notes (and any pictures/photos) when the research project has finished?

There are very strict rules about how I must store everything. The recordings, notes, and any pictures/photos you send, will be stored on a computer with passwords. Recordings will be stored until they can be changed into writing-usually within a few weeks of us meeting/talking. After that the recordings will be deleted. After the study has ended the University of Leeds would like to store written versions of what has been said in a safe way. Your name or address would not be saved. This would only be seen by other researchers who have a good reason to look at it. If you agree, this would be stored for about 10 years. You can still take part in the study even if you do not want what you have said to be stored in this way, for longer.

What happens if I change my mind about taking part?

Sometimes people start research and then change their minds. If you agree to take part, you can change your mind, and this is ok. You can stop being part of the study at any time. You do not need to tell us why, but we will keep information about you that we already have. You can choose not to answer some questions if you prefer not to, but still take part by talking through other questions. That is fine and there would be no need to explain why you do not wish to answer some questions. After the interview if you change your mind and do not wish what

you have said to be part of the study, please tell us within one week of the interview. This is because we start to look at what you tell us very soon after the interview.

What are the benefits of taking part?

This project is all about what young people think about asthma triggers. This is something we do not know very much about. There is no direct benefit to you. If we know more from this project, it can help us and the people who care for young people at hospitals and clinics to support people your age to manage asthma well.

Is there a thank you payment?

We can offer a £5 voucher to thank you for taking part if you choose to. It is best if I can email this to you or your parent/carer, but if not, it can be posted to you.

Why will you speak to my parent/carer too?

This project will focus on triggers at home. Speaking to both of you will tell us if you think the same way or differently about triggers and can tell us how we can support families in the future. There are no right or wrong answers, but you might have different ideas to each other.

Are there any risks?

No, but if anything you talk about makes you feel uncomfortable we can advise you who to speak to, to get help.

What if I have other allergies or skin prick test reactions?

You can still take part if you have other allergies or skin prick test reactions to other things as well as having had a reaction to house dust mite and/or pets/animals. It would be good if you can tell me any that you can remember during the interview. You might have listed them on your asthma action plan.

What to do next: If you decide to agree to take part or would like to ask more questions before deciding, please email me (Grace): hcgml@leeds.ac.uk or call/text: **07874 895723 or 0115 888 0791**

The project team: Grace Lewis, PhD student, School of Healthcare, University of Leeds

(Grace's supervisors) Dr Alistair Duff, Leeds Children's Hospital alistair.duff1@nhs.net; Dr Linda Milnes, University of Leeds L.J.Milnes@leeds.ac.uk; Dr Alexandra Adams, Leeds Children's Hospital alexandra.adams2@nhs.net; Professor Jurgen Schwarze, University of Edinburgh Jurgen.Schwarze@ed.ac.uk

Who is funding the research? This work is funded by Asthma UK as part of the Asthma UK Centre for Applied Research [AUK-AC-2018-01]

Where can I find out more about how my information is used?

- At www.hra.nhs.uk/information-about-patients/
- By asking one of the project team

- By emailing hcgml@leeds.ac.uk
- By emailing the sponsor (University of Leeds) Data Protection Officer: dpo@leeds.ac.uk

What to do if you have concerns/a complaint: Please contact Grace Lewis (hcgml@leeds.ac.uk) or Dr Alistair Duff alistair.duff1@nhs.net Or the PALS & complaints team: 0113 2066261 patientexperience.leedsth@nhs.net

Summary of how we use & protect your data ('we' describes the study sponsor- the University of Leeds): If you are under 16, we ask that your parent/carer reads this section too

In this research study we will use information from you and your parent/carer. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study. Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules. At the end of the study, we will save some of the data in case we need to check it and for future research. We will make sure no-one can work out who you are from the reports we write. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

During data collection (interview) we will follow NHS safeguarding advice should there be any concerns about a participant's safety. You can read more about this at: https://www.england.nhs.uk/safeguarding/policies-annual-report/

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. Please notify us within one week of the interview if you no longer wish us to include what you said in the interview in the research. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study [RADAR: Restricted Access Data and Repository at the University of Leeds].

Thank you for taking the time to read this information. If you have any questions, please email hcgml@leeds.ac.uk Or call/text: 07874 895723 or 0115 888 0791

I am happy to call you back

Asthma UK Centre for Applied Research | UNIVERSITY OF LEEDS School of healthcare

Parent/carers information leaflet

What families believe and do about children's asthma triggers at home

Do you care for a child/teenager with asthma (aged 11-16 years) who has had a positive skin prick test to animals/pets or house dust mite? If so, I would like to speak to you and your child. Please read on to see if you are interested.

You and your child are being invited to take part in a research study. This information sheet describes the study and explains what will be involved if you decide to take part.

What is the study about?

We know that children and young people with asthma often find many things can 'trigger' their asthma. These triggers might include things like being around animals or strong smells which might bring on some asthma symptoms. Since research in the past has not looked into what children, young people and their parents/carers think about asthma triggers in their homes and how you might try to manage these, I am interested in your thoughts and experiences on this. This research is part of a PhD project I am conducting at the University of Leeds, School of Healthcare with Leeds Children's hospital.

What will happen if we take part?

