BELIEFS AND UNDERSTANDING OF FOOD ALLERGY IN CHILDREN AND ADOLESCENTS AGED 11-16 YEARS IN THE UNITED KINGDOM

KRISTINA LUCY NEWMAN
Doctor of Philosophy

ASTON UNIVERSITY
September 2019

Thesis summary

Aston University
Beliefs and understanding of food allergy in children and adolescents aged 11-16 years in the United Kingdom.
Kristina Lucy Newman
Doctor of Philosophy
Year of submission 2019

Abstract

Children and adolescents with food allergy (FA) face significant challenges in managing their condition. Adolescents are at the highest risk of FA reactions and have the highest frequency of fatal reactions. However, previous research about FA beliefs is limited. Furthermore, though previous research suggests the importance of peers, there are no previous studies that explore adolescent peers' beliefs about FA.

This thesis comprises of four studies to explore beliefs about FA in adolescents aged 11-16 years in the United Kingdom. An inductive mixed methods pragmatic approach was adopted for flexibility, with each study informing development of the next in this exploratory research. First, a systematic review of beliefs about FA in adolescents aged 11-19 years was conducted to identify previous research and gaps in knowledge. This informed development of two qualitative semi-structured interview studies in adolescents aged 11-16 years; one for adolescents with FA and one for adolescents with no clinical history of FA. The systematic review and both qualitative studies were analysed with thematic analysis (Braun & Clarke, 2008). From these findings, two scales were developed: The Adolescent Food Allergy Beliefs scale (AFAB) and the Adolescent Food Allergy Beliefs scale: Peers without food allergy (AFAB-P). Both preliminary scales demonstrate good reliability and validity.

Recommendations for future research include further understanding of peer beliefs, especially where interventions include peer-education. Further understanding of the psychological impact of different FA diagnoses should be explored. The preliminary AFAB and AFAB-P, with further validation, may be useful in clinical and educational settings to identify and address beliefs to reduce risk-taking behaviour and peer stigma, and decrease the rate of reactions in this age range.

Key words: Food allergy, paediatric, adolescents, beliefs, peers, scale development, mixed methods

Dedication

To my parents, without whom none of this would be possible, thank you.

And to my soulmate, Derry.

You were right, I can shatter glass ceilings

Acknowledgements

Thank you first and foremost to Midlands Asthma and Allergy Research Association (MAARA) for funding this research, without which this work would not be possible. You funded not only this passionate project but also a lot of chocolate to keep me going through it.

Thank you to my supervisors for their guidance; Dr Rebecca Knibb, who taught me valuable lessons and enabled me to grow; Dr Richard Cooke, who continued to offer encouragement even after he moved to a different university; and Dr Helen Pattison who filled in as associate supervisor and brought new expertise to this project. Also, to Prof Claire Farrow, who took me on late in the PhD when I was at my most stressed; your advice and reassurance was priceless, thank you. I hope I have done you all proud.

To those who never gave up on me when I wanted to give up on myself, believed in me when I did not believe in myself and loved me when I felt at my lowest, thank you. To my friends, and my colleagues for their endless support and patience, thank you for being there and understanding. Also thank you to Jenny especially; a glass of wine, priceless advice, and a good moan did wonders. Ian, you are a stats wizard, thank you for your patience.

To my QMiP community, my DHP family, and my PsyPAG friends, who have supported and encouraged me, thank you. Your support has meant the world to me.

To my parents, my partner Derry, and my partner’s family; especially thank you to you who reminded me to eat, sleep, and function as a human when I would forget to. You supported me through a lot of tireless nights and concerns of not being good enough. Thank you for your endless faith in me.

Thank you to Kato and to Kira, who always knew when I needed a cuddle to brighten the hard times. Dog therapy is vastly underrated.

Thank you to my students, who thought it was ‘pretty cool’ that I was doing a PhD!

To the allergy and research community on Twitter and beyond who keep me grounded and helped me to understand what is needed, thank you for supporting and encouraging me, and especially for sharing my studies. Your support means more than you know.

Thank you to all participants and their families who accepted me and opened up to me. Also, for encouraging me and cementing that my work was worthwhile, and that I was doing something important. This thesis is an accumulation of the stories you shared with me and I hope they do you justice.

Finally, to my examiners, who will have the pleasure of getting to know this project and challenging me to defend it. Years of my life are held in these pages; thank you for taking the time to read this thesis, I hope you enjoy it.

List of Contents

Abbreviations

AAI – Adrenaline auto-injector
AFAB - Adolescent Food Allergy Beliefs scale: Food Allergy Questionnaire
AFAB-P - Adolescent Food Allergy Beliefs scale: Peers Without Food Allergy Questionnaire
ARQ-P - Attitudes towards Risk Questionnaire for beliefs
BBC – British Broadcasting Corporation (Media company in the UK)
BIPQ – Brief Illness Perception Questionnaire
BPS – British Psychological Society
BSACI – British Society of Allergy and Clinical Immunology
CMA – Cow's milk allergy
CS-SRM – Common Sense Self-Regulation Model
EAACI – European Academy of Allergy and Clinical Immunology
Epi-pen – Epinephrine pen (brand of AAI)
EFA – Exploratory Factor Analysis
FA – Food allergy
FA1 – Food allergy subscale 1
FA2 – Food allergy subscale 2
FSA – Food Standards Agency
HBM – Health Belief Model
HRA – Health Research Authority
IgE - Immunoglobin-E (antibodies released by the immune system)
IPA – Interpretative phenomenological analysis
IPQ – Illness Perception Questionnaire
LoC – Locus of control
MHLC-B - Multidimensional Health Locus of Control
NFA1 – No food allergy subscale 1
NFA2 – No food allergy subscale 2
NHS – National Health Service (UK health provider)
NICE – National Institute for Health Care Excellence
PCA – Principal Components Analysis
PRISMA - Preferred Reporting Items for Systematic reviews and Meta-Analyses
QoL – Quality of life
SE – Self-efficacy
UK – United Kingdom

List of tables

List of figures

Chapter 1: Introduction

1.1. Overview

This introductory chapter considers food allergy (FA) as a condition and explores the concept of beliefs about illness. The chapter begins with a background of FA and why it is important, including diagnosis, prevalence and impact. Then, it considers adolescents in relation to risk-taking behaviour. Following this, the role of others is discussed, including peers, schools, and the wider community in relation to Brofenbrenner's Ecological Systems Theory (1994). The rationale for the focus on beliefs, and previous models and theories used in adolescent FA research are detailed and considered. The chapter finishes with a summary and highlights aims and objectives for this thesis.

1.2. A background of FA

1.2.1. FA and diagnosis

FA is defined as an adverse reaction in response to ingestion of certain types of food. The most common allergens are classed by the Food Standards Agency (FSA) (2018), as the 'Top 14' and include celery, cereals, crustaceans, eggs, fish, lupin, milk, molluscs, mustard, peanuts, sesame seeds, soybeans, sulphur dioxides/sulphites (found in wine, beer or as a preservative in dried fruit) and tree nuts, but any food has the potential to become an allergen. A FA may be immunoglobin-E (IgE) mediated or non-IgE mediated. IgE are antibodies produced by the immune system which can trigger severe allergic reactions (Table 1) including anaphylaxis. Reactions to FA differ by person and symptom severity, however anaphylactic reactions can be fatal. Anaphylaxis is an extreme reaction to an allergenic trigger such as food or medication. The NHS (2016) lists the following symptoms of anaphylaxis; collapse or loss of consciousness, confusion and anxiety, clammy skin, a fast heartbeat, breathing difficulties and feeling lightheaded.

FA diagnosis depends on whether the person is suspected of having an immunoglobin-E (IgE) mediated FA or a non-IgE mediated FA (Table 1). FA diagnosis focuses primarily on patient history (Skypala et al., 2015; Boyce et al., 2010), a physical examination and appropriate clinical diagnostic testing such as skin-prick tests. The National Institute for Health Care Excellence (NICE) guidelines for FA diagnosis in under 19-year olds (2011) recommends consideration of skin, gastrointestinal, respiratory and other reaction symptoms (Table 1) but this is not exhaustive, and FA diagnosis should not be dismissed if these symptoms are absent. Where symptoms of atopic eczema, gastro-oesophageal reflux disease or chronic gastrointestinal systems (e.g. chronic constipation) do not respond well to treatment, FA should be considered.

Table 1: Developed from NICE guidelines (2011): Symptoms of IgE and non-IgE-mediated FA

Symptoms	**IgE-mediated**	**Non-IgE-mediated**
Skin	Pruritus (itching), erythema (red or pink ‘blotches’ which can develop into a rash that looks like rings or ‘bulls-eye targets’), acute urticaria (hives), acute angioedema (swelling)	Pruritus, erythema, atopic eczema
Gastrointestinal	Oral pruritus, angioedema (of the lips, tongue and palate), nausea, vomiting, diarrhoea, colicky abdominal pain	Loose or frequent stools, mucus and/or blood in stools, abdominal pain, gastro-oesophageal reflux disease, infantile colic, constipation, food aversion or refusal, perianal redness, pallor and tiredness, faltering growth (in conjunction with at least one gastrointestinal symptom above)
Respiratory	Upper respiratory tract symptoms (nasal itching, sneezing, rhinorrhoea or congestion [with or without conjunctivitis])	
	Lower respiratory tract symptoms (cough, chest tightness, wheezing or shortness of breath)	
Other	Signs or symptoms of anaphylaxis or other systemic allergic reactions	

The cause of FA is still under debate; however, research suggests that FA may be caused by genetics, prenatal exposure, early life exposure or cutaneous exposure (Conroy, 2013). Genetics in particular is considered a high-risk factor as having a close family member such as a parent or sibling with FA results in a sevenfold increased risk of an individual developing the same allergy (Hourihane, Dean & Warner, 1996). This is supported by Sicherer et al.'s (2000) twin study, which revealed a much higher concordance rate in monozygotic twins (60%) than dizygotic twins (less than 10%). Although the incidence of FA is higher if a close family member has the same allergy, this only explains a percentage of FA prevalence and does not consider the cause of FA in an individual with no apparent close genetic ties to FA.

There is currently no known cure for FA and management includes strict dietary observation and avoidance of possible allergens (Sheikh & Alves, 2000). In the event of anaphylaxis, an adrenaline auto-injector (AAI) should be used to stabilize blood pressure, control symptoms and prevent fatality (Sampson et al., 2006) and an ambulance should be called immediately. Following this the allergen should be removed (if possible), and the person should lie down flat (unless they are pregnant, having issues breathing, or are already unconscious) and if symptoms do not improve after 5-15 minutes, a further AAI injection is recommended (NHS, 2016). It is estimated that 10 people in the UK die each year from a fatal reaction from FA (Food Standards agency, n.d.), though Pumphrey and Gowland (2007) previously estimated this to be approximately 20.

Anaphylaxis due to FA has received substantial media attention over the course of this PhD. Two London adolescents were covered in the media extensively and drew attention to the seriousness of FA, increasing awareness in the wake of tragedy. In 2018, London-based thirteen-year-old Karanbir Cheema, who had multiple allergies, including dairy, had a fatal allergic reaction (Davies, G., 2018). A classmate triggered a fatal reaction by placing cheese down his shirt while he was at school. In 2016, 15-year-old Natasha Ednan-Laperouse had a fatal allergic reaction to a baguette from Pret a Manger that was labelled incorrectly (BBC News, 2018; BBC News, 2019). Following this, there have been campaigns to change food labelling laws to protect others with FA. Natasha's family recently successfully campaigned to pass a law on food labelling to include full ingredients on pre-packaged food, to be introduced in England, Wales and Northern Ireland by summer 2021 (BBC News, 2019; GOV.UK, 2019). These adolescent fatalities show the severity of FA and the desperate need for change to policy in food establishments and schools, as well as a need to educate about FA to attempt to decrease the risk of fatal anaphylaxis.

1.2.2. Prevalence and risk factors

The prevalence of FA is currently estimated at 2% of adults and 5-8% of children in the UK (Food Standards Agency, 2017). The European Academy of Allergy and Clinical

Immunology (EAACI) (2015) found that cases of FA have doubled in the last decade. FA related hospital admissions in the UK have increased by 500% since 1990 (Gupta, Sheikh, Strachan & Anderson, 2007) and increased seven-fold in the last decade (EAACI, 2015). The cause for increase in prevalence is still debated but may be due to increased identification and awareness, especially in those with non-IgE-mediated FA. The Australia-based SchoolNuts study (Sasaki et al., 2018) suggested early-onset eczema in males, parents of an Asian ethnic background, and a family history of FA, increased the risk of FA in early adolescence, whereas exposure to dogs in the first 5 years of life was associated with a decreased risk of FA. Lack et al. (2008) have conducted research showing that there is a seven-fold increase in peanut allergy if a parent or sibling also has peanut allergy, and 33-81% of children with infantile eczema also have IgE-mediated FA. A longitudinal study suggests that sensitivity to more than one food in the first 12 months of life also predicts probable FA at 12 and 18 years of age (Alduraywish et al., 2015). Prevalence rates are also dependent on age and allergen, as it is expected the majority of milk and egg allergies in infants are resolved by school age, whereas nut allergies are likely to persist through life (Sicherer & Sampson, 2014).

1.2.3. Impact of FA

There are physical and psychological factors that may be impacted by a diagnosis of FA, for example eating behaviour concerns such as reluctance to try new foods and a restricted diet may be a concern of children and adolescents with FA and their parents. A study on mealtime behaviour (Herbert, Mehta & Sharma, 2017) in children aged 7 years and under with FA found less mealtime behavioural concerns compared to those with diagnosed feeding disorders but more than in typically developing peers. Nutritional impact such as growth-faltering can also be an effect of FA, due to common allergens being nutritionally rich and difficult to replace, such as in cow's milk (CMA), eggs or nuts (Meyer, 2018). Food exclusion diets have also been linked to difficulties in feeding from a young age. Infants with CMA who were on an exclusion diet were reported to be fussy eaters and have feeding difficulties (Maslin et al., 2015). A further study (Maslin et al., 2016) found that children who had followed a cow's milk exclusion diet in infancy but now had cow's milk reintroduced, were slower and more avoidant eaters, with the number of foods avoided associated with an increase in avoidant behaviour. They also reported liking dairy foods less than controls who had never excluded dairy from their diet. Adolescents also have expressed difficulty in trying new foods, especially away from the home (Sommer et al., 2014).

In addition to physical risk factors of reactions, previous research by DunnGalvin et al. (2009) suggested that FA has a great impact on psychological development. DunnGalvin et al. (2009) conducted 15 focus groups with 62 children and adolescents aged 6-15 years and found identity, the meaning of food, autonomy, peer-relationships, risk and safety, and self-efficacy and control to be important factors that impact psychological development in children and adolescents with FA, and that these factors may change with age. Food becomes an area of anxiety, where children are concerned that consumption of foods will lead to reactions. This has a higher impact on older participants, especially the fear associated with not being able to breathe, which was considered the worst symptom.

Beliefs about identity, or how the participants felt about themselves, shifted around 8 years of age. Food previously thought of as their “special” food as labelled by parents, becomes something that marks the children and adolescents as different. The adolescents felt their FA had a strong impact on who they were as a person and the lives they lived (e.g. friends, places visited, and feelings about the self). Parents, especially mothers, were considered a source of safety aged 6-8 years, leading to feelings of confidence when managing FA. This then shifted after 8 years of age when children started expressing concern over what they ate, viewing eating as riskier. For autonomy (independence), control and self-efficacy (control over themselves and confidence in their actions), children aged 9 years and over realised parents cannot keep them safe in every situation. This can lead to conflict as parents and children try to manage autonomy and this can lead to anxiety in both parties. These feelings of increased risk were exacerbated by the belief that FA severity was not generally understood by the general population, as symptoms from FA were thought to be mild and this made eating out difficult.

DunnGalvin et al. (2009) suggested that these views of FA can have a direct effect on child development. At around 8 years of age, children become aware that parents are unable to ensure complete safety. This occurs in a developmental stage where children are learning to be more autonomous and find their independence as they grow into adolescence. DunnGalvin et al. (2009) also suggested that between the age of 8 and 12 years, is considered a stage of ‘growing awareness’. As adolescents grow older through ages 13-16 years their awareness and autonomy grow further as they adapt to new and unfamiliar contexts (DunnGalvin et al., 2018). In FA, a conflict in negotiating independence and the power balance between parent and child can cause further anxiety for both (DunnGalvin et al., 2009). Knowing about these beliefs and challenges associated with having FA in childhood and adolescence, may assist in understanding why adolescence is the age most at risk of fatal reactions to food.

Quality of life (QoL) in both those with FA and their families also has been reported to be affected by FA (Cummings, Knibb, King & Lucas, 2010; King, Knibb & Hourihane, 2009; Valentine & Knibb, 2009). Health related QoL had a detrimental effect on adults who experienced anaphylaxis, with the first experience of anaphylaxis described as frightening, while management was described as frustrating and associated with anxiety (Knibb et al., 2019). A review by Cummings et al. (2010) found strong evidence for the impact of FA on QoL and psychosocial distress in children and adolescents with FA and their families. In one study, children with peanut allergy reported lower QoL than their siblings without FA, however only a small sample of participants with peanut allergy was assessed (King, Knibb & Hourihane, 2009) and there may be differences in those who react to other allergens. Valentine and Knibb (2009) found that FA had an impact on daily life, which included disruption to activities in family life, concern about eating out and a preference to continuously visit places perceived as safe, and patient and parent concerns about FA management in school.

A greater number of allergic conditions (e.g. FA comorbid with eczema) has been associated with higher reported psychosocial impact, with increasing disruption to social family activities (Marklund, Ahlstedt & Nordstrom, 2004). By contrast, following a negative food challenge (not reacting to a food they were previously allergic to), there was a significant improvement in the child and family's social life (Eigenmann, Caubet & Zamora, 2006).

As living with FA can have various psychological and social challenges, adolescents with FA may implement various coping strategies in their management. Sampson et al. (2006) found participants aged 13-21 years considered behavioural strategies such as carriage of their AAIs and reading food labels, in addition to communication with others, as the main coping strategies in managing their FA. DunnGalvin et al. (2009) identified three coping strategies in FA, which were avoidant, minimisation or adaptive. Avoidant strategies focus on reducing stress through avoiding the issue, for example, avoiding places associated with food and therefore reducing the perceived potential for a reaction. This avoidance strategy focuses on the emotions associated with risk and identity, for example, adolescents may conduct risk assessments before going out with friends. Avoidant strategies were associated with low self-efficacy, meaning that when using this strategy, adolescents did not feel confident or in control. Avoidant strategies were also associated with high anxiety, and feeling FA was a big part of their identity. Cognitive minimisation strategies were more prevalent in boys who experienced bullying. This strategy involved rejection of FA as part of their identity and engagement in 'risky' actions, such as not adhering to AAI carriage at all times. By rejecting their condition as part of their identity, they may also in turn reject the severity of FA which may lead to more risky behaviour and increased risk of reaction. Finally, adaptive strategies were associated with more positive behavioural, emotional and cognitive strategies. Adaptive strategies were more common where parents encouraged self-management and independence, which may increase the adolescents' confidence. Positive strategies may include supportive peers and good communication, however peer beliefs about FA have not yet been studied.

1.2.4. FA and parents

FA may be diagnosed at any age; however, most FA affects younger children under three years of age (NHS, 2019). Where children and adolescents are still under the care of parents or guardians when diagnosed with FA, close relatives are also impacted by the diagnosis and may influence the beliefs and behaviour of their children. A study by Marklund et al. (2006) suggested that parents felt the younger their child with FA, the stronger the negative impact was on family activities in everyday life.

Parents of children with FA have been reported to have significantly poorer mental health with higher depression, anxiety and stress compared to parents who do not have children with FA (Birdi, Cooke & Knibb, 2016). A review by Moen, Opheim and Trollvik (2019) on parents' experiences of raising a child with FA suggested that following the first reaction, which parents found traumatic, they experienced fear, guilt and paranoia (Abdurrahman et al., 2013; Broome et al., 2015; Rouf et al., 2012). Parents also felt that family life and food choice was limited by FA (Stjerna et al., 2014). This was difficult for the parents, as they believed they would not be able to do activities with their child and could not easily leave their child in care of others. Siblings have been found to be concerned for the wellbeing of their sibling with FA and can take on more responsibility in the family (Stensgaard, Bindslev-Jensen & Nielsen, 2017). Siblings also experienced anxiety, worried that their sibling with FA may have a fatal reaction (Munoz-Furlong, 2003).

Manageability of FA is influenced by support and knowledge provided by healthcare professionals, which in some studies was stated to be limited (Abdurrahman et al., 2013; Akeson et al., 2007; Gallagher et al., 2012; Lagercrantz et al., 2017; Valentine & Knibb, 2011). Management is also influenced if opinions between mother and father align (Gupta et al., 2008), with a good relationship reducing the mother's fatigue (Alanne et al., 2012). Two qualitative studies reported that parents felt they must be in control of their child's life (Lagercrantz et al., 2017; Stensgaard, Bindslev-Jensen, & Nielsen, 2017). Fathers' and mothers' views may not always align as fathers have been reported as wanting to expand their child's life while mothers tend to focus on sheltering their child (Gupta et al., 2008). These views were also found when parents were separated; in a phenomenological study of parents of children aged 6-12 years, mothers felt they had to relinquish control when their children with FA visited fathers who lived elsewhere (Gillespie et al., 2007). In a Canadian survey, mothers were anxious about loss of control (Abdurrahman et al., 2013) but in both a quantitative (Abdurrahman et al., 2013) and qualitative study (Begen et al., 2018), mothers were also concerned about their child being excluded from social events. Further qualitative studies have highlighted that mothers struggled with balancing reducing stigma and risk, while wanting their child to be included but safe (Dean et al., 2016; Rouf et al., 2012; Yonamine et al., 2013).

Mothers, more than fathers, have been reported to assist with managing the transition to self-management in their children (Gallagher et al., 2012). They acknowledged that in adolescence, with increasing freedom came the potential for increased risk-taking behaviour (Gallagher et al., 2012). However, mothers felt that their adolescents understood the seriousness of their condition (Gillespie et al., 2007). Nonetheless, relinquishing control resulted in parents feeling anxious and concerned (Lagercrantz et al., 2017), while some adolescents felt their parents were controlling and were irritated by their worries (Stensgaard, Bindslev-Jensen, & Nielsen, 2017).

1.3. Adolescents

1.3.1. Adolescence as an 'at risk' age

The age range associated with adolescence varies, but is typically associated with pubertal onset, between 10 and 19 years of age (Sacks, 2003). Adolescents and young adults are at the highest risk of reactions to food (Bock, Munoz-Furlong & Sampson, 2007) and this age group has the highest frequency of fatal reactions (Pumphrey, 2000). This may be attributed to an increased engagement in risk-taking behaviours most common in adolescence (Sampson, Munoz-Furlong & Sicherer, 2006), for example, not carrying their AAI or not reading food labels carefully. Younger children have shown less anxiety and risk-taking behaviour as they depend on parents for their FA management (DunnGalvin et al., 2009). Around 12 years of age, conflict and resentment can arise as adolescents seek independence (DunnGalvin et al. 2009), which may be why risk-taking behaviour increases.

A Texas study (Cohn, MacFarlane, Yanez & Imai, 1995) suggested that adolescents perceived less risk in occasional and experimental activities that may be detrimental to health (e.g. smoking or drinking alcohol) but were less optimistic of avoiding negative consequences such as illness or injury compared to adults, suggesting that adolescents view risk-taking differently to adults. Baruch (2001) considered that adolescent mental health is vulnerable due to a multitude of challenges and a 'propensity to engage in risk-taking behaviour' (p.3). They further considered that being subjected to harmful experiences may have a negative impact on mental health and adolescents may be more vulnerable to psychosocial disorders (p.3). A study by Green et al. (2005) looking at the effect of adolescent trauma on risky behaviour in college women found that even a single exposure to interpersonal violence was sufficient for some risk-taking behaviour, and that ongoing abuse exposure increased risky sexual behaviour, elevated perpetration of violence and suicide ideation. Major depression and post-traumatic stress disorder (PTSD) were also associated with the behaviours (Green et al., 2005). Applying this to FA, experiences such as anaphylaxis or use of an AAI may have a negative effect such as increased anxiety or PTSD.

1.3.2. Risk-taking behaviour in adolescents

Sampson et al. (2006), suggested that risk-taking behaviour may be a core factor in adolescents being at the highest risk of fatal anaphylactic reactions. Adolescent risk factors are thought to be influenced biologically by genetic predispositions, direct hormonal influences, asynchronous pubertal timing, and brain and central nervous system development (Sales & Irwin Jr., 2013). Much research into adolescents considers the effect of risk, impulsivity and sensation seeking. Impulsivity can be considered as acting without thinking, for example eating a ‘risky’ food without checking the label, and impatience in relation to reward (Romer, 2010). Increased sensation seeking has been linked to a rise in dopamine in the striatum (Chambers et al., 2003). The striatum is the input module to the basal ganglia in the brain (Hikosaka, Takikawa & Kawagoe, 2000) and is activated by reward in social situations (Baéz-Mendoza & Schultz, 2013). Increased sensation seeking has been observed in participants aged 14-22 years (Romer & Hennessy, 2007), with males engaging in sensation seeking more than females. Risk-taking has also been associated with disinhibition and risk-taking personality, and to a lesser degree, experience-seeking, invulnerability, thrill and adventure seeking, and boredom susceptibility (Greene et al., 2000).

In psychology, learned, developmental and personality approaches have been considered to try to explain risk-taking behavior (Greene et al., 2000). The developmental approach considers that risk-taking is either a normal exploratory behavior or a negative byproduct of egocentrism in cognitive development (Greene et al., 2000). The learned approach considers risk-taking an act of deviance in problem behavior (Donovan & Jessor, 1985) as a result of a poor environment and family communication and socialization (Gore & Eckenrode, 1994). In addition, adolescents who had Zuckerman's (1979) personality trait of 'sensation seekers' were more likely to view risk positively, especially adolescent males.

Previous research on adolescents and risk tends to focus on common coming-of-age risk-taking behaviours such as smoking, alcohol use, and unprotected sex. The more favourable an option was believed to be, the less risk was associated with it (Romer, 2010), which can be exacerbated by peers with similar views who may reinforce this risk-taking behaviour. While some risk-taking in adolescence is to be expected as young people find their independence, in those with FA, risk-taking behaviour such as eating foods that 'may contain' allergens or not adhering to AAI carriage may have dire health consequences.

Research by Warren et al. (2016) on adolescents with FA and risk-taking behaviour found that these behaviours included eating food with 'may contain' labels, not carrying their AAI at all times, kissing people who recently consumed their allergen or eating homemade or unpackaged food where they were unsure if it contained their allergen. Findings suggested that adolescents with FA were less likely to engage in risk-taking behaviours if they had a peanut allergy, overprotective mothers, teachers who were aware of their FA, supportive female friends, an established education plan or a history of being bullied. Positive views of FA including improved diet, empathy and greater responsibility also reduced risk-taking behaviour. A healthier diet may have helped the adolescents feel more positive about their FA diet restrictions, and heightened empathy, responsibility and maturity.

As little is known about beliefs of those with FA and their peers in relation to risk and management of FA, it is important to explore this further. Risk and management studies often focus on the behaviour, such as reluctance to use an AAI, yet there is limited research on what beliefs adolescents have that may influence the behaviour. Further study of beliefs about FA may allow for further understanding about why adolescents with FA are more likely to experience reactions, which may in turn help to reduce the rates of serious and fatal allergic reactions in this age group. Furthermore, understanding beliefs of those without FA, may provide insight into risk perception of FA, and highlight maladaptive beliefs that cause adolescents with FA distress, such as misconceptions about FA seriousness.

1.4. Influences and effects; FA and others in Ecological Systems Theory

Peers have been highlighted as having an influence on risk-taking behaviour. Social models such as the Ecological Systems Theory (Brofenbrenner, 1994) may help to explain this. This model explores how a child may experience close and acquainted social relationships which may in turn affect cultural beliefs through environment. Brofenbrenner's Ecological Systems Theory (1994) suggests that individuals are affected by people around them and this may influence development. A visual representation of the environments can be seen in Figure 1. This can range from the immediate environment including peers in the ‘microsystem’ and ‘mesosystem’ of connections, to the wider community in the ‘exosystem’, and then to the ‘macrosystem’ which considers cultural attitudes and ideologies but may be extended to beliefs. The chronosystem may consider the enduring nature of these beliefs and how they may change over life, however as this thesis focuses specifically on an adolescent bracket, this stage may not be as relevant. This model offers insight into how peer relationships may have an influence on adolescents with FA, as they are very close to the child in the microsystem whether they are friends, peers in the same school, or peers in the community, such as from clubs, neighbours or religious activities.

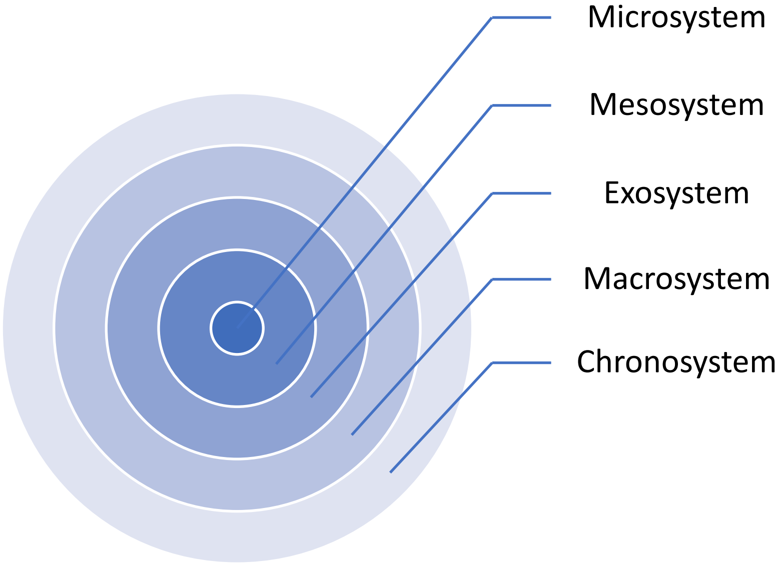


Figure 1: The systems in Brofenbrenner's Ecological Systems Theory (1994)

1.4.1. Peers and social support

Peer relationships are an important aspect of adolescent development and can have an influence on adolescent behaviour including risk-taking behaviour in both a positive and negative way depending on peer norms (Allen, Porter, McFarland, Marsh, & McElhaney,

2005). Peers described as ‘deviant’ are linked to increases in risk-taking behaviour in 11-15-year olds (Ary, Duncan, Duncan & Hops, 1999). This is supported by a study by Chein et al. (2011) who ran a simulated driving task with adolescents, young adults and adults while measuring their brain activity with fMRI and found that adolescents were more likely to engage in risky behaviour if peers were watching. When peers were observing, the participant’s brain showed increased activation in the areas of the brain linked to reward, and activity in these areas predicted subsequent risk-taking. Adolescent brains showed increased reward sensitivity when they took risks compared to older populations.
Female adolescents have been reported to have stronger relationships with their friends (Thomas & Daubmann, 2001) and have more people to support them than male adolescents (Belle, 1987). This is supported by a study looking at diabetes and peer relationships; males felt less supported and had more negative relations with their friends especially when they had diabetes, whilst females experienced greater support in their friendships regardless of whether they had diabetes or not (Helgeson et al., 2007). In this study, support predicted better psychological health for males (Helgeson et al., 2007), suggesting males may benefit from increased peer support. However, for females, it has also been suggested that deeper connections can be a burden through feeling added responsibility and pressure to support their friends (Belle, 1987).

There is little in the literature on peer support for adolescents with FA, but Warren et al. (2016) found supportive female friends led to less risk-taking behaviour. Previous research suggests peer pressure may be an issue (Sampson et al., 2006). In Sampson et al.’s (2006) study, greater peer education was suggested to reduce teasing, bullying and improve general safety. These were issues also highlighted in research by Stensgaard et al. (2017) and Fenton et al. (2013). However, education may be difficult for adolescents to deliver themselves. In contrast, peer support can help adolescents with FA to reduce risk-taking behaviour and keep safe. However, research into direct peer beliefs has not yet been explored.

The sensitivity of social relationships with peers and parents, and personal development in the adolescent period, can have a negative impact on QoL in adolescents with FA (Morou, Tatsioni, Dimoliatis & Papadopoulos, 2014; Cummings et al., 2010; Marklund et al., 2004). Children with FA have been reported as having worse QoL in social and psychological domains than parents (Morou et al., 2014). Social limitations in FA have been highlighted in children of various ages, including a study into 9-year olds (Ostblom, Egmar, Gardulf, Lilja & Wickman, 2008) which reports social limitations compared to those with no FA. Bollinger et al. (2006) supports this by highlighting social events affected by FA with peers, including playing at friend’s houses, sleepovers, parties, field trips and in family social events. This highlights the importance of fostering strong relationships with peers and family to reduce social limitations for adolescents with FA.

1.4.2. Schools

A school environment can also pose a risk for someone with FA. Approximately 84% of children with FA experience a reaction in school, with 25% of first-time reactions also happening in schools (Powers, Bergren & Finnegan, 2007). Previous research highlights that schools are the most common location for anaphylaxis with 16-22% of all reactions occurring there (Novembre et al., 1998; Moneret-Vautrin et al., 2001; Rankin & Sheikh, 2006; McIntyre, Sheetz, Caroll & Young, 2005; Bock, Munoz-Furlong & Sampson, 2007; Young, Munoz-Furlong & Sicherer, 2009). In the UK, there was at least one child at risk of anaphylaxis in 61% of schools in 2006 (Allen, Hill & Heine, 2006) and as prevalence has increased over the last ten years, this is likely to now be higher. All schools should have a protective policy in place for their students with FA, however many of these policies could be improved. Personalised emergency management plans, which detail individual reaction symptoms and a plan of action for when they occur, are not consistently provided (Young, Monoz-Furlong & Sircherer, 2009) and teachers are reported to have poor knowledge about anaphylaxis, including symptoms, triggers and AAIs (Young, Monoz-Furlong & Sircherer, 2009; Greenhawt, Singer & Baptist, 2009; Ercan et al., 2012; Behrmann, 2010), however much of this research is from America, and so there may be differences compared to the UK.

In Canada, adolescents reported that the transition to secondary school was difficult as schools were larger and less organised, which made them feel less safe (Fenton et al., 2011). School policies could also be exclusionary, where adolescents with FA had to sit alone at lunch or were not allowed to attend school trips (Fenton et al., 2011; Dean et al., 2016). Finding their FA embarrassing or shameful can create issues in the school environment for children and adolescents with FA, especially if peers are unaware of the FA (Sampson et al., 2006) due to the adolescents feeling that they must be secretive to protect themselves or avoid bringing attention to their FA. School trips have also been described as difficult and annoying as the adolescent with FA could not eat ‘the same as everyone else’ (Stensgaard et al., 2017). When schools were accommodating of FA, children felt safer and more included (Stjerna, 2014), however this also drew attention to how they were different from their peers (Dean et al., 2016). Understanding peer beliefs may assist with these issues by informing suitable school-based interventions.

1.4.3. Wider community

People with FA may experience a reaction in a variety of community settings such as restaurants, beaches, sports fields, gymnasiums (Mcintyre, Sheetz, Caroll & Young, 2005), and fatalities in places such as restaurants (Uguz et al., 2005), a friend's home and work (Pumphrey & Gowland, 2007; Kapoor et al., 2004). Allergen avoidance training often considers avoidance of allergens in the home, but less so of how to avoid exposure to allergens in the community (Muraro et al., 2014).

Knowledge and attitudes of the community can be a barrier for those with FA, particularly in restaurant staff who directly interact with consumer's food. Confusion has been reported in UK takeaway staff (Soon, 2018), who were reported to be unsure of the difference between milk allergy and lactose intolerance and uncertainty of whether allergens could be transferred by hands. A US study on restaurant workers showed that very few would know how to assist someone experiencing anaphylaxis and staff were not ready to manage FA safely (Dupuis et al., 2016). These attitudes were similar in other EU countries such as Germany (Loerbroks et al., 2019). Further research into food handlers (Shafie & Azman, 2015; Choi & Rajagopal, 2012) also found knowledge could be improved, and suggested that allergy knowledge and beliefs were significantly correlated with practice, with confidence and care of the workers when managing FA increasing with knowledge.

Improved FA knowledge of the general public would be beneficial and is desirable (Muraro et al., 2014) and must accommodate the general public's needs while balancing protecting those with FA. This is an important concern in the UK as well as in other developed countries such as the USA, Canada, Australia and New Zealand (Chafen et al., 2010). However, some policies have already met with resistance, such as nut bans in schools (Gupta et al., 2009). Nut bans in schools are claimed to be extreme and limiting of food choice by those without FA, such as in a Canadian study by Harrington, Elliott, Clarke, Ben-Shoshan and Godfrey (2012). In this study by Harrington et al. (2012), peanut bans particularly faced backlash as peanut butter is an accessible and affordable source of protein in low-income families. In the UK, advice from charities such as Anaphylaxis Campaign is not to use allergen bans as there is no guarantee it could be an environment free of that allergen as children can bring in food from home; this can also create conflict between parents which may instead increase risk (Anaphylaxis Campaign, 2019). As conflict and social exclusion are concerns for those with FA, community interventions should be conducted delicately (Muraro et al., 2014). As there are different governing bodies for health and education, cooperation between healthcare professionals such as doctors and dieticians, the school community and parents are necessary to overcome these barriers (Muraro et al., 2014; Bershmann, 2010). Community interventions may involve addressing misinformation, providing education and addressing FA condition beliefs, for example that FA is not a serious condition.

Given the importance of beliefs, consideration of previous theories and models that assess beliefs may be useful in understanding the factors impacting the lives of adolescents with FA within their close relationships in their microsystem, and their further relationships and interactions in their mesosystem and ecosystem.

1.5. Theories and models incorporating beliefs

Beliefs are important to health research as behaviour is a result of salient beliefs related to that behaviour (Ajzen, 1991). For an individual to initiate positive health behaviours, they must believe they are susceptible to a health concern that it is severe enough to have at least a moderate impact on their life, and that a certain action would have a beneficial effect at reducing this susceptibility and severity (Rosenstock, 1974). Rotter (1954) and Ajzen (2002) also considered beliefs and how these may be internal or external, affecting a person's perceived locus of control (LoC) and their self-efficacy (SE) for managing an issue.

SE looks at a person's beliefs of control over their lives and the success of performing behaviour to a certain outcome, while perceived behavioural control just considers the ability to perform the behaviour, rather than the perceived control of it which is required in SE (Bandura, 1991; Ajzen 2002). Applied to adolescent FA, good SE is important for reading labels or administering their AAI in the event of an allergic reaction. SE is important to measure when promoting behaviour change and coping (Bandura, 1977). Health LoC may be defined as internal or external, with internal LoC considered to be how much control you believe you as an individual have over your health due to your own powers such as in ability or effort. An external LoC gives control to external sources (Rotter, 1966) whether this is spiritual such as fate, or a pilot flying a plane you are travelling on. Applied to FA, an external LoC may be a belief that a reaction to a product with a 'may contain' label is due to fate or a belief that surviving an allergic reaction is due to paramedics. An internal LoC is a belief that the ability to manage your FA lies with yourself. SE implies a level of confidence with this perceived control, while LoC instead focuses on ability and where the control is perceived to be.

Wallston (1992) expanded on Rotter's (1954) theory and created a modified social learning theory for health, suggesting different beliefs interact to predict an individual's behaviour. Wallston (1992) argues that rather than mediating behaviour by being the variable that explains it, beliefs instead moderate behaviour, meaning they have an influence on the strength of the relationship but are not the sole determinant. Wallston (1992) argues that beliefs are only mediated for those with an internal health locus of control, and not for those with an external locus of control. He argues that beliefs instead moderate the relationship between behaviour potential and expectancy measures such as SE beliefs. Beliefs have been incorporated as components in many theoretical models in psychology including the Theory of Planned Behaviour (Ajzen, 1991), the Common Sense Self-Regulation Model (Leventhal et al., 1984), and the Health Belief Model (Rosenstock, 1974), which later was adapted to create the Protection Motivation Theory (Rogers, 1975).

Recent research by Jones et al. (2014; Jones et al., 2015) has explored attitudes to FA using theoretical models looking specifically at adolescents' and young people's adherence to carrying their AAIs using the Health Belief Model (HBM) and Common-Sense Self-Regulation Model (CS-SRM). The HBM and CS-SRM and the concept of beliefs assist in exploring and understanding the exploratory data of this thesis.

1.5.1. The Health Belief Model (Rosenstock, 1974; Janz & Becker, 1984)

The HBM suggests that beliefs might be mediated by structural (previous experience, condition knowledge), social psychological (personality) and demographic variables (for example, age, gender or ethnicity). An individual's view of threat to their health is composed of the health belief constructs of perceived susceptibility, perceived severity and cues to action. Perceived susceptibility assesses the believed likelihood of a negative health consequence occurring (e.g. having a reaction to food), while perceived severity looks at how serious this negative health consequence may be, for example would a reaction to food be hives or anaphylaxis? This then effects the individual's need to act on their health behaviour. Perceived benefits and perceived barriers to healthy behaviour may also influence the likelihood of action. For example, a benefit to carrying an AAI may be a sense of security, but a barrier may be that it is frustrating to carry, or the needle is perceived as scary. These factors all affect how likely it is that an unhealthy behaviour (such as not carrying an AAI if you have a FA) will be reduced, or that a health behaviour (checking all food labels) may be increased. Figure 2 details the HBM (Janz & Becker, 1984) and how the constructs fall under three factors; individual perceptions, modifying factors and likelihood of taking preventative action.

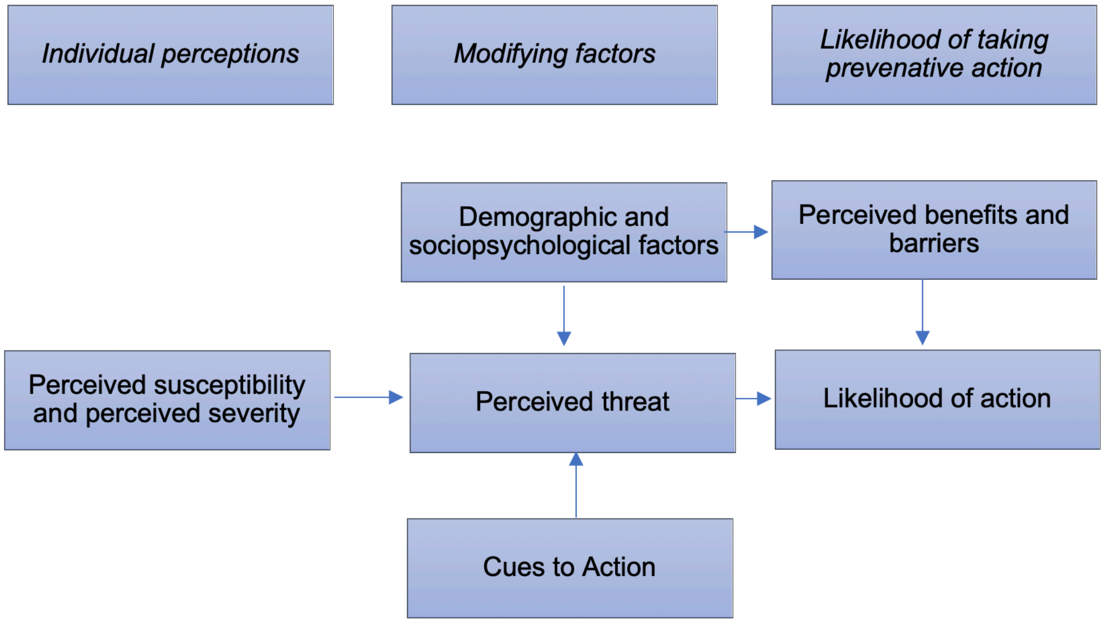


Figure 2: HBM diagram (adapted from Janz & Becker, 1984)

Individual perceptions involve a person's perceived severity and susceptibility of a healthcare issue, whether this is likelihood of a health condition (e.g. diabetes) or of an unhealthy behaviour (e.g. smoking) and how serious an individual believes this to be, which then impacts the perceived threat to that person. Modifying factors include demographic and sociological factors, for example age, gender or socioeconomic status, perceived threat and cues to action. Cues to action may be interventions and health campaigns, such as advice from a general practitioner or media advertisements. Demographics, sociopsychological factors and cues to action may all also influence perceived threat. Demographic and sociopsychological factors may also affect the likelihood to engage in preventative action through perceived benefits and barriers to engaging in action, influenced by factors such as time, cost and capability. The overall likelihood of the action is then impacted by these benefits and barriers, as well as the perceived threat, showing how beliefs may influence behaviour.

Using the HBM to try and explain adherence to AAI carriage in 13-19-year olds, Jones et al. (2014) suggested that adherence improved with increased perceived severity of FA or reduced perceived barriers to allergy management. Jones et al. (2015) recommended addressing anaphylaxis severity beliefs in adolescents and that knowledge-based interventions may reduce barriers to FA management, leading to good adherence behaviours. This is supported with perceived barriers and perceived severity accounting for 21% of variance in AAI adherence behaviours in adolescents with FA (Jones et al., 2015).

1.5.2. The Common Sense Self-Regulation Model (Leventhal et al., 1984) (CS-SRM)

Another model that has been used in FA research is the CS-SRM. The CS-SRM identifies five cognitive dimensions in relation to processing health information (Leventhal et al., 1984); identity, timeline (acute/chronic), consequences, and control/cure and cause. Emotional representations were later added through three cognitive dimensions; cyclical timeline beliefs, coherent understanding of the condition and emotional perceptions of the condition as shown in the basic process model in Figure 3 (Hagger et al., 2017). The coping strategy and illness outcome categories are based on the classification procedure developed by Hagger and Orbell (2003). Hagger et al. (2017) suggests that sociocultural context and the self (biological and psychological characteristics) have an external influence on the rest of the model. Situational stimuli inform cognitive and emotional illness representations, which then inform coping strategies, which are appraised for coping with illness and emotional outcomes. Jones et al. (2015) explored adherence in relation to the Common Sense Self-Regulation Model (CS-SRM) and found in their sample that 25% of variance in adolescent adherence to carrying their AAI was explained by illness identity, emotional beliefs and timeline cyclical beliefs. The HBM and CS-SRM performed similarly for explaining adherence behaviours in adolescents with FA and Jones et al. (2014) recommended that interventions to improve self-care behaviours should incorporate the unpredictable nature of symptoms and beliefs of severity of FA.