If you agree to take part, you and your child will be invited to a research interview to talk about your thoughts and experiences. This type of research is a lot like having a conversation and does not usually feel formal. Before the interview can start, I will need either a signed copy of consent form A (you can email me a photo/scan of the form), or we can talk through the form together and I will audio-record this on the day of the interview. I will also need your consent if your child is being interviewed too and is under 16 years old. This means completing a separate form (form B) and sending it or talking through it with you both. The interview can take place at a time to suit you with either online interviews using Microsoft Teams/Zoom or by telephone interview. Usually, interviews with adults last up one hour but this can be less. If you agree, I will record the interview (audio only), to save me making notes throughout. If you choose to use video conferencing, I will not record the video part. I plan to interview most children and parents/carers separately to give you both a chance to give your views fully, but if you or your child is not comfortable with that, we can arrange one interview all together. Interviews with children are usually shorter and can be tailored to suit the individual, but as a rough guide for children these may be 20-30 minutes. I have also given the option for children to list their triggers, draw pictures, or take photos of things they think trigger their asthma. I have asked that children ask parent/carers' permission to take photos and that they do not include faces. This is optional, and you and/or your child can still take

part in the interview without doing this. The idea is that it might help children think about triggers before the interview.

If we agree to take part, who will interview me?

My name is Grace Lewis, and I am a PhD student at the University of Leeds, and I work closely with Leeds Children's Hospital NHS Trust and Asthma UK Centre for Applied Research.

Do we have to take part? No, it is your choice whether you would like to take part. If one of you wishes to take part and not the other, that is fine. Ideally, we would like to hear both of your views on asthma triggers. If you start the study and then change your mind, you can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We ask that if you later decide you would like to withdraw what you (or your child) have said during interview, that you notify us within one week of the interview. This is because in this type of research we start to look at what each person tells us very soon after each interview. This means it is very difficult to fully remove the influence of what was said in the interview, on the research.

Your child's asthma care will not be affected in any way by your (or their) decision to take part or not. You can still take part even if the child/young person with asthma in your family does not want to take part themselves. If your child also wishes to take part, please read their information with them, and look at the consent/assent forms (forms A & B); if they are 11-15 years old, please complete the 2nd part of their form (form B) to give your permission. Form A is for your consent to take part as a parent/carer and/or for young people aged 16 years. We can talk through these in advance or on the day of the interview. If you child has drawn a picture/taken photos, these can be shown on camera if they have an online interview and sent to hcgml@leeds.ac.uk after the assent/consent forms are completed, if you are both happy to share these.

What will happen to any information we give?

We will need to use information from you for this research project. This information will include your name and contact details and what we discuss in the interview. People will use this information to do the research or to check your records to make sure that the research is being done properly. Any information you give and anything you say will be confidential. Your names and contact details will be stored separately to the interview recording and names will be deleted as soon as possible. Any other details you mention that could be used to identify you or your child will also be removed. In research we use quotes from interviews in our written work to show participants' views and experiences. Any quotes (and/or

pictures/photos) we use in written work will not include your name or any features that could be used to identify you or your child. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you. We will keep all information about you safe and secure.

The university has strict rules about data storage and so any digital data must be stored on a secure, encrypted and password protected computer. Only a professional transcription service based elsewhere in the UK (with privacy and confidentiality agreements in place) and I (Grace Lewis) will have full access to the pre-anonymised recordings. My supervisors (see last page) will have access to short sections of written records for when I need to discuss the research and to make sure it is of good quality. If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study at [RADAR: Restricted Access Data and Repository at the University of Leeds]. With your consent, anonymised data will be stored for approximately 10 years: Anonymised transcripts of what you say will be deposited in the RADAR if you consent to this (you can still participate even if you do not want your transcripts to be stored in this way, for a longer period).

What will you do with interview notes, recordings, and any pictures/photos?

In this type of research, I will listen to interviews straight away to find important areas you have highlighted and compare this to what other parents and carers say to see if people have similar experiences. Once audio-recordings are put into writing (and anonymised at the same time) we will no longer need to store audio versions, and these will be deleted. When all participants have been interviewed and the research findings are complete, I will write a report. You can have a copy of the short version of the report, written for a wider audience. I will ask at the interview if you are interested in receiving this and I will ask you to give an address/email address for this to be sent to you, when you fill out the consent form. Most researchers aim to publish their research in specialist journals aimed at people working in their field. Sometimes quotes, and occasionally pictures/photos are used in these publications, but never any features that could be used to identify you: We will write our reports in a way that no-one can work out that you took part in the study. Once we have finished the study, we will keep some of the data so we can check the results.

What are the potential benefits to taking part?

By taking part in this research study, you can help us, and our wider professional group understand how children and their parents/carers view and understand triggers at home and how easy or difficult you might find managing triggers at home. The research will not benefit you or your child directly. This information is useful to help us to find ways to support children/young people and their parents/carers to manage triggers at home and help control asthma as well as possible.

Are there any risks to taking part?

No, we do not expect there to be any risks. However, should you or your child feel that talking about your/your child's experiences with asthma might mean that you need extra support, I

encourage you to mention this to me, so that I can signpost you to where to get support and advice.

Is there a thank you payment if we take part?

We can offer a £5 voucher to thank you if you choose to take part. It is best if I can email this, but if not, it can be posted to you.

What to do next: If you decide to agree to take part or would like to ask more questions before deciding, please email me: hcgml@leeds.ac.uk or call/text: **07874 895723 or 0115 888 0791** and I can call you back.