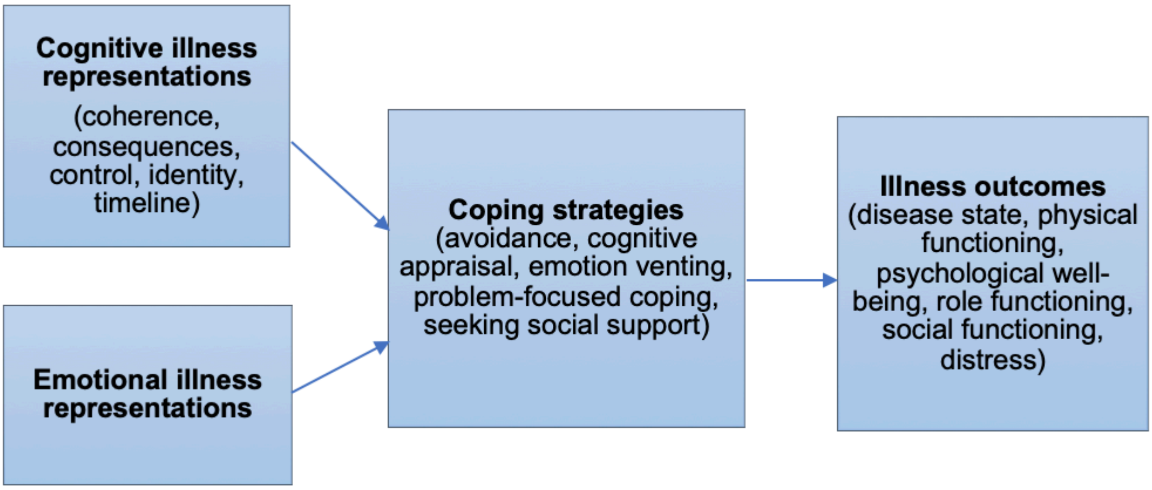


Figure 3: Basic process model derived from the Common Sense Self-Regulation Model (adapted from Hagger et al., 2017, p 129)

1.5.3. Attitudes or beliefs? The rationale for the focus of beliefs

With consideration of the characteristics of FA and previous research, this thesis considered whether to explore beliefs or attitudes. Attitudes towards a health condition can be an important determinant of how that condition is managed. Attitude research has worked to find a definition for the construct for many years, often confusing attitudes with beliefs. In 1981, Petty, Cacioppo and Goodhue defined attitudes from a social psychology standpoint as "used to refer to a general and enduring positive or negative feeling about some person, object or issue" (p.9) (cited in Goodhue, 1988) and were affected by either the quality of the arguments or expertise of the source. In 1984 they suggested attitudes were predictive of future behaviour due to 1) relating previous knowledge and experience and gaining more confidence and willingness to act upon the attitudes, 2) having an evaluation of the object increasing likelihood that the measured attitude is accessible when the behaviour will be used, and 3) having considered appropriate actions regarding the attitude object and therefore having less need to reconsider a relevant behaviour (Cacioppo & Petty, 1984).

Similar to attitudes is the cognitive construct of beliefs. Beliefs are important as they reflect our truth and how we see the world (Halligan, 2006). Belief systems provide 'mental scaffolding' for us to understand the world, new observations, and appraisal of our environment (Halligan, 2007, p358). However, the definition of a 'belief' is more difficult to determine, and although beliefs are mentioned frequently in research, they are rarely explicitly defined (Connors & Halligan 2015). Schwitzgebel (2010) defined a belief as a 'propositional attitude', conviction or mental acceptance of the truth of an idea. Attitudes, by contrast, need a mental stance on the proposition's validity (Schwitzgebel, 2010). However, Connors & Halligan (2015) further argue that people may not be aware of their beliefs as they may be unconscious. Beliefs we are aware of can influence our actions and goals and our appraisal of our environment (Tullett et al., 2013) and thus in psychological interventions, dysfunctional or inaccurate beliefs are often addressed (Beck, 1976; Hofmann et al., 2012; Kronemyer & Bystritsky, 2014).

The main difference between beliefs and attitudes is that attitudes must be evaluative (Eagly & Chaiken, 1993) and linked to behaviour (Fishbein & Ajzen, 1975). Previous research implementing attitudes tends to focus on behaviour, whereas research into illness and health conditions tend to focus on beliefs, as shown in the HBM and CS-SRM. Beliefs may assist us in understanding attitudes and as the research in this thesis is exploratory, beliefs as a broader term is more suitable so that important data may not be excluded if it is not evaluative. It was therefore decided to focus on beliefs for this thesis.

1.5.4. Beliefs in previous health research

Beliefs have been investigated in a range of long-term conditions, one of which is diabetes. Diabetes is in some ways similar to FA, as a condition that is not understood by peers, is affected by diet and involves use of medication with a needle. Health beliefs in people with diabetes have been found to influence how they manage their self-care (Albargawi et al., 2016; Albargawi et al., 2017; Vedhara et al., 2014). Albargawi et al. (2017) looked at beliefs in those with diabetes and measured SE and LoC in a study conducted in Saudi Arabia. They found that high SE and an internal LoC led to good adherence in treatment. When participants had stronger beliefs that their treatment regimen would lead to a positive outcome and that their doctor could help them, they had greater adherence to their dietary instructions. Where they had high SE but believed God controlled their health, they also had high adherence to their medication regimen.

A similar UK based study (Vedhara et al., 2014) looking at diabetes and foot ulcers, used the Brief Illness Perception Questionnaire (B-IPQ) and found beliefs of symptoms, understanding of the condition and perceived control were independent variables of diabetic foot ulcer self-care. Illness beliefs were reported to account for moderately high variance in foot care behaviour, with identity and coherence beliefs significant predictors at six weeks, meaning patients who reported poorer understanding and more symptoms at baseline were more likely to be adhering at six weeks.

Better communication between patients and practitioners has also shown to be important and led to increased patient adherence to self-management and treatment plans (Heisler et al., 2002; Zolnierek & Dimatteo, 2009) as well as increased patient satisfaction (Rathert, Wyrwich & Boren, 2012). Shaak et al. (2018) recommended that a shift in health beliefs for diabetes may be possible through health promotion education focusing on diagnosis awareness and progression of risk, which has been supported by previous research by Birkett et al. (2004) and Safeer, Cooke and Keenan (2006).

Beliefs appear to develop and change as children grow into adolescence and then adults, Children are influenced by the beliefs of adults; adolescents and young people have more positive beliefs about their health, but poorer adherence. An American study looking at beliefs of parents and children found that age was the variable associated with health beliefs and child health behaviours (Dielman et al., 1982). The children were also influenced by their parent's behaviours and beliefs regarding health behaviours such as smoking and snacking between meals (Dielman et al., 1982). In a study of people with HIV, younger participants (lowest age 25) had poorer adherence predicted by low SE and lack of perceived treatment utility compared to older participants (Barclay et al., 2007). For self-reported health however, younger participants were most positive (sample range 14-87), and participants younger than 31 years old were twice as likely to rate their own health as excellent or very good (Renner, Knoll & Schwarzer, 2000). In a study with older participants of 65 years and above however, their health beliefs were at odds with conventional medicine (Conway & Hockey, 1998), suggesting a generational shift in health beliefs.

There is limited research into adolescent beliefs regarding FA, especially in the secondary school age range of 11-16 years. The desire for further research into the transition from a child to an adolescent to support independent self-management has also been requested by participants with FA (Gallagher, Worth, Cunningham-Burley & Sheikh, 2011).

1.6. Summary

We know that adolescence is the age most at risk of anaphylactic reactions, but we do not yet fully understand why. There is also limited understanding of adolescent beliefs of FA. Understanding beliefs of adolescents about FA is important to give insight to how adolescents both with and without FA think and feel about the condition. This may also provide suggestions for how to reduce risk-taking behaviour, improve adherence to AAI carriage, and reduce the likelihood of anaphylactic reactions. Exploration of beliefs may also identify areas where adolescents need more support, for example, in managing FA as they become more independent and keeping beliefs realistic rather than destructive, such as unrealistic optimism of believing a reaction will never happen to them or the belief they are surrounded by danger, leading to high levels of anxiety. For those without FA, the findings may provide further understanding of how they can support their friends with FA in managing the condition.

Condition beliefs may have an impact on behaviour and therefore it is important to understand beliefs in adolescents with and without FA to understand how these beliefs might affect condition management. The need for further research to support independent self-management of FA has been requested by adolescents themselves (Gallagher et al., 2011). Jones et al. (2014; Jones et al., 2015) has published work in FA incorporating both the HBM and CS-SRM, however these were the only studies found incorporating models into FA beliefs.

Many studies reporting beliefs about FA focus on adults' perceptions of food labelling (Ju, Park, Kwak & Kim, 2015) rather than beliefs of children and adolescents. The focus of previous research has been concerned with companies labelling products as potentially containing peanuts (Hefle et al., 2007) or on the attitudes and beliefs of health professionals such as nurses (Twichell, Wang, Robinson, Accebal & Sharma, 2015), primary care physicians (Gupta et al., 2010), and parents (Noimark, Gardner & Warner, 2009) rather than the children themselves. It is important to explore adolescent beliefs about FA further to see how they may relate to FA management and how we can then develop interventions to improve allergy management.

1.7. Thesis aims

The overarching aim of this thesis is to explore adolescent beliefs about FA in the 11-16-year-old population to better understand behaviour of adolescents with FA. Beliefs will be explored qualitatively through semi-structured interviews to gather detailed data of adolescent beliefs and experiences, which will then be used to inform the development of a scale to measure beliefs about FA to quantifiably gather broader data from a larger sample.

This thesis aims:

- To understand current literature, previous research and gaps in knowledge in adolescent FA beliefs, achieved through conducting a systematic review.
- To qualitatively explore beliefs of adolescents both with and without FA, to better understand the adolescent experience of FA and what influences beliefs, through semi-structured interviews and inductive thematic analysis.
- To develop a psychometric scale to assess beliefs in adolescents both with and without FA.
- To compare and contrast beliefs about FA in adolescents with and without FA by looking at qualitative findings

Chapter 2: Methodological approach to thesis

This is an inductive, exploratory, and data-driven thesis, implementing a mixed method approach to include both in-depth and large-scale data to represent the chosen population. Two samples of both allergic and non-allergic adolescents are included to give a more complete view of the adolescent experience of FA, as peer beliefs are given much weight in the adolescent period. Previous research has not considered the beliefs from the views of peers, only what adolescents with FA believe that their peers believe. While this is important, this thesis aims to have an understanding of both perspectives, as peer beliefs may influence beliefs and behaviour of the adolescents with FA, whether this is taking more risks or being put at increased risk of reactions through stigma and misunderstanding. Further discussion of the rationale for using adolescents without a diagnosed FA may be found in the empirical chapter (Chapter 5). This chapter therefore considers a mixed methods approach; a combination of qualitative and quantitative methods, and the methods of each study; a systematic review of beliefs of FA in 11-19-year olds, two qualitative semi-structured interview studies analysed with thematic analysis, and the development of a scale.

2.1. Approach justification

2.1.1. The benefits of mixed methods

Mixed methods research is generally considered to include a method from qualitative and quantitative disciplines to investigate a research topic of interest (Yardley & Bishop, 2015; Dures, Rumsey, Morris, & Gleeson, 2011; Flick, Garms-Homolová, Herrmann, Kuck, & Röhnsch, 2012) for depth and breadth of understanding (Johnson et al., 2007). The use of mixed methods allows flexibility in health psychology research and allows the researcher to find the best fit of method and be responsive to the research (Dures et al., 2011). It is common in health psychology, that when aiming to develop a questionnaire, qualitative methods are first used to identify items that might measure the construct and the formation of a psychometric scale allows reliability and validity to be tested (Bishop, 2014).

2.1.2. Mixed methods and pragmatism

The epistemology of this thesis focuses on the knowledge, beliefs and truth (Walsh & Evans, 2014) of my adolescent participants surrounding the topic of FA. For this research, an inductive approach was implemented with the data as the source. As research into adolescent beliefs around FA was limited, it was decided to work from the data rather than starting with conceptions that may not have been accurate. This research overall takes the paradigm of pragmatism to combine methods and epistemological constructionism; that beliefs are shaped by experiences and assumptions.

Pragmatism (Morgan, 2007) combines a qualitative and quantitative approach in mixed methods research. It is the best paradigm for this thesis due to the goals of the research and the studies undertaken (Yardley & Bishop, 2015). The pragmatic approach looks to use abduction, intersubjectivity and transferability to move between the different methods effectively (Table 2).

Table 2: Pragmatic approach (adapted from Morgan, 2007)

	Qualitative	**Quantitative**	**Pragmatic**
Connecting theory and data	Inductive	Deductive	Abductive
Research process relationship	Subjective	Objective	Intersubjective
Inference from data	Contextual	Generalizable	Transferable

The abductive process has been used frequently in mixed methods research, especially in sequential cases similar to this PhD research where qualitative research informs the development of quantitative work, or vice-versa (Ivankova, Creswell, & Stick, 2006; Morgan, 2006). Intersubjectivity balances the argument that there can be no completely objective or subjective research by recommending duality and a focus on shared meaning and communication (Morgan, 2007). Intersubjectivity is also flexible and highlights that an individual may have their own world of meaning as well as there being a sole ‘real world’ (Morgan, 2007). Finally, transferability focuses on what we may learn in a specific setting and how to use this effectively elsewhere, rather than being strictly contextual or generalisable (Morgan, 2007). Overall, the flexibility and duality of this approach fits most cohesively in this research rather than strictly and rigidly attempting to fit qualitative and quantitative paradigms separately in this one thesis.

At a study level, the quantitative scale is critically realist, while the qualitative study of participants with FA is constructivist and the qualitative study of participants without FA is socially constructionist. In quantitative research, positivism considers a straight-forward relationship between the world, and how we perceive and understand it. Positivist epistemology argues that the goal of research is to produce knowledge, which is objective, free from researcher bias, and considers quantitative methods to be superior in attempting to be objective. However, as the researcher is human and therefore cannot be completely objective, and as qualitative methods are being used in addition, this research is not positivist in entirety. The scale developed within this thesis uses standardized measures such as Likert scales, however it will need to undergo further reliability and validity testing and it is arguably not sufficiently standardized in entirety without procedures such as a test-retest analysis, which is a key element of positivism (Sullivan, 2019). Critical realism on the other hand moves away from strict relativism and considers knowledge is influenced in part by subjectivity but not subjective in entirety (Madill et al., 2000) as it is affected by beliefs and perceptions (Bunge, 1993), which is arguably more fitting for this research.

For qualitative research, positivism is not appropriate. Constructionism is more relativist rather than realist, meaning that it is more subjective and based on individual experiential constructions, as explored through semi-structured interviews. For my interviews with people without FA, social constructionism is more appropriate as a paradigm as the data was created through discourse (Sommers-Flanagan & Sommers-Flanagan, 2012), as outside of the interview and questions presented, the participants may not have considered FA in such a way. For the participants with FA, this was more constructivist as their knowledge was phenomenological and experienced inside themselves (Sommers-Flanagan & Sommers-Flanagan, 2012).

2.1.3. Systematic review

A systematic review was conducted for this project prior to the development of study materials for the qualitative and quantitative studies to explore what had already been studied in this area, what methodology had been used, what results were found and what implications and gaps in research needed further consideration to inform this research. This also identified any influential results to expand on, to inform the subsequent research studies. Authors were identified who were working in similar areas, where in the world they were conducting research and if there were cultural differences to consider. Potential opposing viewpoints were also explored, to justify methodological choices, result interpretation, and further steps.

Awareness of existing theory and research through a systematic review allowed for exploration of what had already been done and how, and what had not yet been done. In the systematic review (Chapter 3), this is considered in more depth, however it gave a basis to work from and informed this PhD of expectations. As the researcher had not had experiential knowledge of the condition and as the work in this thesis is exploratory, there was not a theoretical basis to guide this research.

2.1.4. Qualitative research

Interviews are a useful method to understand the world from the participant's perspective. Hugh-Jones and Gibson (2014) highlighted that semi-structured interviews are a popular method for their convenience through ease to arrange and relatively low costs, flexibility, potential to generate rich data and cultural familiarity in interaction (Atkinson & Silverman, 1997). The freedom to adjust based on participant responses means flexibility depending on the experiences of each participant and focus on more relevant topics (e.g. asking about their reaction experience if they had one previously, versus asking what they thought a reaction would be like). As this research is exploratory, outside of the semi-structured interview schedule, participants were able to express themselves and their own beliefs on the topic without restriction. This was especially useful for the interviews with adolescents without FA, as previous research did not provide an indication of what to expect.

The question of 'how many interviews?' is common and problematic in qualitative research. The idea of saturation of data, where no new themes or information are observed in the data (Guest, Bunsen & Johnson, 2006) and the study is considered to have enough information to be replicable (Fusch & Ness, 2015) informs when data collection has reached a suitable quantity of participants. However, this is difficult to predict ahead of data collection as one sign of saturation is where further coding is not feasible (Fusch & Ness, 2015). Failure to reach saturation can negatively impact the validity of research (Fusch & Ness, 2015). Guest et al. (2006) tested saturation explicitly in their study and reported that saturation occurred in the first twelve interviews, with meta-themes observable from the first six. However, saturation is subjective as each new interview may provide new information. Therefore, the aim was to conduct 15-20 interviews in each qualitative study to aim for good saturation.

Thematic analysis was used for its flexibility as a method, meaning it was suitable for the systematic review with different methods used, as well as for the empirical qualitative studies, suitable both for participants with FA, as well as participants without FA. For later comparison of the two qualitative chapters and the breadth of the focus of beliefs, thematic analysis was used for these studies. For thematic analysis, an orthographic transcript which includes the spoken words and occasionally non-verbal utterances is appropriate (Braun & Clarke, 2008). For other methods such as conversation analysis, the Jefferson method of transcription may be more fitting (Jefferson, 2004; Hepburn & Bolden, 2017) but timing and intonation did not have a significant effect on the analysis of these studies. Transcription is also an effective method of analysing data through familiarisation, in addition to reviewing interview techniques to improve as a researcher (Melia & Newman, 2019).

2.1.5. Quantitative research

Psychometrics involves formulating approaches or theoretical constructs for measurement and then development of measurement instruments and validation (Joshi, Kale, Chandel & Pal, 2015). Psychometric scales encompass statements or items regarding a real or hypothetical situation, where participants express their level of agreement or disagreement on a metric scale (Joshi et al., 2015). Psychometric scales commonly use Likert scales to measure a subjective construct. The strength (measured numerically) and direction (positive or negative) of belief can also be measured (Albaum, 1997). The ability to use psychometric scales with hypothetical questions makes it suitable for the participants in this thesis and so it was felt appropriate to develop a scale to measure beliefs.

2.2. Method

2.2.1. Systematic review

A systematic review aims to identify, select, appraise, analyse and summarise empirical studies to answer a specific question, with methods being explicit and replicable (Perestelo-Pérez, 2013). Standards for a 'good' systematic review are debatable with Waddington et al. (2012) highlighting generalisable conclusions, while Møller and Myles (2016) argue for aspects such as relevance, clarity, a clearly defined research question, public registration of a protocol (e.g. on PROSPERO) and a reproducible report through following guidelines such as the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA). The PRISMA framework (Moher et al., 2009; Liberati et al., 2009) was therefore used as a method to standardise the reporting of the systematic review in this thesis (further information about this process may be found in the empirical chapter (Chapter 3).

2.2.2. Semi-structured interviews

The interview schedules for the qualitative studies were developed from the findings from the systematic review (Chapter 3). For the interviews of adolescents with FA, a constructivist and phenomenological approach was used to understand the meaning of the participants' own experiences and a more hypothetical and social constructionist approach was used in the sample without FA, for example, 'How would you feel if you found out that you had a nut allergy tomorrow?' and 'If your friend experienced that, how do you think they would feel?'

The contrast of how their peer with FA may feel and how they wished to be seen as an onlooker, versus how they hypothetically would feel themselves in scenarios, was an interesting comparison as adolescents were far more supportive of others and more openly negative about themselves in the same situation. The development of interview schedules uniquely for those with FA and another schedule for those without FA, allowed for collection of data relevant to the participants dependent on their own unique experiences; whether they themselves experienced FA, whether they had much experience with FA, or if they were new to FA and had no prior knowledge. The two semi-structured interview schedules thus provide the opportunity for flexibility and for participants to give their own account without questions likely to be irrelevant.

Kvale and Brinkman (2009) considered twelve aspects important to qualitative interviewing; life world (everyday lived experience), meaning (what and how it is said), qualitative (no quantitative language), descriptive (nuanced descriptions), specificity (specific situations, not general opinions), deliberate naiveté (openness to new and unexpected phenomena), focused (thematically), ambiguity (reflecting subject world), change (new insight and awareness), sensitivity (effects of different interviewers), interpersonal situation and positive experience. For life world, interview questions were tied into what was relevant to the participants own lives. An effort was made to get to know participants by asking them warm-up questions about things they felt positive about such as hobbies or a favourite subject in school. This was then interweaved into their interviews if appropriate, e.g. ‘You mentioned that you played tennis, where do you leave your AAI when you play?’ which the adolescents responded very well to. For meaning, questions were delivered carefully so they were not leading or biased, and instead open and encouraging. Similarly, qualitative language such as ‘think’, ‘feel’ and ‘experience’ were used, which were open to interpretation and discussion, rather than more quantitative language which may have made interviews more restrictive. Participants were generally descriptive but received prompts well, and upon questions such as ‘can you tell me a bit more about how you felt in this situation?’ participants expanded as asked. Questions related specifically to FA were followed to make sure the topics were relevant, however due to being exploratory, some questions remained open such as ‘how do you feel when you go out to eat?’ as having FA affects such experiences without needing to be stated. In the interviews of adolescents without FA, questions were more specific to be clearer and this worked well. Deliberate naiveté was practiced, as every individual participant is different and has different experiences for which the interviewer does not know in advance. Different phenomena were openly discussed, which allowed discovery of different themes rather than similar ones across different studies. The interview schedule was used to remain focused based on data from the systematic review and to reflect on subject world appropriately. Openness to change was queried, which was discussed in interviews through adolescents newly diagnosed as well as in the interviews in those without FA where how life may change if they developed FA was discussed.

2.2.3. Scale development

For this thesis two preliminary scales were developed; the Adolescent Food Allergy Beliefs scale: Food Allergy Questionnaire (AFAB) and the Adolescent Food Allergy Beliefs scale: Peers Questionnaire (AFAB-P). The development of two scales allows for audience relevance and for differences in beliefs to be reported by adolescents with or without FA. The individual scales will be have similar questions, but the AFAB-P will be written in a way more suitable for those without a FA (e.g. 'If I had a food allergy…' so not to be disconcerting for participants when completing the scale.

The scale was developed based on recommendations about patient-recorded outcome measures from U.S. Department of Health and Human Services FDA Center for Drug Evaluation and Research, U.S. Department of Health and Human Services FDA Center for Biologics Evaluation and Research and U.S. Department of Health and Human Services FDA Center for Devices and Radiological Health (2006). There are four processes in this recommendation, identify concepts and the developmental framework, create the instrument, assess measurement properties and modify the instrument. In Carpenter's (2018) ten steps to scale development and reporting (Table 3), only the first two relate to development; researching the theoretical concept and developing sampling procedure. In researching the concept, Carpenter (2018) recommends qualitative research to generate items and using feedback to refine the scale.

Identification of concepts and the developmental framework were developed through the systematic review and added to through the qualitative studies. Items for the two scales were also generated from both the systematic review and the qualitative interviews. The scale was developed following guidance from classical test theory, the analysis of results based on test scores (Wu, Tam & Jen, 2017).