Where can we find out more about how my information is used?

- At www.hra.nhs.uk/information-about-patients/
- By asking one of the research team
- By emailing hcgml@leeds.ac.uk
- By contacting the sponsor (University of Leeds) Data Protection Officer: dpo@leeds.ac.uk

What if we have concerns/a complaint? Please contact Grace Lewis (hcgml@leeds.ac.uk) or Dr Alistair Duff alistair.duff1@nhs.net Or the PALS & complaints team: 0113 2066261 patientexperience.leedsth@nhs.net

Where can we find out more about the policies you will follow? During data collection (interview) we will follow NHS safeguarding advice, should there be any concerns raised about a child or young person's safety. You can read more about this at: https://www.england.nhs.uk/safeguarding/policies-annual-report/

For more details on data protection, you can access the University privacy statement for research participants at: https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf.

This study has ethical approval [Research Ethics Committee reference number: 21/SW/0034].

The project team: Grace Lewis, PhD candidate, School of Healthcare, University of Leeds. hcgml@leeds.ac.uk **(Grace's supervisors-)** Dr Alistair Duff (chief investigator), Consultant Clinical Psychologist & Head of Psychology Services, St James' Hospital Leeds. Honorary Associate Professor, Institute of Health Sciences, The University of Leeds Department of Clinical & Health Psychology. alistair.duff1@nhs.net; Dr Linda Milnes, Associate Professor in children's and young peoples' Nursing, School of Healthcare, University of Leeds. L.J.Milnes@leeds.ac.uk; Dr Alexandra Adams, Consultant in Paediatric Respiratory Medicine, Leeds Children's Hospital NHS Trust. alexandra.adams2@nhs.net; Professor Jurgen Schwarze, Centre for Inflammation Research, University of Edinburgh. Jurgen.Schwarze@ed.ac.uk

Who is funding the research? This work is funded by Asthma UK as part of the Asthma UK Centre for Applied Research [AUK-AC-2018-01].

Thank you for taking the time to read this information. If you have any questions, please email hcgml@leeds.ac.uk Or call/text: 07874 895723 or 0115 888 0791

I am happy to call you back if you prefer.

Appendix 7 Tweet posts

Are you 11-16 years old and have asthma? Or do you parent/care for someone aged 11-16 who does?

We want to hear about your experiences. Please follow the link (with a parent/carer if you are under 16) to a 2-3 min survey to see if you may be able to help
https://leeds.onlinesurveys.ac.uk/uk-wide-asthma-trigger-research-survey-and-interview

Please share with your networks!'

(FOR TARGETED RECRUITMENT -THESE COULD COME LATER)

To aid our theoretical sampling (sampling to both maximise balance in our sample and to follow emerging leads in the data so far) proposed re-tweets include

"We need to speak to more females with asthma aged 11-16 years and their parent-carers. Pls read below to see if you may be able to tell us about your experiences"

"We need to speak to more young people (11-16 years) with asthma. Have been told you are sensitive to pets and/or house-dust mite after allergy testing? Pls read below to see if you may be able to tell us about your experiences."

"We need to speak to more parent-carers of 11–16-year-olds with asthma, and allergies or sensitivity to pets or house dust mite shown on testing. Pls read below and see if you might be able to help."

"We need to speak to more dads of 11–16-year-olds with asthma, and allergies or sensitivity to pets or house dust mite shown on testing. Pls read below and see if you might be able to help"

Wording for emails to share study details with professional networks (IRAS: 292697) sent via AUKCAR communications team

Dear colleagues,

Grace Lewis is a PhD student with Asthma UK Centre for Applied Research, based at the University of Leeds. Grace is looking to recruit young people aged 11-16 years (and/or their parent/carer(s) with severe or sub-optimally controlled asthma and allergic sensitisation to pets and/or house dust mite, for qualitative interview online or by telephone. In particular, there have been challenges in recruiting females aged 11-16 years and fathers to the study, which has recruited from Leeds NHS trust only, up until now.

To broaden recruitment, Grace Lewis now has approval to expand and include public advertising and snowballing. We are asking Centre members (Asthma UK centre for Applied Research) and colleagues to share information about the study within their networks to help advertise the study.

More details of the study are outlined below. Please contact Grace directly if you have further questions (hcgml@leeds.ac.uk)

Study title: Understanding family beliefs and decisions in the management of asthma triggers in the home: A qualitative study to inform a grounded theory

About the study:
Indoor environmental allergens and airborne irritants are present in many homes, yet a review of the literature has shown little is known about what children and young people with asthma and sensitivity to indoor allergens (and their parents/carers) believe about asthma triggers or how beliefs and attitudes may influence whether strategies are taken to avoid or minimise trigger exposures at home. To develop an explanation of whether families understand the role of sensitivity to allergens, and if/how families attempt to manage asthma triggers and allergen exposure, qualitative interviews with 11-16-year-olds and parents/carers are being undertaken using grounded theory methodology. The aim is to build an explanation of the phenomena to enable future development of patient-informed programmes to reduce trigger exposures grounded in family understanding and beliefs and experiences with triggers and trigger avoidance.