Table 3: 10 steps of scale development and reporting, adapted from Carpenter (2018)

1	Research intended meaning and breadth of the theoretical concept
2	Determine sampling procedure
3	Examine data quality
4	Verify factorability of the data
5	Conduct common factor analysis
6	Select factor extraction method
7	Determine number of factors
8	Rotate factors
9	Evaluate factors on a priori criteria
10	Present results

2.3. Participants

2.3.1. Inclusion criteria

For the systematic review, the CHIP criteria (Shaw, 2010) was used to screen papers for relevance and to determine whether the papers should be included or excluded from the review. Following CHIP guidelines (Shaw, 2010), the screening process included consideration of the context, how or method, issues considered, and population. For the recruitment of adolescents without FA in both the qualitative and quantitative studies, they were required to be currently living in the UK and to be aged between 11-16 years. Similar inclusion criteria were used in the recruiting adolescents with FA, however the only added criteria was that they be diagnosed with a FA.

2.3.2. Recruitment strategy

A combination of recruitment strategies was used for the FA sample, as some participants were recruited clinically through Leicester Royal Infirmary, while some were recruited through charities and social media. Using only a clinical sample vastly reduces the number of potential participants, especially as clinical recruitment was conducted with one NHS site. Therefore, for a larger sample pool, participants for the qualitative studies were additionally recruited through social media, charity websites and newsletters, and Aston University's newsletter. For the quantitative study, these strategies were also used, but with the added recruitment through a participant panel available through Qualtrics. The participant panel was used to ensure participant numbers were suitable for quantitative analysis. Recruitment strategies for each study are highlighted in the dedicated chapter.

2.4. Analysis

2.4.1. Inductive thematic analysis

Inductive reflexive thematic analysis was conducted for the systematic review and both interview studies. Thematic analysis is defined by Braun and Clarke (2019) as a method that focuses on identifying patterned meaning across a dataset. Thematic analysis was chosen for its flexibility as a method compared to others, as well as the clear guidelines for analysis steps, which means it would be more easily replicable. Thematic analysis also fits well in the pragmatic paradigm, the method's flexibility allowing for both constructivist and phenomenological components. In interpretative phenomenological analysis (Larkin, Watts & Clifton, 2006), it is expected to use a smaller sample to remain close to the data with phenomenology as a theoretical framework and a focus on lived experience, such as in experiences of breastfeeding mothers (Newman & Williamson, 2018). A larger sample of beliefs was desired to represent this exploratory study and to focus more on patterned meaning across datasets. Furthermore, while using phenomenology to underpin the interviews with adolescents with FA may be effective, this would not work in the sample with no clinical history of FA. Grounded theory (Charmaz, 2006) has many variations in the history of its use (Braun & Clarke, 2019) and is considered more suited to social processes and influencing factors, which may have worked in this research, however the flexible and straight-forward use of thematic analysis was more appropriate for this research. Discourse analysis (Taylor & Ussher, 2001) considers the meaning of social objects and detail of language use, which may have been interesting to explore but the focus on beliefs may be lost in the analysis of these discourse analysis aspects.

The systematic review was analysed qualitatively as most of the included studies were qualitative and the quantitative papers used survey responses. The survey responses included numerical data based on survey items, which was then analysed by exploring the written text in the results and discussion sections written by the authors. This interpretation was then used in conjunction with the qualitative papers. Both qualitative interview studies were also analysed using thematic analysis to ensure consistency and enable a comparison across participants in each group.

Inductive thematic analysis is where 'coding and theme development are directed by the content of the data', (Braun & Clarke, n.d.) therefore the analysis is inspired by the data, rather than an existing theory or model. The interviews with adolescents without FA may also be considered constructionist thematic analysis, as some data was created through the discourse of the interviews. Braun and Clarke (2008) recommend a six-phase approach in thematic analysis (Figure 4); familiarisation, initial coding, searching for themes, reviewing themes, defining and labelling themes, and producing the report. This six-phase process was used in the systematic review and both thematic analyses.

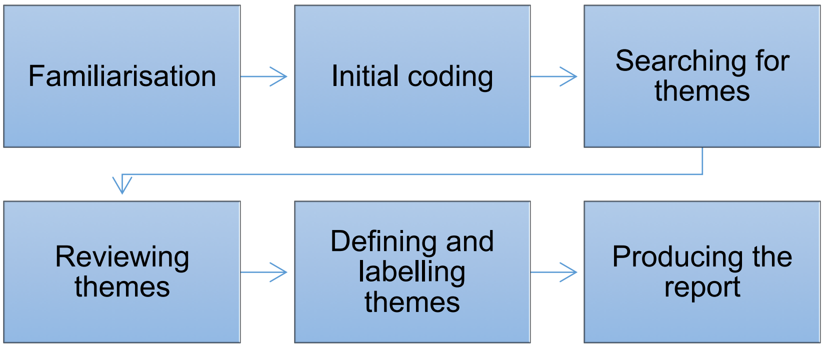


Figure 4: Braun & Clarke's six phase process for thematic analysis

2.4.2. Inductive thematic analysis in the systematic review

To analyse the systematic review, the six-phase approach (Braun and Clarke, 2008); was used. As the systematic review worked with other papers rather than participant data collected directly, the whole paper was considered, including what methods were used, in the analysis. Familiarisation involved multiple readings of the chosen papers to ensure they were relevant to the topic and become closely acquainted with the topics and methods involved. In the initial coding process, each paper was analysed by highlighting points of interest and organising similar data together. Mind maps were created, post-it notes were used, and notes were made of identified beliefs and points similar or different across papers. Themes across codes were analysed, to effectively group together different papers on different topics appropriately into common themes. These themes were then defined and labelled, leaving them broad enough to represent all papers included in the theme.

2.4.3. Inductive thematic analysis in the qualitative studies

Thematic analysis and the six-phase approach (Braun & Clarke, 2008) was also used in the interview studies as there was a large amount of data to analyse effectively. This research also aimed to compare qualitative data on adolescents with FA to a non-allergic sample for scale development later in the thesis. Familiarisation of data involved multiple readings of the interview transcripts, annotating the edges to highlight initial patterns and contrasts. The transcripts were then coded in detail, pulling meaning and context out of the data and highlighting what had been read previously in the systematic review and what was new in this sample. Common topics of discussion were explored, instead focusing more demographically than topically in this study where the patterns and differences appeared the most. For the thematic analysis of participants without FA, the interview data was analysed in a similar way, incorporating the six-phase approach (Braun & Clarke, 2008). During the coding phase, the data from the adolescents with FA was considered to see if beliefs were in line with what had been discussed by them or were unexpected, and why therefore these beliefs did not align. As this study looking directly at FA peer beliefs which is not known to have been done before, this was coded with consideration of the previous studies of adolescents with FA.

2.4.4. Exploratory factor analysis and principal components analysis

Exploratory factor analysis (EFA) is commonly used to examine factor structure of items for a scale. There are a number of methods for conducting factor analysis, one of which is principal components analysis (PCA) which was used for the quantitative study. PCA aims to classify or relate variables to each other (Wold, Esbensen & Geladi, 1987) and was used because it reduces the number of factors and assesses for structural validity. As Tabachnik and Fidell (2007) recommend PCA for an empirical summary of the dataset, PCA was used for analysis to maintain maximum variance and to reduce the scale to a more suitable length.

2.4.5. Reliability and validity

For psychometric scales, it is recommended that the internal consistency of scales be measured using Cronbach's alpha (Croasmun & Ostrom, 2011). Internal consistency checks how items relate to one another and the scale in entirety (Croasmun & Ostrom, 2011). The Cronbach's alpha co-efficient tests how all items in a scale relate to other items in the whole instrument (Gay, Mills, & Airasian, 2006) and is a measure of internal consistency reliability. For the two scales developed for this thesis, Cronbach's alpha was computed and alpha if each item was deleted was examined to optimise the alpha level.

The construct validity of each scale was also assessed. Construct validity examines whether a measure is measuring the phenomenon of interest (Pseudovs, Burr, Harley & Elliott, 2007). This construct validity was assessed through convergent validity. As there were no suitable closely related scales, constructs of illness perceptions, coping, locus of control and attitudes to risk were used. If correlations are low, G*Power may be used for post-hoc power calculations.

Discriminative validity was also assessed. This measures how a scale discriminates between groups that should be dissimilar (Pseudovs et al., 2007). Correlations and t-tests were used to assess differences across gender, age, age of diagnosis, and prescription of AAI. These groups were examined as they were highlighted in the qualitative studies and in previous research discussed in the introduction and systematic review. Correlation analysis was used to look at relationships between scale scores and age of participant, or age of diagnosis of FA.

2.4.6. Cross-sectional validation measures

To validate a new scale, it must be tested against other standardised measures with similar constructs for cross-sectional validation. As adolescents both with and without FA were being explored, FA specific scales for validation could not be used as they would not all apply to the sample without FA. Therefore, four validation scales were used to assess condition beliefs, locus of control, coping, and attitudes towards risk;

- Brief Illness Perception Questionnaire (BIPQ)
- KIDCOPE
- Multidimensional Health Locus of Control (MHLC-B)
- The Adolescent Risk-Taking Questionnaire - Risk Beliefs Questionnaire (ARQ-P)

Further detail about the validation scales and why they were chosen specifically, may be found in Chapter 6.

2.5. Ethics

For the interviews of adolescents without FA, Aston University's School of Life and Health Sciences provided ethical approval, whereas for the interviews of adolescents with FA, NHS Research Ethics Committee and Health Research Authority (HRA) approval was given for patient recruitment at the allergy clinic in Leicester Royal Infirmary. As this research focused on the age range of 11-16-years, parental informed consent was required to take part in the various studies. Participants aged 16 years were able to give their own consent (The British Psychological Society (BPS), 2014), while 11-15-year olds were only able to give assent as they are considered by the BPS (2014) to be a vulnerable population and needed the further permission of a parent or guardian to participate.

An information sheet in line with BPS recommendations (2014) was provided for each study detailing participant ethical rights prior to interviews, explaining what the study entailed, the right to withdraw at any time, benefits, and potential risks of taking part, of which sensitive questions was deemed the only risk. To manage this risk, participants could skip any question they did not wish to answer or to stop at any time. Participants were also verbally debriefed at the end of the interview to check for distress. An information sheet and consent form were created for both the parents or guardians and the adolescent participants to make the information accessible and ensure understanding (The British Psychological Society, 2017). Participants were invited to have the interview conducted in a safe and neutral space of their choosing with their parent or guardian's permission. For face-to-face interviews, adolescents were invited to Aston University or the main researcher attended their family home with their parent or guardian's permission. For Skype interviews, participants were able to choose whether to have the video on, so they could see the researcher, which all did. For telephone interviews, contact details were immediately deleted upon completion of the interview. All participants were able to flexibly choose what day and time they wished for the interview to take place. Anonymity and confidentiality were highlighted, as identifying data would be removed or replaced by pseudonyms to protect the participant's identity. Interview recordings and transcripts were stored on a secure account at Aston University and hard copies were kept in a locked cabinet.

The scale study was also approved by NHS Research Ethics Committee and the HRA for recruitment from Leicester Royal Infirmary for those with FA and via online advertisement of the study to recruit participants with and without FA. For the quantitative study, both the parent/guardian and adolescent participant information sheets detailing ethical rights and consent forms were uploaded to a secure survey platform (Qualtrics) and participants were required to agree to the statements on the consent form before they were able to progress to the questionnaire. Similar to the qualitative studies, the information sheet was accessible for the adolescent audience and highlighted the study rationale and process, and ethical rights such as the right to withdraw. Neither of the scales requested participant names, keeping them anonymous. Participants had the choice to leave a contact email or phone number if they wished to enter a prize draw for completing the study, but this was voluntary and not essential. At the end of the questionnaires, a data protection statement was included for transparency of data use. Data was stored on a password protected Qualtrics account and on a password protected computer at Aston University. Hard copies of the study materials were also available to participants and were posted through Leicester Royal Infirmary and consenting participants returned the study materials to Aston University by post.

2.6. Summary

This chapter provides an explanation and rationale of methods used, both qualitative and quantitative. A systematic literature review provides a detailed foundation to work from for this exploratory project. Semi-structured interviews provide the flexibility to explore individual beliefs and allow participants to explain their own thoughts and experiences. Thematic analysis was used for its flexibility as a method in this data-driven approach, informing each following study. Scales for both adolescents with and without FA were developed so that data on beliefs can be collected on a larger sample or be used on an individual basis to aid FA management. EFA and PCA were used to analyse the scale data because it was a method suited to exploratory data and fit well with the nature of this research. It is important to note, that while this chapter provides a methodological approach to the thesis and provides a rationale for methods used, each subsequent chapter will detail its own specific methods. Following from this consideration of methodology, the next chapters will present each study in depth. The thesis process below (Figure 5) shows how these studies lead into each other.

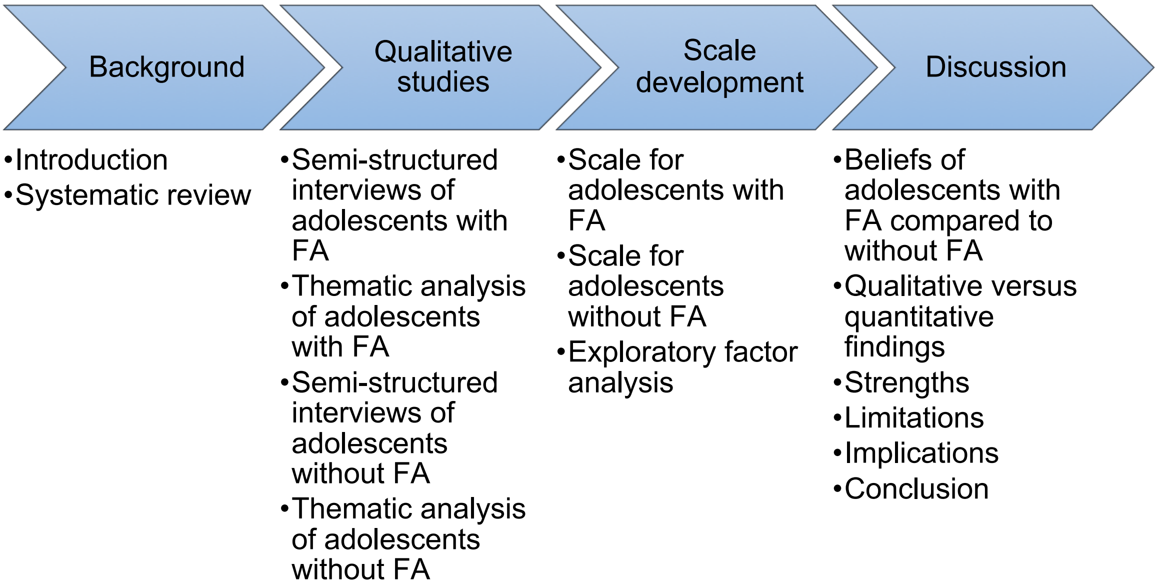


Figure 5: Thesis process

Chapter 3: Beliefs about food allergies in adolescents aged 11-19 years: A systematic review

3.1. Introduction

As has been discussed in Chapter 1, adolescents and young people with FA are the age group that has the highest frequency of fatal reactions due to serious allergic reactions (Pumphrey, 2000). This may be attributed to an increased engagement in risk-taking behaviours most common in adolescence. Sampson et al. (2006) reported that 54% of their sample aged between 13 and 21 years purposely ate potentially unsafe foods while 29% did not always carry their AAI. The impact of FA and how it is managed is thought to change as children develop, with adolescence as a time of transition. Up to the age of 8 years, children tend to rely on parents but after this age they become more aware of the difficulties of managing FA and can report greater anxiety (DunnGalvin et al., 2009). Over the age of 12 years, children have been reported to experience greater conflict with their parents regarding their FA (DunnGalvin et al., 2009) which may lead to risky behaviour as adolescents try to assert their independence.

Research on the impact of FA on adolescents' is mostly qualitative and highlights a number of issues. Research has reported that adolescents hold strong beliefs about their AAIs, expressing the belief that AAIs are inconvenient due to their bulk (MacKenzie et al., 2010; Gallagher et al., 2011) and some adolescents are afraid to use them because use involves a needle injection (Monks et al., 2010; Macadam et al., 2012). Beliefs of peers are also important for adolescents as these can influence the way in which children with FA manage their condition. A review by Johnson and Woodgate (2017) on adolescent experiences of food-induced anaphylaxis found beliefs around the adolescents' identity with FA, balance and controlling the uncontrollable to be themes considered to directly influence the adolescents' experiences.

Studies incorporating the Health Belief Model (HBM) and the Common Sense Self-Regulation Model (CS-SRM) (Jones et al., 2014; Jones et al., 2015) have been utilised to try to explain adherence to self-management of FA, in particular carriage of AAIs. In Jones et al.'s sample of 188 FA adolescents, perceived severity and barriers, constructs of the HBM, accounted for 21% of variance in adherence behaviours. Aspects of the CS-SRM, namely cyclical timeline beliefs, emotional representations and illness identity, accounted for 25% of variance. Jones et al.'s (2014) research suggests that beliefs about FA may be related to FA management and influence behaviour.

There are currently no systematic reviews on beliefs of adolescents about FA and this is important to understand the current knowledge base and what research still needs to be undertaken. This systematic review therefore aimed to explore adolescent beliefs about their FA and identify beliefs about FA that may influence risky FA management behaviours.

3.2. Methods

3.2.1. Search strategy and selection of studies

A systematic literature search was conducted using eight electronic databases: Cochrane Library, ProQuest, PsycArticles, PubMed, Science Direct, Scopus, Web of Science and Wiley, last run in January 2018. Search terms were discussed with an experienced librarian and the PhD supervisors to ensure all key words and variations were acceptable. The following search terms were checked against titles, abstracts and keywords limiters in the databases: (Food allerg* OR food intoleran* OR food sensitiv*) AND (attitude* OR belief* OR understanding) AND (teenage* OR adolescen* OR child* OR pediatric OR paediatric).

The systematic search was conducted by the main researcher. Additional papers were also be searched through reference chaining, which involved systematically searching through references of included papers or excluded reviews for papers of relevance or interest to the topic to see if eligible papers were missed in the original database searches. Article abstracts were read against the inclusion and exclusion criteria and research papers that were categorized as ‘quality of life’ were also read to see if they contain data related to beliefs. Following analysis of abstracts, potentially relevant papers were read in full. Papers will be reviewed by the researcher and the research team and papers will be excluded if they did not meet the inclusion criteria.

3.2.2. Inclusion criteria

The inclusion criteria and search terms were developed using the CHIP (Context, How, Issues, Population; Shaw, 2010) tool, which is explained further in the method chapter (Chapter 2). Inclusion and exclusion criteria are outlined in Table 4 below. As adolescents are the most at risk of fatal allergic reactions, this sample was the focus of this systematic review. To be eligible, research papers were required to have sampled participants within the age range of 11-19 years with FA, explicitly discussed or contained significant analysis relevant to beliefs about FA and be written in English. Papers that did not meet these criteria were excluded as were MSc theses, abstracts, comments, non-academic articles or reviews.

Table 4 - CHIP tool

Context	Food allergy
How	Quantitative, qualitative and mixed methods
Issues	Beliefs about FA
Population	Adolescents aged 11-19 years with FA

3.2.3. Quality assessment

Studies were appraised using the Mixed Methods Appraisal Tool (MMAT; Hong et al., 2018). Four methodological quality criteria are associated with the type of study. Each criterion is worth 25%, resulting in a score between 0 to 100%. Quality appraisals of the included studies using the MMAT were conducted independently by the main researcher KN and then reviewed by the supervisory team.

3.2.4. Analysis of data

Selected papers were read carefully to determine data relevance and points of interest related to the systematic review topic. Data from all studies were then coded and analysed using thematic analysis (Braun & Clarke, 2008) to explore patterns in the data. Results found in both qualitative and quantitative papers were analysed similarly. For qualitative papers, data in the results section, quotes provided, and the discussion of results were included in the analysis. For quantitative papers results from the questionnaires and the authors' analysis in the results and discussion was included in the analysis. Analysis of subgroups of age, gender, geographical location and allergen were also conducted. The review was also registered on PROSPERO (registration number: CRD42019133576) (Appendix 1.2), which is recommended by Møller and Myles (2016) as a factor necessary for a 'good' systematic review.

3.3. Results

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) framework (Liberati et al., 2009) was used to standardise the reporting of results (Figure 6). A total of 2219 research papers were identified during the database search, with 4 additional papers found through reference chaining. Article abstracts were read against the inclusion and exclusion criteria and research papers that were categorized as 'quality of life' were also read to see if they contained data related to beliefs. Following analysis of abstracts, 23 potentially relevant papers were read in full. Papers were reviewed by the researcher and the research team and 6 papers were excluded as they did not meet the inclusion criteria (Appendix 1.1).

3.3.1. Description of Studies

The search revealed 17 studies, 14 that used qualitative methods and three that used quantitative methods. Papers reported data on participants aged 6-19 years, however, results reported for participants not within the age range for this review were excluded from analysis. Participants were recruited from Canada (n=3), Ireland (n=1), The Netherlands (n=1), Denmark (n=1), Sweden (n=2), and the United Kingdom (n=9). Included papers were published from 2007-2016. Interviews and focus groups were the main methods used, however the quantitative studies used questionnaires. Table 5 provides details for each included study and the themes in this systematic review that each study fits into.