How can you help?
We are asking for assistance in advertising the study. Volunteer participants can self-identify their eligibility by following the links on the study posters/ social media posts.
Grace is looking to recruit participants aged 11–16-years with severe or sub-optimally controlled asthma and co-existing allergic sensitisation to pets and/or house dust mite, and/or their parent/carer(s).
If you work in areas where children, young people and/or parents/guardians/carers may be present, Grace would appreciate if you could display the attached study poster, where allowed*(add links once approved)* or email hcgml@leeds.ac.uk with your postal address to request a paper copy of the poster by mail.
Please feel free to share the following social media posts for the study with your social and professional networks: (*links to be added after the initial post is shared*)
Contact for the study: Grace Lewis- email: hcgml@leeds.ac.uk

Example Tweet used to promote study recruitment nationally.

Appendix 8 Interview topic guides

<u>CYP topic guide:</u> Introduction and icebreaker:

***if verbal consent has been recorded, introductions will have been completed first with consent. If participant has sent consent form electronically, the researcher will check that this still stands and whether there are any outstanding questions before the interview starts.**

Introduce project and aims and how interviews work generally (no 'right or wrong' answers)

Length of interview (explain thumbs down system to show discomfort with question online), breaks

Invite questions about the study

Background:

- Household composition/ living situation/ *Probes*: larger/smaller family, all in one location? urban or rural- city/countryside/town (example: *can you tell me a little bit about where you live and who with?*)
- Day to day activities: *Probes* (school currently open and/or COVID lockdown or tier for example) links to -time spent at home: do you spend most time indoors/at home or outside at the moment (might depend on timing/season of interview)

Asthma:

Opening question: Can you tell me about having asthma?

Probes: How severe (last attack? How often use rescue inhaler? How often goes to hospital appointments or emergency visits?) self-management and support for (what self-management means to them? Who takes charge in managing asthma at home?)

Asthma triggers:

Opening question: Can you tell me about anything you notice that makes your asthma worse or sets it off?

Probes: It can help to think about things in the air, sometimes things you can see or things you can smell (if they have taken photos/drawn a picture this can be discussed here). Why do you think these might be triggers for you?

-do you have an asthma action plan? Do you have triggers written there? Do you talk about triggers at home?

[link to next topic]

Allergic sensitisation: Can you remember whether you have had a skin prick test at a clinic/hospital? What did you think about the results/can you remember your results?

Probes: *What did you think about the results when they told you? (if needs further probe- was it what you expected/surprised? Why is that?). Did drs/nurses talk to you about it?*

-Did the results make you think any differently about asthma triggers or did you stay the same? How about others at home- were they surprised/ did they change anything?

Behaviour change/future intervention needs (enablers and barriers):

Do you think it helps to avoid triggers or use extra care (measures such as things they may have mentioned earlier, parent/family cleaning, not letting pets in rooms)? Do you think more of this would help control your asthma better? If not, can they explain why they think that?

-What kinds of things might help you to avoid triggers? Or recognise them if there is difficulty with that? / What might encourage you? Do you feel in control of triggers or what support/might help you feel you have better control?

Is there anything else that affects whether you avoid triggers or not, that we have not covered yet?

If we were to look at ways to help families reduce triggers at home, what do you think would be helpful?

Probes- If they still lack info, what formats would be most useful, delivered by whom?

OTHER REMINDERS FOR INTERVIEWER-

-Remind can decline to answer questions

-Offer breaks

*Remember to check back with participants that my understanding of what's been said fits with participant's meaning – repeat back what they say in summary and check that my (interviewer's) understanding of what they have said matches what they have meant.

<u>Interview topic guide – parents/carers</u>

Introduction and icebreaker: *if verbal consent has been recorded, introductions will have been completed first with consent. If participant has sent consent form electronically, the researcher will check that this still stands and whether there are any outstanding questions before the interview starts.

Introduce project and aims and how interviews work generally (no 'right or wrong' answers)

Length of interview (re-explain thumbs down system to show discomfort with question for online interviews)

Invite questions

Background & SES:

- Can you tell me a little about you? (probe- do you work at the moment? / if not, did you work/study previously?)
- Household composition/ living situation/ *Probes*: larger/smaller family, all in one location? urban or rural? (example: *can you tell me a little bit about where you live and who with?*). Post code if happy to provide.

Child's asthma:

Can you tell me about your child/son/daughter's asthma?

(probes if needed- how long since diagnosis? How well controlled they think they are? Are they managing well? How severe (last attack? How often use rescue inhaler? How often goes to hospital appointments or emergency visits?) self-management and support for (what self-management means to them). Who takes charge in managing asthma at home?)

Asthma triggers:

Opening question: Can you tell me about anything you notice that makes your child's asthma worse or sets it off?

(probes-do you have an asthma action plan? Do you have triggers written there? Do you talk about triggers at home? Do you think you all agree on triggers and what to do about them, if anything? Can you tell me about any of the things you do/don't do because of triggers?)

Allergic sensitisation: Can you remember whether your child had a skin prick test at a clinic/hospital? What did you think about the results/can you remember their results?

*Can you tell me a little about what you thought the results meant for your child's asthma?

Probes: *What did you think about the results when they told you? (if needs further probe- was it what you expected/surprised? Why is that?). Did drs/nurses talk to you about it?*

-Did the results make you think any differently about asthma triggers or did you stay the same? How about others at home- were they surprised/ did they change anything?

Behaviour change/future intervention needs (enablers and barriers):

Hopefully leads in from the last section- if report advised to avoid/take measures to reduce allergen load can ask if they do this/or have tried to. If not, can they talk about how they decided or whether they just carried on as they were?