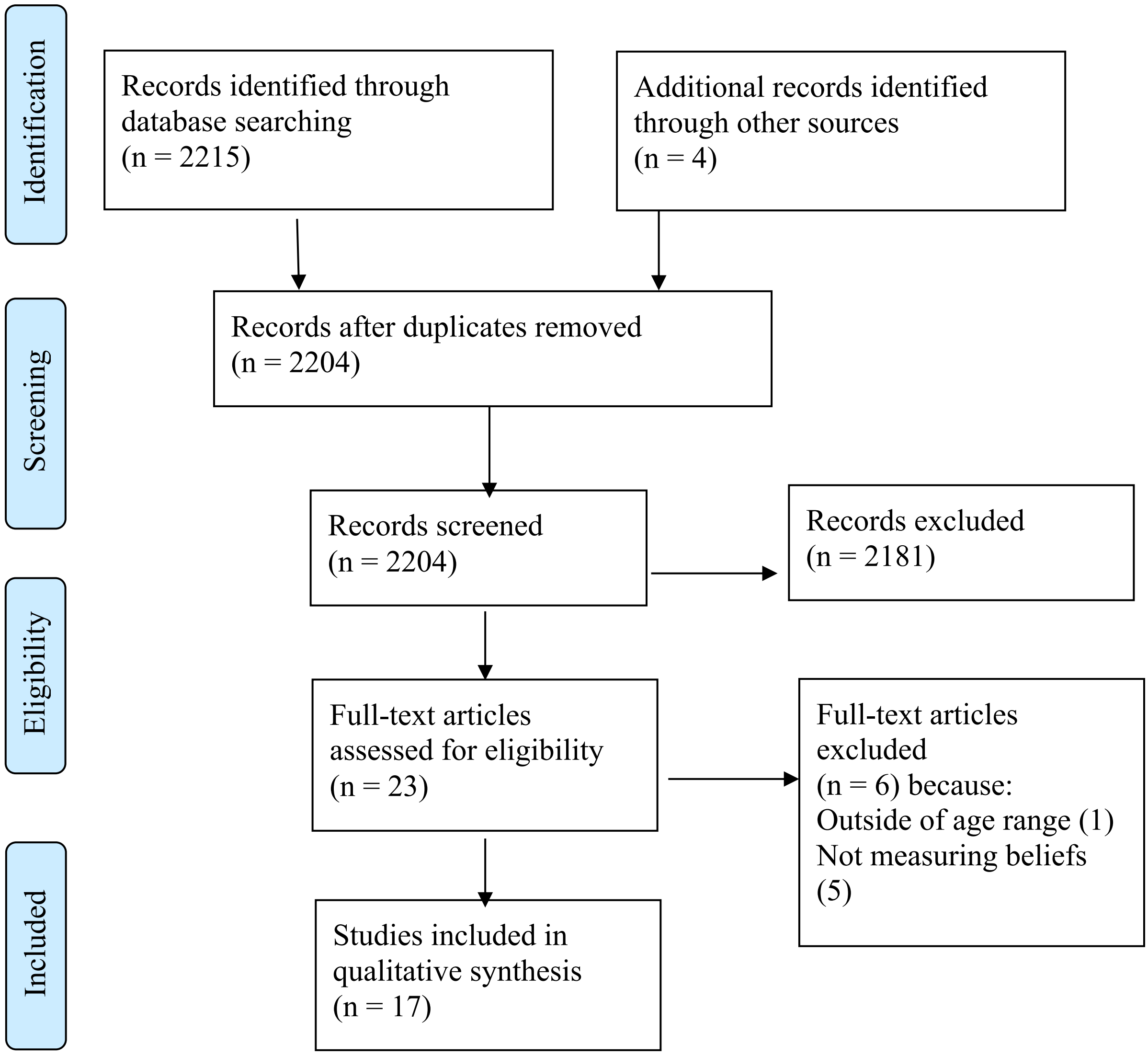


Figure 6: PRISMA Flow Diagram

Table 5: Study characteristics

Authors	Participants	Method	Results	Themes
Akeson et al. (2007)	7 adolescents (13-16 years), South of Scotland, UK. 'Clinician-diagnosed anaphylaxis.'	Semi-structured interviews analysed using the framework approach.	Anaphylaxis was believed to have low impact on day-to-day life. Adolescents also believed there was a sense of burden about social restrictions. 'May contain' labels were believed to be companies 'covering their backs' and some adolescents ate these foods as a result of frustration. Themes: Allergy perceived as 'not a big deal'; Mostly respect for and confidence in managing the allergy but less knowledgeable than parents; Mistrust in food labelling; Lower and narrower perception of risk in comparison with parents; Inconsistency in carrying adrenaline due to practical and psychosocial obstacles	2, 5
Dean et al. (2016)	10 children (8-12 years), 10 youth (13-17 years), Ontario, Canada. 'Food allergic children and youth at risk of anaphylaxis.'	20 semi-structured interviews analysed using thematic analysis based on grounded theory.	Participants believed that being 'outed' as having FA initiated discriminatory behaviour. They believed they were unsafe in their classrooms and were treated unfairly by teachers and peers. Adolescents also considered their allergy "a big deal" compared to the younger sample. Main theme: Health-related stigma. Sub-themes: Disclosure; Stigmatisation; Normalisation; Tension and disclosure.	1, 4, 5
DunnGalvin et al. (2009)	62 children, 6-15 years, Cork, Ireland.	15 focus groups held with 62 children,	Teenagers believed FA had a strong impact on who they were. They believed not being able to breathe was the scariest symptom of a reaction, and reactions can result in	3, 4, 5

Authors	Participants	Method	Results	Themes
	'All children had been issued with an AAI.'	analysed using grounded theory.	peer judgment, being labelled as weird and 'ruining' events. Themes: Meanings of food; Peer relationships; Autonomy, control and self-efficacy; Risk and safety; Self/identity; Coping strategies.	
Fenton et al. (2011)	10 children (8–12 years), 10 adolescents (13– 18 years), Canada. 'Clinical diagnosis of life-threatening FA.'	Interviews and illustrations/ narrative descriptions analysed with thematic analysis, reflective analysis and depth analysis.	Beliefs included missing out because of allergies and that elementary schools were safer than high schools. Adolescents believed they had to fend for themselves, that their allergy was a big deal and it was 'life or death'. Themes: Social and environmental barriers to safety; Emotional burden of responsibility; Coping strategies; Balance of responsibility (transitions); Redefining 'normal'.	1, 3, 4, 5
Fenton et al. (2013)	10 children (8–12 years), 10 adolescents (13– 17 years), Ontario, Canada. 'Anaphylactic allergy.'	Interviews and illustrations/ narrative descriptions analysed with thematic analysis, reflective analysis and depth analysis.	Adolescents identified various environmental and social barriers that they believed were the factors that resulted in them feeling isolated, excluded, or teased. They also believed that they were missing out compared to their peers. All participants viewed elementary schools as safer than high schools. Themes: Socio-material spaces; Exclusionary spaces; Transitioning spaces.	1, 3, 4
Gallagher et al. (2011)	26 adolescents (13-19 years) Scotland, UK. 'History of anaphylaxis.'	Interviews, 8 adolescents and 10 parents took part in the focus groups. Data	There was reluctance to carry AAIs if risk of reaction was believed to be low and the AAI inconvenient to carry. Some did not use their AAI when they should have due to	1, 2, 5

Authors	Participants	Method	Results	Themes
		was thematically coded.	reasons such as panic during a reaction, fear around using the AAI, being optimistic that the reaction would resolve itself and denial about severity. Themes: Carrying and storing auto-injectors; Training in auto-injector technique; Identifying an anaphylactic reaction; Administration technique; Knowing when to use an auto-injector; Potential interventions to improve epinephrine auto-injector use among adolescents.	
Gallagher et al. (2012)	26 adolescents (13-19 years) Scotland, UK. 'At risk of anaphylaxis.'	Interviews, data was thematically coded.	Balance between living a normal life and managing the seriousness of the FA was a concern. It was difficult to judge risks and reactions sometimes took place even after checking ingredients. Themes: Experiences of anaphylaxis; Managing allergies and preventing further reactions; Eating away from home; Risk and 'may contain' labels; Support from healthcare professionals; Transition from parental to self-management	1, 4, 5
Jones et al. (2014)	188 adolescents (13-19 years), South-East England, UK. 'Diagnosis of severe FA and prescription of an AAI.'	Questionnaire developed from HBM* & CS-SRM** analysed using factor analysis multiple regression.	Health beliefs, specifically perceived severity and barriers accounted for 21% of the variance in adherence behaviours. CS-SRM constructs, illness identity, timeline cyclical beliefs and emotional representations explained 25% of the variance.	2, 5

Authors	Participants	Method	Results	Themes
Jones et al. (2015)	188 adolescents (13-19 years), South-East England, UK. 'Hospital prescribed AAI for FA.'	Questionnaire scale developed from HBM*. Logistic regression was used in analysis.	Adherence was more likely if adolescents believed their FA was severe and perceived fewer barriers to disease management. Belonging to a support group and having an anaphylaxis management plan were also predictors.	1, 2
Macadam et al. (2012)	20 participants (12-18 years), UK. 'Food or venom allergies.'	Interviews were thematically coded.	Adolescents considered their safety and performed risk assessments on whether to carry the AAI. Factors such as attitudes of others, place and the physical features of the AAI were considered. Themes: The type of allergy; Role of circumstances; Factors associated with device design; The responsibility and attitude of others; Teenager's feelings and concerns.	1, 2, 4, 5
MacKenzie et al. (2010)	21 participants (13-18 years), (Isle of Wight & Portsmouth), UK. 'Evidence of IgE-mediated food hypersensitivity (FHS).'	Interviews analysed by the phenomenological method of Giorgi and Giorgi.	Living with FA was seen as a way of life but burdensome, as the need for vigilance was tiresome and frustrating. Management was based on risk assessment dependent on situational beliefs resulting in varying levels of precaution. Themes: Living with FHS as a way of life/coming to know FHS as a way of life; Living with FHS as experiencing and coping with burden; Alleviation/exacerbation of the burden of living with FHS; Living with FHS involves managing acceptable risk.	1, 2, 3, 4, 5

Authors	Participants	Method	Results	Themes
Marklund et al. (2006)	17 participants (14-18 years), Stockholm, Sweden. ‘Exclusion diets due to food hypersensitivity.’	Three focus group interviews and six individual interviews analysed with qualitative content analysis.	Adolescents believed themselves to be competent and courageous but avoided the extra attention of asking for special food considerations. Beliefs of being disregarded were expressed, as well as facing unreliability and a lack of understanding from others. Self-conceptions were essential for management and beliefs around the condition. Themes: Perceiving oneself as being particular; Feeling constrained; Experiencing others' ignorance; Keeping control; Feeling it's okay.	1, 3, 4, 5
Monks et al. (2010)	18 participants (11 -18 years), Southampton, UK. ‘Teenagers with FA’, ‘recruited from clinic.’	Questionnaire (demographics and allergy management) and interviews analysed using a thematic approach.	Teenagers reported eating foods labelled as ‘may contain’ and believed they are unlikely to contain an allergen. They only carried their AAI when they thought they were particularly at risk of a reaction. More than half believed that educating other students at school about the seriousness of FA would make it easier to live with their FA. Themes: Allergen avoidance; Being prepared for reactions; Treating reactions.	2, 3, 4
Saleh-Langneberg et al. (2016)	55 adolescents (13-17 years), The Netherlands. ‘Food-allergic adolescents prescribed an AAI.’	Questionnaires: FAQLQ-TF***, FAIM-TF****, IPQ***** & STAI******. Analysis: Spearman’s correlations, Fisher’s	Adolescents were (extremely) positive about AAIs. Those reporting a greater burden of treatment believed that they were less likely to be able to deal with a reaction successfully. Low burden of treatment was reported by adolescents who believed the AAI has an agreeable shape	2, 3

Authors	Participants	Method	Results	Themes
		exact test, Mann–Whitney U-test.	and gives a feeling of safety. High burden of treatment was associated with the belief AAI carriage was inconvenient.	
Sommer et al. (2014)	25 participants 7 with FA & 18 with no FA. (12-18 years). Isle of Wight, Portsmouth and Southampton, UK. ‘Food-allergic teenagers.’	One focus group with no FA (n = 11) and 14 interviews (7 with FA and 7 with no FA).	Adolescents felt cautious about trying new foods outside of the home so preferred parental judgment, which made them feel safe. Some felt their FA hindered their ability to try new foods and have variety in their diet. Themes: Variety and enjoyment of food as a learning process; Body awareness, feelings and temptations of foods; Parental control vs convenience; Eating as social experience; Routine, tradition and environment; Knowledge shapes understanding of foods.	1, 3, 4, 5
Stensgaard et al. (2017)	5 families (adolescent participants 15-16 years), Denmark. ‘Adolescent with peanut allergy.’	Individual semi-structured interviews analysed with Ricoeur’s theory of interpretation.	FA was considered restrictive and prevented doing the same as others. They viewed their AAIs as ‘scary’ and worried about the consequences of using it. They felt making new friends was difficult, worried about being a nuisance and feeling vulnerable. Some of the adolescents also believed their parents were too involved but believed the biological parent must ensure safety with stepfamily. Themes: The nuclear family – safety and understanding; When the nuclear family is challenged; The importance of having a social life.	2, 3, 4, 5

Authors	**Participants**	**Method**	**Results**	**Themes**
Stjerna (2015)	10 participants, (11-17 years) from Sweden 'with food allergies.'	Interviews analysed thematically.	Participants expressed that home was the safest place and that dependence on adults was necessary to be safe in managing health risks. They also believe they must be vigilant in their checking of food, even at school where their allergy is known. Some adolescents felt they could never be completely safe, and they must never lose control of the situation. Themes: management of health risks; Management of social risks in different places.	1, 3, 4, 5

*HBM: Health Belief Model, **CS-SRM: Common Sense Self-Regulation Model, ***FAQLQ-TF: Food Allergy Quality of Life Questionnaire: Teenager Form, ****FAIM-TF: Food Allergy Independent Measure: Teenager Form, *****IPQ: Illness Perception Questionnaire, ******STAI: State-Trait Anxiety Inventory

Note: Theme numbers relate to the themes detailed below in the thematic analysis: 1) from home to holidays: navigating different places; 2) carriage and use of adrenaline auto-injectors; 3) managing the risk of anaphylaxis; 4) behaviour and understanding of others; and 5) food-allergic identity and condition beliefs.

3.4. Thematic Analysis

Through thematic analysis five themes were identified: 1) from home to holidays: navigating different places; 2) carriage and use of adrenaline auto-injectors; 3) managing the risk of anaphylaxis; 4) behaviour and understanding of others; and 5) food-allergic identity and condition beliefs. A summary of the papers included in each theme may be found above in Table 5, in the 'theme' column.*3.4.1. Theme 1: From home to holidays: Navigating different places.*

3.4.1. Theme 1: From home to holidays: navigating different places

Beliefs about safe and unsafe places for managing FA and differences in management in different spaces such as friends' houses, school, restaurants and abroad on holidays were discussed by adolescents in N=11 studies. Illustrative quotes can be found in Table 6.

Table 6: Theme 1: From home to holidays: Navigating different places

Theme	**Quotes**
From home to holidays: Navigating different places	*"I think it is difficult because they might say 'well then, but what shall we cook then?' Then you feel like this, that you are a hassle to those who do the cooking. I feel like, 'well then, now I'm a bother again'." (Marklund et al., 2007, p5)* *Um , I'm much more nervous about eating out when I'm on holiday because like it's a different language and I don't really know how to, and I don't know how to ask, um, whether something has nuts in it, so normally I'd just kind of eat stuff that seems like very safe…' (Laura, 15 years, food-allergic) (Sommer et al., 2014, p450)* *I am like afraid if I go to school and stuff, I usually don't eat lunch because I might touch the desks and everything and they might have had something. Like the person who sat there before me and they touched the desk, so I don't really want to ingest anything with my hands at all. (Bruce; 15 years old) (Fenton et al., 2013, p287)* *No food allowed. Whatsoever. Past this doorway, there is no food allowed. You are lucky if you get past here with food. And it is not for FA reasons. It is the teacher's rule. You don't want to get food in instruments. It's the only safe place in my school. (Fenton et al., 2013, p290).* *"it is the safest place. This is the safest place on earth for me." (Fenton et al., 2013, p288).*

Illness beliefs about safe and unsafe places were affected by perceived risk, predictability, familiarity and distance from external help (Macadam et al., 2012) such as hospitals (Akeson et al., 2007). Overall, the safest spaces were believed to be the family home or where a parent was present (Fenton et al., 2013; Stjerna, 2015; Marklund et al., 2007) as the adolescent could relax and leave the responsibility of their safety to someone else. The further from home a place was, the riskier it was considered to be (Stjerna, 2015; Macadam et al., 2012; Akeson et al., 2007). Adolescents also felt comfortable going to places where they had visited numerous times without having an allergic reaction. The proximity to home or a hospital where a parent or doctor was within reach if something did happen, reassured adolescents and reduced their fear of the unknown.

Some adolescents felt that they were missing out due to their belief that some places made it difficult to manage their FA. Restaurants and school trips were described as annoying as the adolescent could not eat 'the same as everyone else' (Stensgaard et al., 2017). Beliefs about the expertise of catering staff when eating out were an important factor in the eating out experience. Younger individuals (age not reported) in Gallagher et al.'s (2012) study were embarrassed at having to ask staff about an allergen. Where staff were believed to be indifferent (Marklund et al., 2007; Monks et al., 2010) this also made asking more difficult. Some adolescents were concerned about food prepared in unknown places (MacKenzie et al., 2010; Marklund et al., 2007). Similar beliefs were also expressed on holidays abroad which entailed dealing with new foods and a different culture. Adolescents preferred to eat foods they knew were safe or rely on parental judgment, especially if there was a language barrier (Sommer et al., 2014).

Schools were believed to be risky places depending on how supported the adolescents felt, if the school had policies in place to protect them, and how efficient these policies were believed to be. Secondary school was viewed as more dangerous than junior school (Fenton et al., 2011), partly due to less organization and control from teachers, but also as school policy made adolescents feel isolated by making them sit alone at lunch or excluded them from school trips (Fenton et al., 2011; Dean et al., 2016). However, it is not clear whether this was due to teacher choice or school policy. Adolescents believed they must be cautious regarding the management of FA at school due to difficulty determining risk and lack of trust in teachers. Some adolescents did not feel safe either due to concern of contamination or previous experience of bullying, including threats to contaminate food or having their allergen thrown at them (Stensgaard et al., 2017; Fenton et al., 2013). Bullying is an issue in need of attention as it can lead to tragic fatalities, as with the loss of a thirteen-year-old London boy with a dairy allergy who had cheese 'thrown down his shirt' triggering anaphylaxis (Davies, 2018).

Older participants described instances where they left the classroom against teacher wishes because they did not feel safe (Dean et al., 2016). Dean et al. (2016) do not specify the age but it can be assumed these adolescents were in the higher age range of ‘youths’, classed as 13-17 years. It was also suggested by adolescents that teachers were often seen as unable to help due to the adolescent with FA being a minority in the classroom compared to their peers (Fenton et al., 2011). Fenton et al.’s (2011; Fenton et al., 2013) research supported this with their adolescent participants describing their beliefs that there was greater potential risk of encountering allergens or a reaction due to a high volume of students, unsupervised lunch areas, common eating areas and untrained staff.

Where schools had attempted to accommodate children with FA, such as using allergen-free ingredients in food technology classes, children felt safer and included (Stjerna, 2015). Other adolescents believed that special treatment because of their FA highlighted them as different to their peers (Dean et al., 2016). Some adolescents believed avoidance was the best way to cope with this, finding a safe space where food was not allowed (Fenton et al., 2013) and managing their stress by reducing their risk of having an allergic reaction. Safe spaces in schools where no food is allowed was seen as especially helpful as they were not being singled out for special treatment.

Overall, adolescents’ beliefs about a place directly influenced their behaviour when navigating risks. Home was believed to be the safest place with the presence of parents and familiarity of safe foods. Outside of the home, places were believed to be more unsafe the further away the adolescent was from parents and the family home with holidays perceived as the most dangerous. School was believed to be risky and adolescents highlighted a transition from safe and supported to feeling unsafe when moving to secondary school, which had less structure and routine.

3.4.2. Theme 2: Carriage and use of adrenaline auto-injectors

Beliefs about AAIs were discussed in N=9 studies in this review and were associated with likelihood of the adolescent carrying their AAI at all times. A selection of illustrative quotes from the selected papers may be found in Table 7 to support this theme.

Table 7: Theme 2: Carriage and use of adrenaline auto-injectors

Theme	Quotes
Carriage and use of adrenaline auto-injectors	*We're meant to carry them [EpiPens] around school but I don't. I don't think there's much point…because I have a packed lunch* (P11, female, aged 14) (MacKenzie et al., 2010, p600) *I think it's just another thing to carry around sometimes; it's just a bit, it kind of weighs you down more* (P20, female, aged 14) (MacKenzie et al., 2010, p600) *they see the Epi-Pen pouch or whatever people wear, they think to themselves, there is something different about you. Automatically, you are tagged as a person who is different* (Fenton et al., 2013, p289) *I'm quite feart tae [scared to] use it to be honest with you, like I don't know, like people say I thought they caused irregular heart beat but I don't know . . . something just scares me about it . . . I don't think I'd be able to do it myself, because I'd go to do it and stop because I know what's coming . . . there's something really aboot [about] taking this EpiPen that just, I'm terrified, I don't know why, so I just try to avoid it at all costs* (Lisa, 16) (Gallagher et al., 2011, p874)

Beliefs about AAI carriage seemed to be influenced by situational factors such as where they would be going, distance from home or parents, possibility of the allergen being present and whether they had been to a place before (Macadam et al., 2012; MacKenzie et al., 2010; Gallagher et al., 2011; Monks et al., 2010). Adolescents discussed the barriers to AAI carriage such as the inconvenience of the AAIs and that they were large, bulky and difficult to use (Sampson et al., 2006; MacKenzie et al., 2010; Gallagher et al., 2011). Some adolescents were also afraid to use them due to fear of the needle, even in the event of a reaction (Monks et al., 2010; Macadam et al., 2012).

In a quantitative study examining the predictive ability of the Health Belief Model, Jones et al. (2014) found that the perception of barriers such as AAIs highlighting adolescents as different or AAIs being inconvenient to carry resulted in lower carriage of AAIs. Whereas, adolescents with FA with higher perceived severity and susceptibility to having an allergic reaction were more likely to carry their AAIs as they considered it a tool to protect themselves. It was also found that adolescents who viewed their FA as unstable, unpredictable and episodic were less likely to be adherent to self-care behaviours. This may be due to the infrequency of reactions leading to the belief that carrying an AAI is unnecessary as it is unlikely to be required (Jones et al., 2014). Those who strongly identified with their FA and had stronger feelings such as anger or anxiety in relation to their FA were more likely to carry their AAI (Jones et al., 2014). Findings from Gallagher et al. (2011) in a qualitative study suggested that barriers such as fear and uncertainty of how to use the AAI and failure to recognise anaphylaxis were suggested to reduce AAI use.

When the perceived risk of an allergic reaction was low, such as going to play football, adolescents were less likely to carry their AAIs or forgot to carry them (Monks et al., 2010; Akeson et al., 2007). More boys reported being inconvenienced than girls by the size of AAIs, stating they were too large for a pocket (Gallagher et al., 2011; Macadam, et al., 2012; Monks et al., 2010) and they would be more likely to carry them if they were smaller (Monks et al., 2010). Adolescents also talked about being embarrassed about their AAIs and were less likely to carry them because of feelings of shame, fear of being seen as different or irritation at having to explain themselves. However, some adolescents acknowledged that the benefits outweighed the inconvenience (Gallagher et al., 2011). Participants reported reducing the discomfort of having the AAI on their person by leaving it with a friend, teacher, or in their bag nearby (Macadam et al., 2012).

Beliefs about how to use AAIs were also salient and discussed in five studies in this review. Jones et al. (2015) found the majority of their sample believed they could correctly use their AAI with 40% feeling ‘sure’ and 37% feeling ‘absolutely sure’. This contrasts with the findings of qualitative papers, where adolescents stated that they did not believe they could use their AAIs properly and expressed a fear that they would use it incorrectly (Gallagher et al., 2011; Saleh-Langenberg et al., 2016). Saleh-Langenberg et al. (2016) suggested that the lack of confidence using AAIs can result in a higher perceived burden of treatment. As some adolescents with FA were unsure of how to use AAIs, this could lead to misfires or reluctance to use the device (Macadam et al., 2012). Stensgaard et al. (2017) found that adolescents and their siblings were afraid of using the AAI and of contacting emergency services, preferring to use antihistamines which were believed to be an easier option due to their familiarity. Anxious beliefs around the needles resulted in preferring someone else to administer the AAI (Gallagher et al., 2011; Monks et al., 2010) or for the AAI not to be used at all (Macadam et al., 2012).

Within this theme, AAI carriage was influenced by beliefs surrounding situational factors, and spaces where the AAI was considered unnecessary usually resulted in reduced carriage. The AAIs were believed to be inconvenient due to their size, especially by males. Reluctance to carry their AAI was attributed to fear of needles and concern of judgement from others. On the other hand, other adolescents believed their AAI to be necessary and therefore still carried them. Only studies by Jones (2014; Jones et al. 2015) used a theoretical model to explain beliefs regarding AAIs and found similar results to papers that did not use a theoretical model. The theoretical perspective emphasised barriers as important in understanding low adherence to carriage and use of AAIs.

3.4.3. Theme 3: Managing the risk of anaphylaxis

Adolescents generally believed it was difficult to manage the risk of an allergic reaction (Stensgaard et al., 2017) and these beliefs were discussed in N=11 of the studies. Illustrative quotes can be found in Table 8.

Table 8: Theme 3: Managing the risk of anaphylaxis

Theme	Quotes
Managing the risk of anaphylaxis	*I'm like terrified because it's bound to happen sometime. I don't think I can live my life without ever getting a allergic reaction, because I'm bound to get one, that's what I believe. Like, I'm almost certain that I will and it feels like every day could be that day in some way* (Joanna, aged 16) (Stjerna, 2015, p289) *I don't really think about it…It's just like when you cross the road you think; working out whether you'll get across in time…It's in the background humming away all the time* (P19, female, aged 16) (Mackenzie et al., 2010, p598) P9 (F18): *Yeah, so it's just a judgement thing really because most companies put it on there just in case to save their backs really* (Monks et al., 2010, p1536)

Adolescents were either dismissive towards high-risk behaviours that may potentially result in anaphylaxis or expressed a great fear of allergic reactions, which they associated with severe danger (Stjerna, 2015; DunnGalvin et al., 2009; Marklund et al., 2007) and 'life and death' (MacKenzie et al., 2010; Fenton et al., 2011). Some adolescents presented both beliefs, being very aware of their allergy yet simultaneously viewing it as 'no big deal' (Akeson et al., 2007).

Beliefs around risk and the possibility of having an anaphylactic reaction also depended on who was present, with some adolescents more likely to eat a food with a warning label if a parent was present compared to just friends, as they felt safer. However, where peers were all eating a food which potentially contained an allergen, this did increase the chance of an adolescent with FA taking a risk and also trying it (Monks et al., 2010). Some adolescents believed that certain foods were worth the risk of having a reaction (Marklund et al., 2007) despite warning labels, which may be more likely with popular food such as chocolate (Stjerna, 2015) as they didn't want to feel as if they were missing out. It was suggested that eating a potential allergen despite the risk of anaphylaxis was undertaken to 'fit in' and gain the trust of others, as well as to increase independence, control and empowerment (Fenton et al., 2013). This suggests that peer beliefs may influence the adolescents with FA's own beliefs and behaviour, and that adolescents would be more likely to eat risky foods if encouraged by their friends.

The majority of adolescents were dismissive of 'may contain nut' warnings unless the product was made in a factory that made peanut products specifically (Monks et al., 2010). Adolescents were also sceptical towards the legitimacy of the presence of allergens in foods with 'may contain' labels and the process of constant checking was believed to be annoying (Mackenzie et al., 2010) and restrict their food choices. Participants believed less use of these 'defensive' warnings where risk was low as well as simpler and more consistent allergy warnings could improve allergen avoidance (Monks et al., 2010) as labels may be taken more seriously.

In summary, the threat of anaphylaxis and the belief it could happen at any time led to strong feelings of anxiety and feeling out of control in some participants who perceived their FA as severe (Stjerna, 2015; DunnGalvin et al., 2009; Marklund et al., 2007; MacKenzie et al., 2010; Fenton et al., 2011), a contrast to other participants who were more relaxed about their FA (MacKenzie et al., 2010; Gallagher et al., 2011; Akeson et al., 2007). Frustration at being restricted through less food choice at restaurants or from 'may contain' food labels that were considered to be inaccurate, sometimes led to acts of rebellion and consumption of allergens. The beliefs of peers also affected beliefs of those with FA with the desire to fit in sometimes pushing the adolescents with FA to take more risks.

3.4.4. Theme 4: Behaviour and understanding of others

Beliefs towards FA from others such as friends, classmates, school staff, parents and the wider community were discussed in N=12 of the studies in this review and illustrative quotes can be found in Table 9.

Table 9: Theme 4: Behaviour and understanding of others

Theme	Quotes
Behaviour and understanding of others	*I remember a few years ago when I wanted to go to camp, the same camp as my friends, but they wouldn't let me come because of my allergies" and "I feel left out because I can't have everything, like my friends and the other people in my family* (male, aged 16) (Fenton et al., 2011, p177) *I'd only mention it if it came up…if I had to say why I couldn't have something, I'd say that I didn't like it or I wasn't hungry* (Boy, aged 13) (DunnGalvin et al., 2009, p10) *Some, especially adults, they don't take it seriously when I tell them that I'm peanut-allergic (...) they think you exaggerate. In fact, it is mostly adults. When you are at a restaurant and so on. So you have to make it clear to them that if I eat this it ... it'll be the ambulance that's next* (Marklund et al., 2007, p7) *the same thing again and again…be careful, be careful…do you have your pen…watch what you eat… I need to have a life* (Boy, aged 15). (DunnGalvin et al., 2009, p12) *I think to myself and hope my dad will say [to his girlfriend] "Hey listen, please take the other knife". He should do it, because I don't like to say it. It's not me who should do it, he is the grown-up* (AX fam X) (Stensgaard et al., 2017, p3375)

Adolescents in n=7 of the studies said that once their allergy was disclosed to their classmates, they experienced discrimination due to their classmates being mean-spirited (Dean et al., 2016). Some adolescents also expressed frustration that peers tended to focus on the limitations of their FA and what they could not do, identifying them as different and making the situation more difficult to cope with (Stjerna, 2015). To avoid being excluded, some adolescents purposely did not tell their peers about their FA, only confiding in close friends (DunnGalvin et al., 2009), keeping their condition hidden, believing that others would not understand. Classmates were highlighted as needing more education and information to increase understanding of FA (Monks et al., 2010).

A lack of education and awareness of others was considered by adolescents to be the greatest barrier to adolescents with FA being understood, accepted and becoming independent (Fenton et al., 2011). Adolescents also believed they could not necessarily trust adults due to a lack of understanding of FA and thus the adolescents felt they needed to take control themselves to prevent a reaction. This lack of awareness around FA, for example thinking an allergic reaction could just cause a rash rather than be life-threatening (DunnGalvin et al., 2009; Stjerna, 2015), sometimes led to adolescents feeling uncertain about how to manage different situations such as ordering food (MacKenzie et al., 2010). Adolescents in Marklund et al.'s (2007) sample expressed that there were several occasions where their allergy was disregarded, and they were frustrated over the lack of understanding from others. Generally, adolescents felt that their FA was not taken seriously by others and often ignored, such as in schools by teachers and peers (Stjerna, 2015) and even in situations where allergen information is important such as restaurants.

Parental beliefs and behaviour may also affect how adolescent beliefs develop and these were discussed in N=8 of the studies (Dean et al., 2016, DunnGalvin et al., 2009; Fenton et al., 2011; Fenton et al., 2013; Gallagher et al.,2011; Gallagher et al., 2012; Sommer et al., 2014, Stensgaard et al., 2017). Some adolescents discussed the approach their parents had to managing FA, highlighting the risks, encouraging hypervigilance and reminding adolescents of possible consequences. This sometimes led to conflict between the adolescent and parent (DunnGalvin et al., 2009; Fenton et al., 2013; Gallagher et al., 2011). Other adolescents accepted that though irritating, it was their parents showing that they cared and therefore viewed their parents' behaviour as positive as they felt safer (Sommer et al., 2014). Stengaard et al.'s (2017) study was the only one to consider divorce and the effects this can have. Where parents were divorced, adolescents believed it was the responsibility of the parent to educate new members of the family. In the cases where the adolescent felt unsupported by their parents, this led to less trust in the adolescent's parents which led to anxiety at home. Further conflict may result in a breakdown of routine when with grandparents, who were described as being more lenient (Fenton et al., 2013). When there was a family member or friend who also had a FA, adolescents felt more accepted compared to adolescents who had no family or friends who had FA (Macadam et al., 2012; Stjerna, 2015) as these family members struggled to empathise.

The beliefs of peers and adults had an impact on the beliefs of the FA adolescents themselves and adolescents with FA believed that education was essential to improve the beliefs and attitudes of others. Parental conflict as adolescents moved into teenage years was believed to be an issue as adolescents moved to manage their independence and take more control of their FA. However, parents were also expected to take control where adolescents were unsure, such as with introducing a new partner to the family. Attitudes and behaviour of others reflected on the beliefs of the adolescents who came to view their FA as more burdensome or manageable dependent on the responses of others.

3.4.5. Theme 5: Food-allergic identity and condition beliefs

A total of N=16 studies discussed beliefs related to identity and FA and illustrative quotes can be seen in Table 10.

Table 10: Theme 5: Food-allergic identity and condition beliefs

Theme	Quotes
Food-allergic identity and condition beliefs	*Quite a lot of my friends' kind of go and kissing the boys and things and it's kind of awkward for me because I'll have to kind of ask them if they had been eaten nuts. And you can't really do that in a club because you can't really hear what the person is saying, so it's quite hard. And to explain to someone that you don't know things like that . . . so I just kind of don't . . . I can't really (A4).* (Akeson et al., 2007, p1216) *There are people who have things much worse. So you just need to think about them. (...) If I think things are hard for me, they must live through hell every day. I don't even think about it as being hard for me* (Marklund et al., 2007, p8) *It doesn't really bother me because I've had allergies all my life…It's a way of life almost isn't it?* (P15, female, aged 17) (MacKenzie et al., 2010, p598). *Because in no way do allergies, EpiPen, and medic alert define me as a person. Like sure, I have an allergy. That makes me no different than the person living up the street kind of thing* (Robert) (Fenton et al., 2013, p292)

Generally, adolescents expressed acceptance of their FA but felt that it should not define them as a person. They adopted optimistic beliefs and considered how their FA 'could be worse', that others had a worse experience than them, or that their allergy had improved compared to when they were younger (MacKenzie et al., 2010; Marklund et al., 2007). Some were hopeful that they may someday outgrow their FA and therefore it was only a temporary issue rather than a life-long burden (MacKenzie et al., 2010). Across the papers, differences in beliefs could be attributed to different ages, suggesting that this may impact beliefs about identity.

Some adolescents, however, believed their FA was a big part of their identity, believing they were powerless and their FA was unmanageable. In response, maladaptive coping strategies such as isolating themselves from others or excessive hand washing were reported (Fenton et al., 2011). Believing it was necessary to depend on others and feeling a lack of control in relation to their own bodies was difficult for some adolescents (Stjerna, 2015), especially at an age where their peers were becoming more independent. The idea of burdening others concerned participants in Stjerna's (2015) study with some adolescents worrying about restricting others and forcing them to adapt because of their FA and concerns about the exclusion that may come as a result. Those who engaged in risky behaviour, such as eating food which 'may contain' allergens, felt less fear around their FA and had a stronger sense of self with increased confidence (Fenton et al., 2013; Mackenzie et al., 2010). For these adolescents, anaphylaxis was considered the same as any other risk such as crossing the road.

A belief that FA is part of life was demonstrated in some of MacKenzie et al.'s (2010) sample aged between 13 and 18 years, as they had learned to adapt over the years to having a FA. On the other hand, younger adolescents were more frustrated by the barriers that they experienced because of their FA. In contrast, Dean et al.'s (2015) sample showed that younger participants (8-12 years) were more relaxed and considered FA in terms of a 'diet' whereas older participants (13-17 years) reported that it was 'a big deal' and considered life or death. Fenton et al. (2011) supports the shift in attitudes across age as all participants in her study reported stronger feelings of safety in elementary school partially due to parents being more present but also due to supervision from trained staff and a more consistent routine.

After having FA for some time, some adolescents grew accustomed to having it as part of their life and expressed acceptance and resignation with regards to their FA (Marklund et al. 2007). Redefining life as normal (Fenton et al., 2011; Fenton et al., 2013) was one way to embrace having FA and this acceptance may lead to a more positive perception of their condition. Similar thoughts were found across other papers with adolescents looking to balance risk, so their FA did not dominate their lives (Gallagher et al., 2011; Sommer et al., 2014).

Beliefs around independence and the future were also fairly positive. Gaining choice and control led to empowerment and gaining trust in themselves and their environment, resulting in a more positive outlook (Fenton et al., 2011). When reflecting on a future away from parental safety, some adolescents felt that although they would never be completely safe, they can get increasingly better at managing their FA (Stjerna, 2015) and in their own safe space would have control over what food was brought into their home (Marklund et al., 2007).

3.4.6. Subgroup analysis

Subgroup analysis was conducted on age, gender, geographical location, method and allergen to determine whether this may influence results. Gender differences between participants were limited, with the main belief highlighted as different being the frustration with AAI carriage which was reported as more substantial in male participants (Gallagher et al., 2011; Macadam, et al., 2012; Monks et al., 2010). Studies did not explicitly discuss differences in beliefs dependent on allergen.

Interestingly, there were more beliefs around anaphylaxis and food allergies as 'a way of life' in UK samples (Akeson et al., 2007; MacKenzie et al., 2010) compared to increased fear of safety, especially in relation to severe reactions, in the Swedish samples (Stjerna, 2015; Marklund et al., 2007) and the older 13-17 year olds of Dean et al.'s (2016) Ontario sample who viewed FA as a 'big deal'. A factor that may have influenced Dean et al.'s sample was Sabrina's Law, which was enacted after the death of a 13-year-old girl in Ontario, where this study was conducted. However, Fenton et al. (2011) also discusses this study and is based in Canada yet focuses more on coping with illustrative methods while Dean et al. (2016) considers stigma with more typical qualitative interview methods. DunnGalvin et al. (2009) explicitly discussed a period of transition around 12 years of age, where increased conflict with parents was reported. Conflict with parents was also reported in Fenton et al. (2013) and Gallagher et al. (2011) though the specific age of this conflict emergence was not discussed.

3.4.7. MMAT: Quality appraisal of studies

A quality appraisal (Hong et al., 2018) of the studies included in the systematic review was completed to acknowledge that the assessed 'quality' of these studies and their limitations may influence the interpretation of results. The studies included were all assessed by the main researcher and no studies were deemed unsuitable for analysis due to poor quality, no studies receiving a score of less than 50% in line with Pluye et al.'s (2011) ranking recommendations. However, noted limitations included that: Akeson et al.'s (2007) study contained only 7 interviews with adolescents which is arguably low for data saturation in thematic analysis, however there were also 8 parent interviews to supplement this. In MacKenzie et al.'s (2010) study, participants are listed as having food hypersensitivity (FHS) yet have been diagnosed as IgE-mediated in an allergy clinic by skin-prick testing, positive food challenge or serum-specific IgE results. As this is a different term, yet has not been clearly identified as FA, despite questions using the term ‘how do you feel about having a FA?’ (p596), this creates some confusion on diagnosis and suitability of data. Macadam et al. (2007) uses both interviews and focus groups yet analyses them in the same way without discussion of how data from the two data collection methods are similar or different. Sommer et al. (2014) also discusses use of focus groups and interviews but provides a rationale for why they chose to focus on interviews instead. Only 7 of Sommer et al.’s (2014) participants had FA, which is an arguably small sample size for thematic analysis. Stjerna (2015) recruited 10 participants in their thematic analysis, which also may be perceived as low. Monks et al. (2010) claim to use a thematic approach to analyse their data but do not determine how the data is analysed, especially as it is not conducted in line with Braun and Clarke’s (2006) recommendations for conducting thematic analysis, Recruitment to the Saleh-Langenberg et al. (2016) is arguably low at only 55 participants with participant demographics such as age and gender not stated. Non-response bias cannot be determined as there is no indication of the number of participants who declined or did not respond.

3.5. Discussion

This systematic review has uniquely identified five themes regarding beliefs about adolescent FA. These are; from home to holidays: navigating different places, carriage and use of adrenaline auto-injectors, managing the risk of anaphylaxis, behaviour and understanding of others, and food-allergic identity and condition beliefs.

Within the first theme, the further from home a place was, the riskier it was considered to be (Stjerna, 2015; Macadam et al., 2012; Akeson et al., 2007). The more familiar the place was from numerous visits without a reaction occurring, the more comfortable adolescents were attending there. Schools were believed to be risky places depending on how supported the adolescents felt, and secondary school was viewed as more dangerous than junior school (Fenton et al., 2011). Applying this to Ecological Systems Theory (Brofenbrenner, 1994), it may be argued that adolescents feel safer in their microsystem, their immediate environments, and that anxiety around managing FA increases the further away from the individual the social relationships and social places that the adolescents are in. For example, this supports that adolescents feel safer at home with their parents, and less safe in community settings with people they do not know. Educating those with FA about risk rather than allowing fear to be a barrier may assist in improving beliefs towards the safety of places. Teaching adolescents how to manage risky situations such as navigating restaurant menu ingredients or eating with friends may also help increase independence.

In the second theme, ‘Carriage and use of adrenaline auto-injectors’, AAIs were a big concern. Carrying their AAI despite its perceived inconvenience could be attributed to increased perceived severity of FA. A re-evaluation of AAI model design to make the medication and packaging smaller could increase the likelihood of carriage and more positive feelings towards them (Monks et al., 2010). More reassurance about the needle and appropriate training may help with apprehension using the AAI. More frequent training and provision of trainer pens may also increase confidence on how to use them and refresher training to correct techniques and giving the opportunity for adolescents to ask questions to correct confusion on when an AAI is needed. Jones et al. (2014) reported that adherence to AAI carriage in adolescents improved with increased perceived severity of FA or reduced perceived barriers to FA management, highlighting application of the HBM. This suggests that taking the FA seriously, seeing the FA as something that could have severe consequences, understanding their susceptibility to a reaction and viewing fewer barriers such as worries of peer’s perceptions, may increase AAI carriage. This use of a health model provided an interesting basis for the data to be analysed and further use of models such as the HBM and CS-SRM may be useful in future research. However, concerns about perceived severity may also lead to fear and anxiety in adolescents (MacKenzie et al., 2010), suggesting support is needed to manage this anxiety to prevent a decline in quality of life and address anxiety as a barrier to FA management. Management of anxiety and addressing maladaptive beliefs of AAIs (e.g. that they are difficult to use) should be a priority of psychologists and clinicians working with adolescents with FA.

The third theme discussed managing the risk of anaphylaxis, where adolescents found it difficult to balance becoming more independent and accepting more responsibility for their FA. Risk was generally met with beliefs that were either dismissive and relaxed or hypervigilant and anxious, both with negative connotations. Research suggests that both parents and adolescents sometimes struggle to correctly interpret risk levels (Gallagher, et al., 2012) suggesting that some risk-taking is due to error, misjudging severity, or a lack of information. In Greenhawt et al.’s (2009) study featuring college students, risky behaviour seemed to be more prevalent compared to the adolescents in this review with 60.3% (173 students) not always avoiding consuming a known allergen, providing various reasons such as no previous serious reaction (37.6%) or the perception that it was not a risky behaviour (20.8%). This suggests that a shift in beliefs and behaviour may begin in adolescence, leading to the potential for further risky behaviour as adolescents get older and try to develop their self-efficacy. More research into how beliefs and attitudes change throughout development, especially in transition periods such as moving to further years of education would be beneficial to understand this in more depth and give insight in how to prepare for these challenges.

A common risky behaviour was dismissal of ‘may contain’ food warnings and consuming foods that may not be safe. Adolescents across the studies reported that they felt food companies were more concerned with protecting reputations than keeping people safe, resulting in a lack of trust. This lack of trust and scepticism may also be due to struggling with locus of control, as adolescents struggle to become more independent and develop a more internal locus to manage their own lives, yet in the case of food labelling where adolescent safety is forced to be external with limited information and trust, this may lead to tension. It was also suggested that label warnings were sometimes unnecessary and were therefore ignored, especially in known brands. Barnett et al. (2013), in a study looking at food choices in nut-allergic consumers, highlighted three strategies affecting food choice and assessing risk: past experiences of food consumption; sensory factors to determine risk; and quality of the product or the place the food originated from. Previous research around FA labels and FA consumers also found that the visual aspect of the allergen labels such as where they were located on the packaging was important (Ju, et al., 2015). Increased visibility of the label is important and may reduce accidental ingestion of allergens. In addition, greater information about the production of food and what is involved in regulations and the labelling process may encourage adolescents to take labels more seriously and reduce scepticism.

The fourth theme indicated that peer relationships were difficult to manage due to the lack of knowledge of FA among peers both at the level of close friends and in classmates, depending on how close to the microsystem they are in the adolescents ecological system. As adolescence is a sensitive time for social relationships and personal development, this may be especially distressing and lead to negative emotions and reduced quality of life (Morou et al., 2014; Cummings et al., 2010; Marklund et al., 2004). Changing the beliefs and therefore behaviours of peers through education could improve the beliefs and behaviours of the individuals with FA themselves and therefore reduce risky behaviour. Educating the wider community, beyond immediate peers, is also important for decreasing risk of reactions in public spaces such as restaurants as this is further still from the microsystem and may cause increased anxiety with less self-efficacy. In the event of a more external locus of control, these strangers in the exosystem may be perceived as less trustworthy or capable than parents or family friends familiar with FA.

In terms of family relationships, parental support and conflicts with independence were common in adolescents with FA. Stensgaard et al.’s (2017) sample found that despite most participants having a good relationship with their parents, some felt their parents wanted to 'control their lives' (p3377) and preserve an external locus of control for the adolescents, where they relied on their parents rather than themselves. Previous research by Van der Velde et al. (2011) suggests that increased perceived severity of FA and poorer illness comprehension is linked to adolescent-parent conflict in Dutch adolescents aged 13-17 years. Stjerna (2015), Macadam et al. (2012) and Sommer et al. (2014) however, found that adolescents in their sample preferred parents to help them navigate risk and keep them safe, especially outside of the home. Stensgaard et al.'s (2017) sample may be more independent due to cultural differences as the study was conducted in Denmark which may have different parenting styles, however more cross-cultural data would be required to draw any conclusions.

The final theme highlighted that adolescents with FA respond to their FA status in different ways. As adolescents grew older and developed increased self-efficacy and a more independent identity, they balanced managing responsibility with their parents and gaining more independence with keeping safe, striving for normalization (Fenton et al., 2011; Fenton et al., 2013). Speaking with the parents as part of a management program both in allergy clinics and in psychological services may be useful for navigating responsibility and reducing conflict (DunnGalvin et al., 2009; Fenton et al., 2011). An increase in normalization may be reached through education around FA and FA management from clinicians and online resources, such as from charities such as Allergy UK and Anaphylaxis Campaign, so that FA is better understood and more manageable. A greater understanding from healthcare professionals about the importance of beliefs and how they relate to behaviour and the necessity for increased information in all areas from schools to restaurants and the wider community is important to support adolescents with FA. Adolescents in all studies expressed that further education is important for moving forward and improving peer beliefs and the beliefs of the FA adolescents themselves, increasing self-efficacy and developing a more internal locus of control so adolescents may feel their FA is more manageable and that they can handle challenges that come with having FA.

Cultural differences and differences based on recency of the study were also factors of interest across the studies reviewed. There were more beliefs around anaphylaxis and food allergies as 'a way of life' in UK samples (Akeson et al., 2007; MacKenzie et al., 2010) compared to increased anxiety of reactions, in the Swedish samples (Stjerna, 2015; Marklund et al., 2007) and the older population (13-17 years old) of Dean et al.'s (2016) Ontario sample who viewed FA as a 'big deal'. This difference in beliefs may also be attributed to a shift across time, as the more anxious beliefs are displayed in more recent studies, which may be linked to an increase in FA prevalence. Cultural differences may be related to various factors such as parenting styles, education, healthcare systems and policies, although future research would be required to explore these factors. In parenting, Sweden has made more strides in involving the father in parenting compared to England, where many fathers wanted to remain in their traditional gender role (Plantin, Månsson & Kearney, 2003). Sweden's stronger sense of equality was also found in the school system, where a comparison of schooling in England and Sweden (Alexiadau et al., 2016) found that Sweden was more focused on equality and diversity through local variation, freedom of choice and responsibility in their schooling system. England on the other hand was more segregated, and factors such as socioeconomic status, religion and ethnicity determined opportunities for success. In England, schools were encouraged to compete over 'good students' as this was tied to financial resources and league tables, while as Sweden is highly privatised, focus was more on social inclusion, justice and citizenship (Alexiadau et al., 2016). As such, the more competitive nature of schools in England may lead to adolescents being reluctant to draw attention to their FA, while the more inclusive nature of schools in Sweden may allow adolescents to be more open about FA concerns. In Sweden, all preschool children receive free meals and legislation requires meals to be nutritious, while the UK is varied (Lucas, Patterson, Sacks, Billich, & Evans, 2017). With Swedish children all having access to free dinners, this may have caused more stress for those with FA as it was less common to bring food from home.