Do you think more of this (if they mention avoidance/reduction strategies) would help control your child's asthma better? If not, can they explain why they think that? Is it based on experience or information -where from etc?

-What kinds of things might help your child to avoid triggers at home? Or recognise them if there is difficulty with that? /what might encourage you work towards avoidance? Do you feel in control of triggers or what support/might help you feel you have better control?

Is there anything else that you think affects whether your child avoids triggers or not, that we have not covered yet?

If we were to look at ways to help families reduce triggers at home, what do you think would be helpful?

Probes- If they still lack info, what formats would be most useful, delivered by whom if in person?

OTHER REMINDERS FOR INTERVIEWER-

-Remind can decline to answer questions

-Offer breaks

*Remember to check back with participants that my understanding of what's been said fits with participant's meaning – repeat back what they say in summary and check that my (interviewer's) understanding of what they have said matches what they have meant.

Appendix 9 REC/HRA approval letters

NHS
Health Research Authority

South West - Cornwall & Plymouth Research Ethics Committee

Bristol HRA Centre
Ground Floor
Temple Quay House
2 The Square
Bristol
BS1 6PN

Telephone: 02071048071
Fax:

23 March 2021

Dr Alistair Duff
Leeds Teaching Hospitals NHS Trust,
Great George Street,
Leeds
LS2 3EX

Dear Dr Duff

Study title:	**Understanding family beliefs and decisions in the management of asthma triggers in the home: A qualitative study to inform a grounded theory**
REC reference:	**21/SW/0034**
IRAS project ID:	**292697**

The Research Ethics Committee (REC) reviewed the above application at the meeting held on 16 March 2021. Thank you for attending to discuss the application.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

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

Number	Condition
1	Please make it clear in the PIS that photos will be used for research purposes. Please also explain how the photos will be used and stored.
2	Each consent statement in the Consent Form should be under a separate bullet point and participants should be able to consent for each statement separately. Further guidance on Consent Forms is available on http://www.hra-decisiontools.org.uk/consent/examples.html
3	The language in the questions are expected to be made more user-friendly and simpler for the lay readers.

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

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

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

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

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

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/

If you have not already included registration details in your IRAS application form, you should notify the REC of the registration details as soon as possible.

Further guidance on registration is available at: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

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

After ethical review: Reporting requirements

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

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland)being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Slip to add to appointment letter]	1	19 February 2021
Copies of advertisement materials for research participants [Study poster]	1	10 February 2021
Copies of advertisement materials for research participants [Powetrpoint slide advert]	2	19 February 2021
Covering letter on headed paper [Cover letter]	1	12 February 2021
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional indemnity proof of cover]	1	01 October 2020
Interview schedules or topic guides for participants [Interview topic guide parents/carers]	2	19 February 2021
Interview schedules or topic guides for participants [Interview topic guide (children/young people)]	2	19 February 2021
IRAS Application Form [IRAS_Form_26022021]		26 February 2021
Other [Online Eligibility survey]	4	19 February 2021
Other [Note for after initial agreement to take part (young persons)]	1	10 February 2021
Participant consent form [Form A adults consent form (parent-carers and over 16s)]	7	19 February 2021
Participant consent form [Form B young person assent & parent-carer consent]	7	19 February 2021
Participant information sheet (PIS) [Young peoples' information leaflet]	1.7	19 February 2021
Participant information sheet (PIS) [Parent-carer information leaflet]	1.6	19 February 2021
Research protocol or project proposal [Protocol version 6 for IRAS no 292697]	6	24 February 2021
Summary CV for Chief Investigator (CI) [CV for CI]	1	18 February 2021
Summary CV for student [Student CV Grace Lewis]	1	19 February 2021
Summary CV for supervisor (student research) [CI/supervisor CV]	1	18 February 2021

Membership of the Committee

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

There were no declarations of interest

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

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 use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 292697	**Please quote this number on all correspondence**

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

Yours sincerely

pp Dr Stephen Coles
Chair

E-mail: cornwallandplymouth.rec@hra.nhs.uk

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

"After ethical review – guidance for researchers" [SL-AR2 for other studies]

Copy to: Jean Uniacke

approvals@hra.nhs.uk

South West - Cornwall & Plymouth Research Ethics Committee

Attendance at Committee meeting on 16 March 2021

Committee Members:

Name	*Profession*	*Present*	*Notes*
Mrs Suzanne Blowey	Nurse - Pain Management	No	
Dr Rachel Clarke	Clinical Psychologist	Yes	
Dr Stephen Coles (Chair)	Retired	Yes	
Professor Ann Demaine	Specialist Register for Diabetes and Endocrinology	Yes	
Dr Kass Gibson	Lecturer	Yes	
Mrs Sarah C Jones	Research Governance Specialist and University HRA Sponsor Representative	Yes	
Professor Stephen Lewis	Consultant Gastroenterologist	Yes	
Miss Helen Moore	Support Pharmacist	Yes	
Dr Tomasina Oh	Associate Professor & Dementia Care Programme Lead	Yes	
Mr Richard Parnell	Associate Lecturer	Yes	
Miss Rosalyn Squire	Research Nurse	Yes	
Mr Duncan Trotter	Retired	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Mr Rajat Khullar	Approvals Officer
Sharon Northey	Approvals Manager