Further education on managing risks, encouraging independence and improving beliefs in adolescents' capability and perceived control could be beneficial, reduce anxiety surrounding allergic reactions and lead to more positive attitudes and beliefs. The need for further research to support independent self-management of FA has also been requested by adolescents (Gallagher et al., 2011). Some adolescents in this review have also suggested that they would rather have another person with FA teach them about FA instead of a healthcare professional, believing that support from someone with personal experience may be helpful. Others were happy with the support from allergy clinics, who may also support parents (Stensgaard et al., 2017). FA support groups may also be a beneficial resource to consider when improving attitudes and beliefs.

3.6. Strengths

The main strength of this review was the identification of themes that were not present in the original papers but appeared after synthesizing results across studies, offering novel findings that have not been previously investigated in this age range, as individual papers focused on more specific topics (e.g. on adrenaline auto-injectors). A further strength of this review was the inclusion of both qualitative and quantitative research of various methodologies offering different perspectives, which has not been explored previously. Quantitative studies provided larger sample sizes, whereas qualitative papers had more depth and offered possible explanations for the quantitative results.

The findings of this review are supported by the results from papers using various methodologies including more typical qualitative methods such as interviews and focus groups and more creative methods such as illustrations and narrative (Fenton et al.) as well as quantitative methods such as questionnaires, including Jones et al.'s (2014; Jones et al., 2015) work which used the HBM and CS-SR. Similar results were found regardless of methodological differences. This systematic literature review also considers the effectiveness of papers that included theoretical models (Jones et al., 2014; Jones et al. 2015) compared to those that did not and found the mention of barriers to be a key component of adolescent behaviour, as well as severity, which is considered in qualitative studies where adolescents feel peers do not understand the seriousness of FA as a condition. Registering the protocol on PROSPERO means that the methods are reproducible.

3.7. Limitations

The main limitation of this review is that many of the papers included did not primarily aim to explore beliefs regarding FA, resulting in data having to be extracted and interpreted. Although themes found were agreed upon by the supervisors, there is subjectivity in interpretation and other researchers may interpret the findings differently. The review was further limited by the information (quotes or data) included in the original papers as the original transcripts or data sets were not available. With the open science movement gaining traction, these resources may be available to future reviewers and collect data that may otherwise be missed. Also, while search terms were discussed with an experienced librarian the terms included were not exhaustive. Further terms such as synonyms of the original terms, for example 'view', may have increased the results of papers for consideration in the systematic review. Grey literature and unpublished studies were also outside of the inclusion criteria and may have had interesting material for consideration, and the open science movement may make these materials, as well as data such as original transcripts, more accessible.

Included papers also had some limitations which may impact the quality of the research in line with MMAT appraisal, with four studies featuring 10 or less relevant participants for data analysis which is an arguably small sample size for thematic analysis (Akeson et al., 2007; MacKenzie et al., 2010; Sommer et al., 2014; Stjerna, 2015), Saleh-Langenberg et al.'s (2016) study also appeared to have a small sample size for a quantitative study, with 55 participants who were not demographically defined. Non-response bias is also an issue in this study, as response rate was not reported.

3.8. Implications

Beliefs are affected by various factors including place, AAIs, risk, peers and identity. As a lack of trust was reported in secondary schools, especially in teachers (Dean et al., 2016), it would be useful to develop educational interventions for 11-16-year olds, during a time when they experience transition into secondary school. Teachers could also benefit from training regarding managing FA and how to navigate risk. Peers in school should receive further education about FA, which may help reduce bullying and stigma (Dean et al., 2016; Fenton et al., 2011; Fenton et al., 2013). With increased peer acceptance and understanding, beliefs may change, and this may help to shape attitudes towards FA, its impact and management. The consideration of these beliefs would also be useful clinically, both in allergy clinics and in psychological support services. Concerns around AAIs and reactions should especially be addressed, as increasing self-efficacy in regard to these factors may improve management of these reactions. Furthermore, has good adherence has been seen in previous research into diabetes, high self-efficacy and an internal locus of control (Albargawi et al., 2017). Health beliefs around FA, such as the condition being life or death or by contrast not being serious, should be addressed clinically so adolescents are better equipped to appraise their FA and how they can keep themselves safe. Health beliefs have been highlighted as important in previous research into diabetes to influence how they manage their self-care (Albargawi et al., 2016; Albargawi et al., 2017; Vedhara et al., 2014). A shift in health beliefs for diabetes has been suggested through health promotion education focusing on diagnosis awareness and progression of risk, which was supported by previous research (Shaak et al., 2018; Birkett et al., 2004; Safeer, Cooke & Keenan, 2006), which may also work well for FA.

The three included quantitative papers support the qualitative data regarding AAI carriage, however more research is required to further investigate other areas of living with FA such as checking food labels, management in daily life and ingestion of potential allergens. As the use of models (HBM, CS-SRM) were only used in two of the quantitative papers, further research considering theoretical models may be useful to manage data specifically in health research and the suggest application of this data and how it may be used in behaviour.

Despite being the age group most at risk for a fatal reaction, the results of this review show that there are few studies exploring beliefs about food allergies in the 11-19 age group, highlighting a need for further research. Notably, only the North and South of the UK and select areas of Canada, Ireland, Netherlands and Sweden have explored beliefs in adolescents with FA. It may be particularly important to look at ages of transition such as the move from primary to secondary school, and then the move to college or University. These age groups are also important to focus on as it is at this age that adolescents seek further independence and responsibility for themselves and take further control of managing their FA.

3.9. Conclusion

This systematic review suggests that adolescents with FA hold a variety of beliefs about their FA; some beliefs are likely to increase the risk of behaviour that could lead to an accidental allergic reaction, while others may reduce this risk. Further research into understanding adolescent beliefs about FA is essential to reduce stigma and increase the independence of adolescents with managing their FA. It was highlighted throughout the themes that education is key in improving knowledge and understanding about FA. An increase in normalization may be reached through education around FA and FA management, so that FA is more understood. A greater understanding from healthcare professionals about the importance of beliefs and how they relate to behaviour and the necessity for increased information in all areas, from schools, restaurants, and the wider community, is important. Adolescents in all studies expressed that further education is important for moving forward and improving peer beliefs and the beliefs of the FA adolescents themselves, which may help shape both attitudes and behaviour. The following two chapters aim to address this gap in the literature by exploring in more depth the beliefs of adolescents both with and without FA.

Chapter 4: “People don’t know how severe some of them can be”: An exploration of beliefs in adolescents with food allergy

4.1. Introduction

In the general introduction it was discussed that FA reactions are more common in the adolescent age group (Pumphrey, 2000). Sampson et al. (2006) reported that in their sample aged 13 to 21 years, half purposely ate potentially unsafe food. The impact of FA and how it is managed is thought to change as children develop, with adolescence as a time of transition. A review by Johnson and Woodgate (2017) on adolescent experiences of food-induced anaphylaxis found that beliefs around the allergic self, balance, and controlling the uncontrollable to be themes considered to directly influence the sample adolescents’ experiences. However, this review does not consider beliefs of adolescents with FA in the absence of anaphylaxis. It is important to include adolescents who have not experienced anaphylaxis as previous reaction severity is not indicative of future reaction severity, meaning that adolescents with an IgE FA who have not previously had an anaphylactic reaction may do so in the future.

In the systematic review (Chapter 3) it was found that areas of importance regarding beliefs of adolescents with FA included place, AAIs, peers, risk of reactions and beliefs about the condition. Adolescents believed that secondary schools (Fenton et al., 2011; Dean et al., 2016; Stensgaard et al., 2017; Fenton et al., 2013), holidays (Sommer et al., 2014), and carriage of AAIs (MacKenzie et al., 2010; Gallagher et al., 2011; Macadam et al., 2012; Monks et al., 2010) all came with difficulties and barriers to managing their FA. Home was considered a place of safety for FA management and a good peer support system was felt to be important. Use of AAIs (Monks et al., 2010; Macadam et al., 2012) and the potential for general reactions and anaphylaxis (Stjerna, 2015; DunnGalvin et al., 2009; Marklund et al., 2007; MacKenzie et al., 2010; Fenton et al., 2011) was scary for some adolescents and resulted in anxiety. However, many adolescents accepted their FA as part of life and believed that their symptoms or allergens could be ‘worse’ (MacKenzie et al., 2010; Marklund et al., 2007). There was some concern of management in the future and what limits they may experience, though they believed they would get increasingly better at managing their FA (Stjerna, 2015; Fenton et al., 2011; Marklund et al., 2007).

The systematic review identified that few studies explored beliefs as the primary aim and those that did, focused on specific issues such as use of AAI. The review also identified that transition to and managing FA in secondary school was an important period for adolescents.

Therefore, this study aimed to explore beliefs about FA in adolescents aged 11 to 16 years who have been diagnosed with FA.

4.1.1. Rationale

As previous research suggests beliefs may have an impact on FA management and behaviour, this study aimed to explore whether a current UK sample supports these findings. This is currently an under-researched group and there are limited studies looking at beliefs about FA generally. Previous research tends to focus on specific beliefs, such as in relation to AAIs but does not explore the full experience of FA and beliefs about FA as a whole, including illness condition beliefs, the effect of FA in social interaction and managing school. This research will specifically focus on a UK secondary school age range where the risk of reaction is high and research into beliefs about FA is limited. Further understanding of beliefs associated with these factors and why adolescents have these beliefs is important to inform ways in which we may be able to reduce risk-taking behaviour and address anxious beliefs that cause high levels of distress. This study therefore aims to explore beliefs of adolescents with FA in a currently under-researched population, to understand the effect of having FA on an adolescent's life.

4.2. Methods

4.2.1. Study design

This was a qualitative study, using semi-structured interviews. Ethical approval was granted by the Health Research Authority (HRA) and Leicester Hospitals NHS Trust (IRAS ID: 226560, 26/01/2018) and can be found in Appendix 2.1.

4.2.2. Study setting

Semi-structured interviews were conducted with adolescents aged 11-16 years, who were living in England, either via phone (n=5), face-to-face at their home (n=9), or Skype (n=6).

4.2.3. Participants

Twenty adolescents participated in this study, 14 females and 6 males. The mean age of participants was 13.1, SD = 1.5 (age range = 11 to 16 years). Of these, N = 18 were recruited through Leicester Royal Infirmary and N = 2 were recruited via social media and

Aston University’s staff newsletter ‘Aspects’. All participants were required to have a diagnosed FA. Table 11 provides a summary of the sample's demographic characteristics (all names presented are pseudonyms).

4.2.4. Data collection

Semi-structured qualitative interviews were used to collect data. Interviews were undertaken because of their flexibility, where participants are free to discuss their experiences (Pope, van Royen & Baker, 2002). Further details about the rationale for choosing interviews can be found in the Methods chapter (Chapter 2). The interviews explored participants’ beliefs about FA as a condition. The interview schedule (Appendix 2.10) was developed as a topic guide and was based on findings from previous literature and the systematic review discussed in Chapter 3, suggesting areas of importance to explore such as food labelling and AAI carriage.

Table 11**:** Participant demographics of the sample with FA

	Name	Age	Gender	Food Allergens	Other	Medication	Age Diagnosed
1	Hera	13	F	Chickpea, nut, kiwi, grapes, coconut, carrots	Eczema, pollen, dust, grass	Antihistamines, AAI	3 years
2	Naomi	15	F	Peanut	Eczema, hay fever	Antihistamines, AAI	3 years
3	Freya	15	F	Peanut, tree nut, cashew, pistachio	Asthma, hay fever, (used to have eczema)	Antihistamines, AAI	3 years approx.
4	Urali	13	F	Peanut	Hay fever, tree pollen, grass pollen	AAI	Very young – not certain
5	Eric	11	M	Peanut, cashew, almond, cow's milk, egg	Asthma, eczema, hay fever, tree pollen	Antihistamines, AAI	6 months
6	Charlotte	15	F	Cashew, pistachio	Eczema, hay fever, tree pollen, grass pollen	AAI	14 years
7	Jack	13	M	Cashew, pistachio	Eczema, hay fever, tree/grass pollen sensitivity	Antihistamines, AAI	12 years
8	Andy	12	M	Peanut, pistachios, cashews, walnuts,	Asthma, eczema, tree pollen, grass pollen	Antihistamines, AAI	7 years

				hazelnuts, almonds, brazil nuts and pecans			
9	Jasper	12	M	Cashew, pistachio, fish	Eczema	Antihistamines, AAI	11 years
10	Selena	13	F	Walnut, pecan	Only reaction itchy throat	Antihistamines	12 years
11	Freddie	16	M	Almonds, apples, plums, cherries, peach	Hay fever, tree pollen	Antihistamines	15 years
12	Aria	11	F	Peanut	N/A	Antihistamines, AAI	10 years
13	Joshua	14	M	Cow’s milk, cashew, walnut, pistachio, brazil nuts	Asthma, eczema, hay fever, grew out of peanut	Antihistamines, AAI	Birth (milk), nut aged 5
14	Hillary	15	F	All nuts	Asthma, hay fever, grass pollen	Antihistamines, AAI	5 years
15	Holly	11	F	Peanut	Tree pollen, grass pollen, asthma, eczema, hay fever	Antihistamines, AAI	18 months
16	Shazi	12	F	Walnut, hazelnut, pecan	Hay fever, tree pollen, grass pollen	Antihistamines, AAI	8 years
17	Alice	12	F	Pistachio and cashew nuts	Surgical tape, asthma, eczema, hay fever	Antihistamines, AAI	8 years

18	Ella	12	F	Cow’s milk, egg	N/A	Antihistamines, AAI	Less than 1 year
19	Kaya	12	F	Cashew, pistachio, peanut	Eczema, colouring/ preservative allergy, outgrown egg, outgrown strawberry jam,	Antihistamines, AAI	4 months old (strawberry), 3 years (egg), 5 years (cashew and pistachio)
20	Nalini	15	F	Peanut, all nuts, cow’s milk, egg, fish, shellfish	Eczema, hay fever, tree pollen, grass pollen	Antihistamines	Not certain (approx. 7 years)

4.2.5. Procedure

The study was advertised through letters sent via Leicester Royal Infirmary's patient database (Appendix 2.2), online via Aston University's newsletter 'Aspects' and through social media channels Twitter and Facebook (Appendix 2.3). Interested participants (or their parent/guardian) were invited to contact the researcher via email. Following email contact, participants and parents or guardians were provided with parent and adolescent versions of information sheets (Appendix 2.4 and 2.5) and consent forms (Appendix 2.6, 2.7 and 2.8), in addition to a demographics form (Appendix 2.9). Information sheets and consent forms highlighted participants' ethical rights and explained the procedure of the study. Upon return of consent forms, participant interviews were then arranged based on the participant's availability. For interviews not conducted in person, consent forms were completed and posted or scanned and emailed back prior to the start of the interview. Consent or assent was also asked for verbally at the start of each interview to ensure the participant was happy to take part.

Prior to the interview starting, participants were reminded of their ethical rights such as the confidentiality of their data and their right to withdraw before the interview and invited to ask questions. Participants were asked questions from the semi-structured interview schedule (Appendix 2.10), which was used flexibly and adapted to fit participant answers. Upon completion of the interview, participants were thanked, debriefed, and received a £10 'Love to Shop' or book voucher for their time.

4.2.6. Data analysis

Following data collection, data was transcribed verbatim to prepare for analysis. Analysis was conducted according to Braun and Clarke's (2008) six-phase approach for thematic analysis, further information for which may be found in the Methods chapter (Chapter 2). Observed themes of interest were clustered together and developed into overarching themes aiming to capture significant data for further analysis. Interpretation of themes involved further re-reading, mind-maps and theme tables to attempt an accurate reflection of the interviewed children and adolescents. The initial analysis was conducted by the main researcher, and this was discussed with the supervisory team. After discussion, themes were refined where needed and theme names agreed upon.

4.3. Results

Four themes were developed through thematic analysis of the data: 1) “I think everyone would take it more seriously.” - Nut allergies as more serious than other FA, 2) “I don’t like talking about the needle, it just scares me.” – Adrenaline auto-injectors and needle anxiety*,* 3) “They’re annoying, don’t get me wrong, but they’re not super life threatening.” - How severity of FA symptoms affects beliefs, and 4) “I would like to have been born with it and grown up with it because then I would have understood it more and I wouldn’t be so worried.” Challenges of recent diagnosis.

4.3.1. Theme 1: “I think everyone would take it more seriously.” - Nut allergies as more serious than other FA

This theme considers the belief that nut allergies were the most serious allergen for adolescents with a FA. This belief was held by all participants, regardless of if they were allergic to nuts or not or if they had history of anaphylaxis. Multiple nuts were considered more difficult to deal with due to lack of labelling specificity, while common ingredients such as milk and egg involved more dietary changes and challenges.

The majority of participants felt that nuts were the most serious of allergens, even those who had nut allergies themselves. Peanuts are legumes, not nuts, but this is often not a distinction made by the public or even patients, and participants included peanuts in their description of nuts. Only two of the participants did not have an allergy to nuts, Freddie and Ella. Those who had nut allergies but had not experienced an anaphylactic reaction still felt nuts were the most serious but believed that they themselves had a less severe FA, if it was just ‘one nut’ they were allergic to rather than multiple nuts, or a nut that was believed to be ‘not as serious as peanut’.

> *I think it makes me feel quite safe because nut FA’s quite a big FA and gluten is as well, but I think dairy and eggs quite small as an allergy – Eric, M11*

> *Nut food allergy’s probably more dangerous so I’m not sure how I’d take it – Freddie, M16*

However, Freddie expands to say that although he considered nuts to be the most serious allergen, he felt the treatment of adolescents with nut allergies was excessive and not something he personally would appreciate. He believed that he would find it annoying and felt that it would also annoy peers around him by drawing unnecessary attention. Whether this is due to a combination of his age, gender and perceived low risk of anaphylaxis or simply a facet of his personality would require further research.

> *I think everyone would take it more seriously but in I dunno a bit over the top in a way - Freddie, M16*

Interestingly, even those with nut allergies considered that those with allergies to multiple nuts and peanuts were more severe than those with cashew and pistachio allergies. As a result, these were believed to be more limiting.

> *Well, obviously my allergy isn't to all nuts but like if it was then it'd impact a lot more because I'd have to be careful not to eat anything that says 'may contain' nuts so it'd limit my food by quite a lot – Charlotte, F15*

Allergen warning labels were perceived negatively by participants of all allergies as often unnecessary and with questionable accuracy. Nut allergen labelling was seen as especially problematic due to how types of nuts were rarely specified and were very commonly used. The participants with a nut allergy felt restricted in their food choices and were frustrated by the lack of clarity in warning labels, especially if they only had a specific nut allergy such as cashew.

> *It's like if it means 'may contain peanuts', but I think it means all nuts, I could have eaten that food... I'd like to try and eat foods which I can eat, which is a problem really because like it annoys me when they put 'may contain nuts' because does it just mean one nut? Because they should specify but they don't - Shazi, F12*

> *Because I bet you'll find everything in this kitchen will say 'may contain' – Selena, F13*

For those with a peanut allergy and no history of anaphylaxis, they believed that peanuts were more likely to be listed if there was a risk of them being in the food. As such, they tended to consume foods with nut warning labels and avoid those with their allergen mentioned specifically. There was a strong belief across participants with all allergens that food-labelling, especially in nuts where there could be ambiguity, should be more specific.

> *If it if it says 'may contain' nuts and that it doesn't really bother me but if it says peanuts then I'm a bit more aware with what I'm doing – Naomi, F15*

> *Well, I'd like it better if they did specify what nuts they are because like 'may contain nuts', I'm like, "What type of nuts?" It could be like hazelnuts and I'm like, "Are there any peanuts or something?" - Aria, F11*

While nut allergies were considered the most serious, they were also believed to be the most known among the community and that other allergens were less understood. Other allergies were believed to be less severe, especially cow's milk allergy (CMA) which was often confused with lactose intolerance, and allergies to fruit and vegetables (e.g. carrot) were considered more to do with dislike than an actual FA. Freddie mentioned that his parents and grandparents did not believe he was allergic, which was a factor in his late diagnosis.

> *I feel like a lot of people know about nut allergies, but they don't know about allergies for different foods – Naomi, F15*

> *Because they didn't believe me at first because it's always the common thing of "oh he doesn't want to eat his fruit this means he's going to pretend he's allergic to it isn't he" – Freddie, M16*

However, although participants considered nuts to be more severe, they felt that milk or eggs may be more difficult to manage as they are a more common ingredient in food, which would lead to more dietary changes. This was also discussed by participants with these allergies, for example Kaya reflected that when she had an allergy to eggs which she has since grown out of, she found this more difficult.

> *It was only when I had egg allergy when I felt a bit... I don't know. Just annoyed because everyone got to eat proper cakes and stuff. I had egg-less cakes - Kaya, F12*

> *They do in like… they do put milk in lots of foods, like… you'd have to be really, really careful. Like, you be limited from a lot of foods – Shazi, F12*

By contrast, Freddie felt that allergies were overall well understood, regardless of what allergen they related to. He believed that his peers generalised their knowledge of FA, mostly to nuts, and applied this to FA as a condition rather than to specific allergens.

> *I think people know what an allergy is... You know, it's like everyone knows what a peanut allergy is, for example, if you say you have an apple allergy, they just replace peanut with apple and it's like I guess it's the same but with apple – Freddie, M16*

In summary, participants discussed their belief that nut allergies were the most serious of allergens, linked to increased likelihood of strong reactions. However, the oldest male participant felt that treatment of those with FA was 'over the top' and garnered too much attention. Participants believed that multiple nuts are the most difficult to manage, especially when trying to navigate food warning labels as these often do not specify which nuts are included. Other allergens such as milk and egg, while considered less severe, were believed to be more difficult to manage as they were believed to be an ingredient in more food and therefore required more dietary alteration.

4.3.2. Theme 2: "I don't like talking about the needle, it just scares me." – Adrenaline auto-injectors and needle anxiety

This theme considers adolescent beliefs about AAIs, particularly apprehension around needles. Participants that were prescribed an AAI believed they were unlikely to have to use it and that carriage was inconvenient. Those not prescribed an AAI believed that they would take their allergies more seriously if they were prescribed an AAI. There was concern about using the AAI and that it would hurt, however those who had used their AAI in the past were not concerned by this and so past experiences had an impact on beliefs.

Both male and female participants believed that carriage was annoying as it was necessary to take a bag with them whenever they went out, which they viewed as inconvenient. Joshua also explained that the challenges with carriage meant that he did not take his AAI with him as much as he believed he should do. However, contrary to previous research, the male participants in this study were generally more positive about carrying their AAI, even if they did not consider themselves at risk of anaphylaxis, such as Andy in the quote below who felt that he could easily fit his AAI into his bag. Those who did not have an AAI felt it would be annoying to carry them around but could understand the need for them.