NHS
Health Research Authority

South West - Cornwall & Plymouth Research Ethics Committee

Ground Floor
Temple Quay House
2 The Square
Bristol
BS1 6PN

Tel: 0207 104 8019

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

04 January 2022

Mrs Grace Lewis
PhD student
sponsor- University of Leeds
School of Healthcare Postgraduate research suite: 2.30
Baines Wing, University of Leeds
Leeds
LS2 9JT

Dear Mrs Lewis

Study title:	**Understanding family beliefs and decisions in the management of asthma triggers in the home: A qualitative study to inform a grounded theory**
REC reference:	**21/SW/0034**
Amendment number:	**amendment number one**
Amendment date:	**09 December 2021**
IRAS project ID:	**292697**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

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

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Completed Amendment Tool [292687_amendment number one]	1	09 December 2021
Letters of invitation to participant [Draft participant reminder and follow up]	1	09 December 2021
Research protocol or project proposal [Protocol version 7 with amendments]	7	09 December 2021

Membership of the Committee

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

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

Statement of compliance

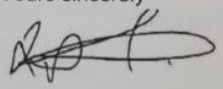
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS Project ID - 292697:	**Please quote this number on all correspondence**

Yours sincerely



Dr Stephen Coles
Chair

E-mail: cornwallandplymouth.rec@hra.nhs.uk

South West - Cornwall & Plymouth Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 22 December 2021

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Stephen Coles	Retired	Yes	
Miss Helen Moore	Support Pharmacist	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Ms Zainab Tauqeer	REC Assistant

NHS
Health Research Authority

South West - Cornwall & Plymouth Research Ethics Committee

Ground Floor
Temple Quay House
2 The Square
Bristol
BS1 6PN

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

08 April 2022

Mrs Grace Lewis
PhD student
sponsor- University of Leeds
School of Healthcare Postgraduate research suite: 2.30
Baines Wing, University of Leeds
Leeds
LS2 9JT

Dear Mrs Lewis

Study title:	**Understanding family beliefs and decisions in the management of asthma triggers in the home: A qualitative study to inform a grounded theory**
REC reference:	**21/SW/0034**
Amendment number:	**Amendment number two**
Amendment date:	**08 March 2022**
IRAS project ID:	**292697**

The above amendment was reviewed on 23 March 2022 by the Sub-Committee in correspondence.

Ethical opinion

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

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Completed Amendment Tool [292697_Amendment number two_]	5	08 March 2022
Copies of materials calling attention of potential participants to the research [email wording for amendment 2 IRAS 292697 version 5 March 7 2022]	5	07 March 2022
Copies of materials calling attention of potential participants to the research [social media post wording for IRAS 292697 for amendment two]	2	24 March 2022
Copies of materials calling attention of potential participants to the research [Study poster IRAS 292697 amendment no 2]	4	24 March 2022
GP/consultant information sheets or letters [GP HP letter version 2 IRAS 292697 March 1 2022 for amendment no two]	2	01 March 2022
Non-validated questionnaire [Self eligibility survey IRAS 292697 for amendment 2]	8	24 March 2022
Research protocol or project proposal [Protocol updated for amendment no two IRAS 292697 version 10 March 7 2022]	10	07 March 2022

Membership of the Committee

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

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Amendments related to COVID-19

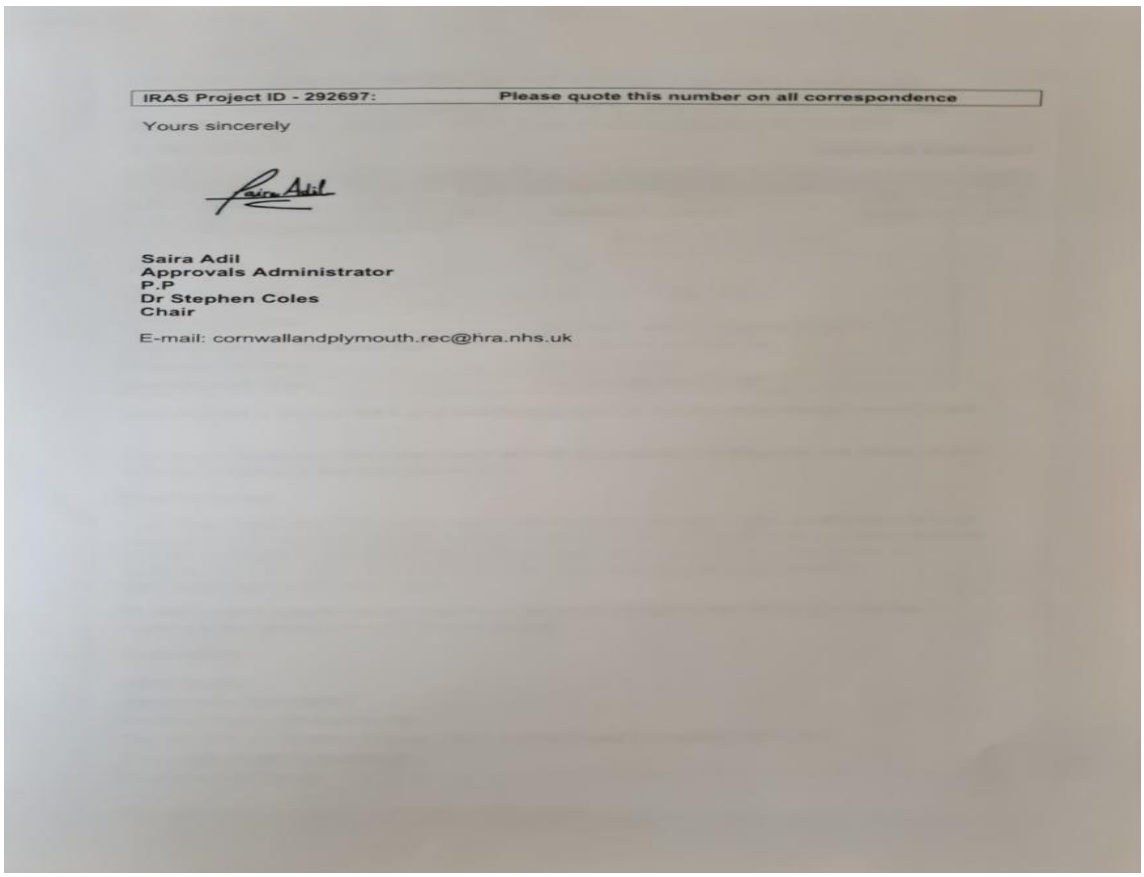
We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

Statement of compliance

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

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/



IRAS Project ID - 292697: Please quote this number on all correspondence

Yours sincerely

Saira Adil

Saira Adil
Approvals Administrator
P.P
Dr Stephen Coles
Chair

E-mail: cornwallandplymouth.rec@hra.nhs.uk

Amendment no.2 for IRAS 292697: version 2

Appendix 10 Consent & assent forms

School of healthcare

Consent to take part in: What families believe and do about children's asthma triggers at home (**Form A**- for those over 16 years of age only, and parent/carers who are taking part)	Add your initials next to the statement if you agree
I confirm that I have read and understand the information sheet dated [23/03/2021 & version: 7/ or young persons' leaflet 26/03/2021, version 9] explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw at any time and without there being any negative consequences, but I understand you keep information about me that you already have.	
I understand, should I not wish to answer any question or questions, I am free to decline.	
I understand if I decide to withdraw what I have said during interview, I must notify the research team within one week of the interview. [The chief investigator for the study is: Dr A Duff, telephone: 0113 206 5897. The lead researcher & interviewer is Grace Lewis, **telephone: 07874 895723 or 0115 888 0791**]	
I understand that members of the research team may have access to my anonymised responses but that these will be kept confidential.	
I understand that my name will not be linked with the research materials*, and I will not be identified or identifiable in the report or reports that result from the research. • * If you are 16 years old and sent a photo or drawing, are you happy for this to be used in reports? (Your name would not be used)	

I understand that relevant sections of the data collected during the study, may be looked at by individuals from the University of Leeds or from regulatory authorities where it is relevant to my taking part in this research.	
I agree to take part in the above research study and will inform Grace Lewis should my contact details change.	
I understand that the data collected from me may be stored and used in relevant future research in an anonymised form and will be stored at the University of Leeds data repository [RADAR] if I agree to this.	
Would you like a copy of the short results summary at the end of the study? If so, the researcher will need to keep an email/postal address for you up until this time. Please initial and add an address here if you agree- **Address/email:**	

Name of participant		
Participant's signature		Date:
Name & signature of researcher	Grace Lewis	Date:

Asthma UK Centre for Applied Research

UNIVERSITY OF LEEDS School of healthcare

Form B, Part 1: This part is for the 11-15-year-old to read and fill out

Project title: What families believe and do about children's asthma triggers at home

**Please cross out yes or no, to show your answer to each question below*

Has somebody explained this project to you?	*Yes/no
Do you understand what the project is about?	Yes/no
Have you asked any questions you want to ask?	Yes/no
Have your questions been answered in a way you can understand?	Yes/no

Do you understand you can stop taking part at any time, but we will keep information about you that we already have?	Yes/no
Do you understand that if you change your mind about taking part, after the interview, you will need to tell us within one week?	Yes/no
Are you happy for short quotes (things you have said) to be used in project reports? (Your name would not be used)	Yes/no
If you sent a photo or drawing, are you happy for this to be used in reports? (Your name would not be used)	Yes/no
Are you happy to take part?	Yes/no
Are you happy for written copies of what you say (without your name) to be stored safely for up to 10 years? Only researchers with a good reason to, will be allowed to look at these and use them for more research.	Yes/no
Would you like a copy of the short results summary at the end of the study? If so, the researcher will need to keep an email/postal address for you up until this time. Please add that here if you agree:	Yes/no

If you have answered *no* to any question, it is ok, we can talk about those now. If you *do* want to take part, please write your name below-

Name:	
Date:	
Researcher: Grace Lewis-	**Date:**

Part 2 (form B): This part is for a parent/guardian of an 11-15-year-old to read and complete: For young people under the age of 16 years it is a legal requirement for a parent/guardian to provide consent for the young person to participate in the research study. We ask that a parent/guardian reads the children & young peoples' study information sheet and considers the following before signing to provide their permission.

Consent for your child take part in: What families believe and do about children's asthma triggers at home	Add your initials next to the statement if you agree

I confirm that I have read and understand the information sheet dated [26/03/2021, version: 9] explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand that my child's participation is voluntary and that they are free to withdraw at any time without giving any reason and without there being any negative consequences, but I understand you will keep the information you have already collected. [The chief investigator for the study is: Dr A Duff, telephone: 0113 206 5897. The lead researcher & interviewer is Grace Lewis, telephone: 07874 895723 or 0115 888 0791]	
I understand that should my child not wish to answer any particular question or questions, they are free to decline.	
If I or my child decide to withdraw the interview (or drawing/photo, if included and sent to the researcher), I understand we must tell you within one week of the interview.	
I understand that members of the research team may have access to my child's anonymised responses, but that their name will not be linked with the research materials, and we will not be identified or identifiable in the report or reports that result from the research.	
I understand that my child's responses will be kept strictly confidential.	
I understand that relevant sections of the data collected during the study, may be looked at by individuals from the University of Leeds or from regulatory authorities where it is relevant to my taking part in this research.	
I agree for my child to take part in the above research project and will inform Grace Lewis (hcgml@leeds.ac.uk) should my contact details change.	
I understand that the data collected from my child may be stored and used in relevant future research in an anonymised form and will be stored at the University of Leeds data repository [RADAR] if I agree to this.	

Name of parent/guardian	
Parent/guardian's signature	Date:
Name & signature of researcher	Grace Lewis Date:

*If you are able, please scan or take a photo of the completed form and send to hcgml@leeds.ac.uk If not, we can talk through the form instead, at the beginning of the interview.

Appendix 11 Memo for dyadic interview

Immediately after interview (25/02/22-noted first on paper)

The 13-year-old in this interview was initially quite challenging to engage. Mum was very chatty and sometimes took charge of the interview and re-directed questions to the CYP or sought his clarification. However, there were times when Mum seem to silence the CYP. I was unclear whether Mum didn't think these points were relevant, thought the CYP was being dishonest or rather was revealing more than Mum was willing to have him share. I also wondered whether some of what the CYP said was aimed at deliberately antagonising Mum by contradicting her or making comments that weren't directly relevant.

The CYP used a lot of non-verbal communication which would have been missed had we not used Zoom. Conversely, perhaps he would have been more verbal on the phone. I had to make a physical note of nods and thumbs up and other non-verbal communication by noting the mins on the Dictaphone and nods++ etc. I don't think participants really noticed my short notetaking, but it really helped with transcription, and I think it would have been difficult to do this much later in time, had a professional transcribed the recording.

There were quite a few 'on the surface' contradictions in the interview; it would be easy to presume these were contradictions but perhaps they actually reflect some misunderstandings on Mum's part- -such as Mum saying people should take allergies seriously and knowing the dog was flagged as a positive SPT result but allowing the dog to sleep with the CYP. Initially I thought this was a direct contradiction but on thinking further and (28/02/22) after transcription and early coding I wondered if it really reflected that Mum did not understand allergic sensitisation in the absence of other allergic symptoms (e.g., described itchy eyes and runny nose on cat exposure and quite immediate reactions to dust that persist, but no clear, observable reactions to dogs of any sort). Likewise with cats, the CYP directly contradicted what Mum said about reactions to cats, but then they don't have a cat, so I really thought here that the CYP was trying to get a rise out of Mum.

It was interesting that Mum suggested if an observable reaction/effect on asthma was seen they would re-consider the dog sleeping in CYP's bedroom, but the CYP totally refuted this.

Although I'm not directly analysing language or tone etc (as GT doesn't usually) it was noteworthy that Mum often gave a short laugh when discussing dog sensitisation and keeping the dog, as if she knew I would be interested in this particular allergy and behaviour.

Smoking/vaping:

This was a bit of an awkward topic as the CYP described dad smoking near him after I'd brought up smoke in general as a possible trigger. Mum quickly corrected the CYP and went on to say dad smoked previously but now vapes. I tried to engage on questions about vape, but both seemed quite reluctant to elaborate and with what Mum had said about anxieties

about a previous social services visit I did not want to push it- especially as moving from smoking to vaping is currently seen as a positive move in public health.

The only other thing I would have liked to probe more on but was conscious about not pushing was the comments the CYP made about being cold and how this affected asthma in the home as well as outdoors- I made a comment about the increasing costs of fuel/heating (in the current context) but Mum did not comment on this and carried on with what she was focussed on. I was conscious that discussing costs may be uncomfortable for parents who may wish to keep this private from an interviewer and from research quotes but may also prefer not to discuss finances in front of children who may not be aware if there were problems with that. In short, it seemed unethical to try to ask about this any further than I did after Mum had changed the subject once.

It wasn't until after the interview, when transcribing and changing postcodes to MDI that I noted they do live in the most deprived decile. I had noticed they were quite wrapped up (big jumpers etc) on screen in the interview as if they weren't in an overly warm room (but it is February). Again, I was conscious not to exacerbate Mum's anxieties about the home especially as she described building up to agreeing to a home visit.

I was glad I had gone with my gut instinct and not continued to probe and potentially made the participants uncomfortable.

Also, I for other participants who used de-humidifiers, I was concerned that perhaps I hadn't probed enough about how they managed these costs, but after this interview, I realised that I may then have been pointing out that de-humidifiers are expensive to run and this may have caused further anxiety and debate over whether to use them as much, if I had pointed it out.

Later note-

The interview also informed my skills for future interviews, as I began to say aloud things like '*ok you're nodding/shrugging there now, so you're not sure?*' to help with transcription and to give the reader fieldnotes and descriptions of how participants expressed themselves.