> *No different really because it's quite small and I can easily fit it in places in my bag – Andy, M12*
>
> *Well, I take it basically everywhere. It's a bit annoying because it's quite big and I can't really fit it in my pocket. I have to take a bag with me everywhere or like fit in my coats now, but obviously I have to – Freya, F15*

Participants who were prescribed an AAI felt calm when they believed that they would not have to use it. However, they believed that their AAI was scary when they thought about having to administer it and many talked about being anxious about needles. Participants who had used their AAI believed it was less scary than those who had not. They were more relaxed, and their attitudes were generally more positive, as their experience showed them that it did not hurt as much as they thought it might.

> *Because I think I feel quite okay about it. I don't think I'm ever going to have to use it – Eric, M11*

> *I’ve never used it before. It was the first time. So, we were scared, like, how do you use it? I thought it that it’s going to hurt so much – Hera, F13*

When Hera recalls the first time that she used her AAI, her beliefs were very different to her beliefs now. She had anxiety about the needle, believed that the AAI would be very painful and was scared and resistant to use the AAI as a result. After using the AAI, she felt that her beliefs were different to reality and her needle anxiety reduced. As a result, she believed she could manage the situation in the future.

> *Yeah, I felt like I was not going to put it in a proper place and then like we didn’t know how to do it… And then once we reached there and I had the EpiPen, I felt like it wasn’t too bad, I could do it again myself – Hera, F13*

This belief that they may not be able to administer the AAI correctly was discussed by other participants who had not used the device. Younger adolescents stated they would prefer an adult administer the AAI instead where possible.

> *I’d rather someone else do it because I wouldn’t be strong enough to jab it into myself – Aria, F11*

The belief of Aria that strength is needed to correctly administer an AAI suggests a lack of understanding of how the devices work. The presence of the needle was thought to make the medication for FA more difficult to manage than other conditions, for example, Hillary reflected that her asthma inhalers were easier to use. Many of the participants had never used an AAI and did not know what to expect. Not knowing what to expect made them more uncomfortable and anxious about the needle and using their AAI, viewing it as scary and strange, even in those who had no issues with other kinds of needles. Andy felt that seeing the needle made him believe that using an AAI would be scarier. He admitted to playing around with his AAI and accidentally setting off the injector and seeing the needle. Since then, he has been more reluctant to use it if he needed to in a reaction. Seeing the needle but not experiencing the injection during a reaction may have had an influence on his beliefs with focus on the needle and potential pain.

> *I'm quite brave with needles but because I've never used it it's scary - Urali, F13*
>
> *Since I saw a huge needle come out of it, it just makes me a bit shivery - Andy, M12*

Hera shared that the AAIs that were used when she was on holiday in India were different. As she believed that the device and needle were bigger, she did not want to use the foreign AAI. This may have shaped her beliefs that the UK AAIs are not as bad by comparison.

> *Yeah, because one thing, the injection was slightly bigger. It was really big and I didn't want to take it – Hera, F13*

While acknowledging that they believed administering the AAI would be painful and unpleasant, participants generally understood that this was necessary to prevent a fatality, especially if their symptoms were more severe. The AAI was therefore believed to be a tool of protection and safety, despite the juxtaposing beliefs related to pain and fear. For these participants, there was a general belief that because it could save their lives, it was worth the hassle of carriage and the unpleasantness of the injection. The added security of having the AAI meant that they felt reassured and had positive attitudes towards it.

> *Kind of scared I need to get stabbed with it at any time but it's not that bad, it keeps me alive – Charlotte, F15*
>
> *Well, I feel safe because I know that if anything does happen, I always have an EpiPen to tackle the problem - Hera, F13*

Some participants believed using the AAI would be fine even though they had not used it before. As Freya was older and her FA was diagnosed when she was young, this may be why she believed she would find the AAI easier to manage.

> *I've never used it, but it seems reasonably simple to use and never had a problem with it – Freya, F15*

When they did not have their AAI, participants felt less safe and believed if they began to have a reaction and did not have their AAI with them, they were not sure what would happen. They were anxious over potential consequences; the term 'paranoid' suggests that Charlotte believes these beliefs are not realistic yet acknowledges the anxiety she would feel.

> *Kind of paranoid and like worried because if I eat something and then I don't have it with me – Charlotte, F15*

Participants believed their peers and friends were apprehensive and did not really understand AAIs and how it felt to have to carry and use one. This belief may be stronger in those that have experienced using an AAI before, such as Hera. However, with the increase in FA, AAIs are becoming more common and this may make them less of a novelty and less scary to peers, as discussed by Kaya below.

> *They do know what it is but they obviously don't know, like, how it is, what it looks like, you know, how sharp the needle is – Hera, F13*
>
> *Because a lot of people know what Epi-pens are. Someone in my class had one and they were just fine with it - Kaya, F12*

The trainer pens helped some participants feel safer and were believed to be useful while others disliked them. The opportunity to practice using the trainer pens with family and friends helped the participants feel that they and the people around them would know how to use the AAI in the event of a reaction. Alice and Aria, on the other hand, felt the trainer pens were uncomfortable due to the faux needle. Alice's guardian worked with her using humour when using the trainer pen, which helped Alice to come to believe that the AAI was less scary.

> *We practiced the EpiPen. We feel safe knowing that everyone knows how to use it – Shazi, F12*
>
> *I had a practice one and they replaced the needle with a really short, like, pointed bit of plastic. So, it's horrible - Aria, F11*

In summary, this theme has considered the challenges of AAI use such as apprehension and anxiety over injecting the needle, and the belief that this is scary. AAI carriage was believed to be inconvenient by males and females due to needing to carry a bag just for the AAI. For those that had used their AAI, they now have a stronger belief that the AAI is less scary and painful than they initially believed, and they felt more capable of using their AAI in the future. While trainer pens were considered useful, the emotional and psychological components of using an AAI were not mentioned in training.

4.3.3. Theme 3: "They're annoying but they're not super life threatening." - How severity of FA symptoms affects beliefs and support

When considering the severity of the symptoms of their FA, participants viewed their symptoms as less severe than others with FA with the same and with different allergens. AAIs were considered a marker of severity among those with FA and their peers. For those that managed their FA with antihistamines, they viewed their FA as far less severe and often took more risks with foods.

> *Yeah, I think they understand because if I show them my EpiPen they're like, "Oh. Yeah."- Selena, F13*
>
> *When I told them, "Oh, I have an EpiPen. I am actually allergic to nuts," they were shocked - Shazi, F12*

Perceived severity also differed in those who were prescribed an AAI. Those who had no history of AAI use, believed their symptoms were not serious and did not view the AAI as something necessary but as something that was there 'just in case' as a backup.

> *I just leave it in the bottom of my school bag to collect dust – Selena, F13*
>
> *I haven't had to use my EpiPen before. It's been more swollen lips and itchy throat where I have to have cetirizine, but it's only that really. I haven't had to use my EpiPen – Shazi, F12*

The participants tended to downplay the severity of their symptoms, believing their symptoms were not as serious as others and that there was a scale for FA severity. Those that only used antihistamines, viewed those with AAIs as having more severe allergies. Those that had an AAI but did not use it, viewed their FA as less serious than those who had used an AAI. Those that did have an AAI which they had used due to an anaphylactic reaction believed if their symptoms were not triggered by contact and airborne food particles, their FA was not severe. This occurred in a range of experienced symptoms including hives and swelling.

> *I think everyone's got a different scale… of allergies. I'm not that severe, but I have a young cousin who can't touch like certain foods because he'll get an allergy – Hillary, F15*
>
> *My allergy really isn't that serious compared to other people because other people go into anaphylactic shock. I'm just like, "Oh, I just have an itchy throat" - Selena, F13*

For the participants that did not believe they were at risk of anaphylaxis, both those who were prescribed an AAI by doctors but had not had a previous severe reaction and those who were not prescribed an AAI, felt their FA was not severe, and they managed their FA reactions with antihistamines. They did not avoid foods as they believed the risk from a reaction was low, so all tried foods they could be allergic to and then treated the reaction when it happened.

> *I only ever have a tiny little bit to see if I'm going to have an allergic reaction, and then if I don't in the next 20 minutes or so, then I will eat it – Shazi, F12*

If the participants considered not at risk of anaphylactic reactions were to experience a severe reaction or find out that their symptoms had become more severe from the doctor, they believed that their behaviour would change as a result with this increased perception of severity, for example Selena (F13) felt that "I would check labels a lot more than I do" – Selena, F13. They believed that they would check labels and ingredients more carefully, avoid foods with their potential allergen and adhere more to FA warnings and carrying their AAI with them. Participants also considered they would feel more worried and annoyed at the higher perceived risk.

> *I'd be a little more worried and annoyed, and I probably would stay clear of the 'may contain' as well, if they got worse - Ella, F11*

The perceived severity of symptoms also seemed to affect beliefs of peers and the social support experienced. Female participants who had an AAI reflected that their female friends were supportive, sometimes to the extent of being seen as too overprotective. Male friends of female participants were less interested in their FA. Shazi's friends had all been shown how to use the trainer pens, which made her feel more confident when she was with them, regardless of the place she was at. For Urali, whose symptoms were believed more severe, she felt comfortable with supportive friends but still preferred the safety associated with family.

> *It's the same everywhere because like my friends all know about it. They know like about why I need an EpiPen – Shazi, F12*
>
> *They know not to give me anything unless they look at it before. So my friends are quite good about my allergy as well – Shazi, F12*
>
> *I don't really mind because I know that my friends understand. But, obviously, family is a bit more close – Urali, F13*

Selena used humour with her friends to manage her beliefs about using the AAI. As she considers her symptoms to be mild and the threat of anaphylaxis to be small, this may be why she uses this coping mechanism. Freddie echoed this sentiment, preferring humour with his friends rather than talking seriously about his FA. He discussed how his friends had thrown an apple at him, knowing he was allergic to it. Other male participants preferred to not talk about their FA, and only two male participants had prior experiences they classed as bullying due to their FA.

> *It's just funny because they argue about who is going to save me when I'm dying – Selena, F13*

> *Taking the piss is the right way to go in my opinion – Freddie, M16*

For Urali and Hera however, they were concerned with how their friends may react if they had to use an AAI as they believed that their friends may be scared to use the needle. As these girls are the same age as Selena, perceived severity and the belief that a reaction needing to be treated with an AAI is more likely, may be a contributing factor to the difference in beliefs.

> *Because it's like an injection to them so, you know, they might be scared – Hera, F13*

Overall, participants agreed that their friends should know about their FA, regardless of the coping strategies and social support implemented thereafter. There was a consensus that friends should be able to identify a reaction and know what to do if one happened, the education a form of protection. However, all participants considered the likelihood of a friend having to support them in a reaction unlikely.

> *Yeah, I don't mind because I kind of want them to know things so that they know. So that if anything does happen, they'll know what to do. Yeah. But they're probably not going to get the opportunity to use the EpiPen on me anyway - Selena, F13*

While the participants tended to downplay the severity of their symptoms when discussing their own FA in comparison to others or discussing them with friends, they highlighted the belief that peers and the wider community did not understand FA severity. While Freddie discussed that FA knowledge can be generalised across allergens, this is without a perceived risk of anaphylaxis. The participants expressed that they believed others did not understand how serious reactions could be, leading to immediate hospitalisation or in extreme cases, death.

> *They think it's just like a tummy ache or a rash or I'll just be sick. It's not I have to be rushed off to hospital – Aria, F11*

The older females in the sample, felt that peer and community beliefs about severity was the area most in need of education. While nut allergies were believed to be more serious, generally participants believed that FA severity and impact were not understood. Further education about different allergens (including the difference between dairy allergy and lactose intolerance), what a reaction looked like and what to do, what an AAI was and how it was used, and challenges they manage such as checking ingredients, were all factors highlighted that would benefit from further awareness.

> *I feel like some people don't know like how severe some of them can be – Naomi, F15*

> *I have had people say, "Why don't you just eat it and use your EpiPen afterwards?" I don't think people understand that it's unpleasant to eat them – Hillary, F15*

> *Yeah, sometimes people forget and they ask me like, because I say dairy, sometimes they ask me if it's lactose, but I'm not lactose intolerant. Sometimes people completely forget and they ask me if I have gluten allergies – Eric, M11*

Managing misconceptions about FA severity was believed to be most difficult on school trips away from home, especially where participants believed the school was not supportive. This belief was discussed by participants who believed their FA was more severe and who had an AAI, while those who were not prescribed an AAI or felt their FA was not severe, did not believe school trips to be as inconvenient. Ashley believed school trips were the worst place to manage FA as she felt very excluded compared to her peers, relying on packed food from home as the catering staff did not accommodate to her FA and the only alternative was a food she did not like. Kaya also highlights that alternative food was made for people who did not like the food served, but not for her with her FA.

> *If they would have, as I said earlier, take out the nuts from the recipes, like make one or two without nuts, and label them, so we could actually fit in a bit more – Ashley, F12*

> *Sometimes it's really annoying because on school trips sometimes... Well, this happened one time. We went to this temple place. Because a lot of people didn't like the Indian food they made fish and chips. But I wasn't even allowed that. So, it was a bit annoying - Kaya, F12*

Managing FA was considered especially difficult on school trips abroad, where if the trip was held somewhere isolated, the participant believed they may not be able to get support and treatment in the event of a reaction.

> *What I am conscious about is because it's in the mountains, if I had a reaction, where is the nearest hospital? I don't know if it'll be… because I've never been to a ski resort. I don't know if they're directly in the mountains or they're like at the side of it so there's roads everywhere – Jack, M13*

This concern about being abroad was reduced when participants were on holiday with their families. Family strategies believed to be effective included learning how to ask about the FA in the relevant language, revisiting places where holidays had been successful before, and looking up food choices beforehand and taking their own food if necessary. Some adolescents were concerned with language barriers and differences in food preparation, but others believed with modern technology language barriers could be managed. This was also seen in Jack's beliefs, where he did not express the anxiety about his safety or managing his FA while on holiday with his family.

> *I'm not nervous because I know that we can just check if something's safe and that hotels are usually good with it so we can eat there if we need – Jack, M13*

> *I'll have to ask about it in a different language, but it's not really that big of a deal – Freya, F15*

> *In Portugal, in the place we go to, there are quite a lot of shops. We go to a self-catering place. Portugal are quite good at doing free-from stuff – Ella, F11*

When considering the future where they may go on holiday alone, the absence of parental support appeared to be the main factor which influenced beliefs about whether holidays were easy or difficult when managing FA.

> *it's going to be quite hard maybe going on holiday without my parents because I won't know what I can and can't... It's going to be a bit of a different... Like, restaurants and stuff like that – Urali, F13*

The only participant who believed family holidays abroad may be a challenge was Hera, who visited family in India. She believed her grandparents were not familiar with FA and this limited understanding of FA made FA management in India more difficult.

> *because it's a new thing to them. They don't know - Hera F13*

Regardless of perceived severity, home was believed to be the easiest place to manage FA. This was due to the perceived security provided by parents and because participants believed they knew what food was available and that food containing their allergen was less likely. Homemade food also strengthened beliefs of safety, even outside of the home.

> *We don't eat nuts, except my sister, at home. So that makes me feel safer – Andy M12*

> *They're always aware of my allergies and it's just… it makes me feel safe when I'm at home really, like I can just trust that they know my allergies and they always try and make me comfortable – Shazi, F12*

> *Just having packed lunch is enough because it's food from home and I know it doesn't have nuts in - Shazi, F12*

However, at home, some participants believed it was more acceptable to engage in risky behaviour such as eating food with an allergen warning label. They believed this was because their parents were there and that if they needed treatment, this could be done quickly.

> *Like at home when I know I'm in a safe place where I like to think help is accessible or whatever, then I'll most likely have it, so I'm safe and if not, then I'll just stay away from it – Freya, F15*

In summary, this theme considers the effect of severity on adolescent beliefs of their condition. AAIs were considered a marker of severity, but participants that had not previously used an AAI felt their allergies were less severe and that their AAIs were unlikely to be needed. For all participants with AAIs, they felt that it was unlikely they would need their friends to support them through a reaction. While adolescents downplayed the severity of their condition in comparison to others with FA and to their friends, they felt that their friends should be aware of their FA. Those with more severe symptoms felt that FA was not understood by peers outside of close friends or the wider community. In relation to place, school trips were believed to be the most difficult for FA management in those who felt their symptoms were more severe, with restricted food choice and concern about treatment. Holidays were believed to be difficult due to language barriers, but these may be addressed through technology, and presence of parents reduced concern. Finally, home was perceived to be the safest place regardless of severity but was also considered the best place to eat foods that may be risky.

4.3.4. Theme 4: "I would like to have been born with it and grown up with it because then I would have understood it more and I wouldn't be so worried." Challenges of recent diagnosis

The participants reflected that they would prefer diagnosis at a younger age as they believed they would be able to adapt to their FA better. Those that had been diagnosed at a young age felt that growing up with the FA allowed it to become a part of life, whereas those that were diagnosed later felt it would be easier if they had known about their diagnosis from a young age.

The participants in this study included an under-researched sample of six adolescents who had been recently diagnosed within the last year, all above 10 years of age. These participants felt that they had less experience with FA and generally expressed a preference for younger diagnosis for better management, however felt that they had learned to manage their FA since diagnosis.

Since I've only been diagnosed for a year or so, I haven't really had that much experience with it – Jack, M13

If I was born with it, I would just get used to it over time. But I think I'm used to it now – Jack, M13

Alice, who was diagnosed at age 8, supports this as she felt she would be less careful if she found out about her diagnosis recently.

If I found out this year, then I don't think I'd be as careful because I'd just found out – Alice, F12

For those who were diagnosed later in life, they and their peers found their diagnosis surprising and found it difficult to understand. However, they all felt that they were able to manage their FA. This was especially true of less severe reactions, where participants did not know their symptoms were because of FA.

People are sometimes surprised because I only realised last year or however long ago. People I've known for quite a while, if I see them again and I'll be like, "Has that got nuts in it?" I'm like, "Oh yeah. I've got a nut allergy." They're like, "Since when?" - Selena, F13

But when the tummy ache came, I didn't know, so I was quite shocked as well when I found out it was an allergic reaction – Shazi, F12

Selena considered that it may be difficult to be diagnosed very young as this is the age where children are trying many new foods. However, she also reflected that if she had been diagnosed earlier, she believed she would have experienced fewer allergic reactions.

It would probably be harder because you're trying a lot of new foods between the ages of three plus - Selena, F13

Because if I'd have found out when I was three then I wouldn't have had all those allergic reactions. I've had three. Probably like three until I told mum - Selena, F13

For Freddie who experienced reactions to mainly fruits, his family were reluctant to believe he was experiencing symptoms of FA and Freddie believed that they thought he just did not want to eat fruit due to his age. This suggests that allergens that are less known about by the public are more likely to be diagnosed late.

> *My grandad in particular was for like the longest time "you don't have an allergy, I don't believe you" and he was like "get it tested" – Freddie, M16*

Shazi who was diagnosed when she was eight, felt that there would not be much difference in finding out age eight versus if she found out the previous year. This suggests that finding out very young compared to in adolescence may be believed to be different to finding out just a few years prior. However, she did believe that she would have more of an understanding of a diagnosis at 11 years of age, which may be a positive factor of late diagnosis.

> *I'd still be old enough to know about it properly. I'd understand it, but yeah, I wouldn't really change, like because I'd only eat when I found out about it, it was like I got it, but I didn't get it that well. But I'd only be 11 if I found out last year, so I think I would get it more than I did when I was eight – Shazi, F12*

Selena was also happy once she got her diagnosis as it meant she understood what was going on with her FA and was then able to manage it. The diagnosis, though late, gave her autonomy and she viewed it as a positive experience.

> *Yeah, I was quite... I felt kind of happy that I knew I had an allergy and I knew I was safe and I had an EpiPen – Selena, F13*

All participants with a late diagnosis had nuts as their allergen. As such, they felt that the nuts were easy to remove from their diet and they believed managing their FA did not affect their eating behaviour much. Not liking the allergen made for an easier transition to excluding the food.

> *I think that nuts are pretty easy for me to stay away from because, as I said, I'm not adventurous with my foods. Before I realised I had a nut allergy I didn't really like nuts anyway – Selena, F13*

For the participants who were diagnosed at a young age in childhood, they showed a strong preference for their early diagnosis. They believed this helped them adapt to their FA management as they grew up. They felt that if they had been given a diagnosis later in life, they would be more concerned with use and carriage of AAIs and would not be as thorough with checking food labels. Furthermore, they also considered that they may miss foods that they were suddenly unable to eat.

> *As I did it from a young age, I got used to the dairy and egg-free stuff really quickly. I'd probably feel like I was missing out on a lot more if I'd had this stuff before that had dairy and egg in – Ella, F11*
>
> *I think I wouldn't be comfortable carrying my medicine. I think I'd rely more on my parents. I think I'd forget to check things … so I think it's better I had it as a child, so that I could get used to it, and I think if I had it a year ago, I'd also miss out on a few things as well because I could eat them as a child and I couldn't now, I'd feel a bit more annoyed - Hillary – F15*

In summary, later diagnosis was believed to be more challenging than finding out about FA diagnosis in early childhood by all participants. It was believed to be easier when growing up with FA as management becomes part of life as they become used to adherence of AAI carriage and label checking as routine. Participants who had been diagnosed as an adolescent all had allergens to nuts and felt the impact of their FA to be small as they already did not like nuts and believed they could be easily avoided.

4.4. Discussion

This study explored the beliefs about FA in adolescents who had themselves been diagnosed with a FA. The thematic analysis of the interview data led to the development of four themes: 1) "I think everyone would take it more seriously." - Nut allergies as more serious than other FA, 2) "I don't like talking about the needle, it just scares me." – Adrenaline auto-injectors and needle anxiety*,* 3) "They're annoying, don't get me wrong, but they're not super life threatening." - How severity of FA symptoms affects beliefs, and 4) "I would like to have been born with it and grown up with it because then I would have understood it more and I wouldn't be so worried." Challenges of recent diagnosis. The majority of these themes describe beliefs that were either not seen in studies from the previous systematic review (Chapter 3) or not considered in depth. The different beliefs surrounding nut allergies compared to other food allergens suggested that adolescents with FA consider nuts the most serious of allergens, with multiple nut allergens even more severe. FA severity affected beliefs and behaviour as adolescents who viewed themselves with less severe symptoms took more risks. This included adolescents both with and without prescribed AAIs and was also prevalent in those with late diagnoses.

Age of diagnosis also seemed to be important in relation to beliefs about FA, with six adolescents of the sample being diagnosed within a year of the interviews. These adolescents believed being diagnosed younger would be easier than finding out later in life, perhaps as this was a point in life when they had a more external locus of control as they relied on parents, and so it may have been easier to transition into their FA with this support while they were developing their own self-efficacy, independence and a more internal locus of control. However, as all adolescent diagnoses had nut allergies, they found it easier to adapt their diet as they already disliked their allergen.

The first theme considered multiple nut allergies as the most serious of allergens to react to. This may be due to more awareness of nut allergies as participants felt peers and the community had heard of nut allergies more than any other, and so may be better equipped to identify and support those with an FA to nuts. Risk of reactions was not considered an issue by the majority of participants either because their reactions were considered mild or because adolescents felt confident in managing their allergies, suggesting high self-sefficacy. Severe anxiety or feelings of 'life and death' (Stjerna, 2015; DunnGalvin et al., 2009; Marklund et al., 2007; MacKenzie et al., 2010; Fenton et al., 2011) were not apparent in this sample and beliefs expressed by the participants were more in line with Akeson et al.'s (2007) findings of FA not being 'a big deal', and having a more relaxed view of their condition (MacKenzie et al., 2010, Gallagher et al., 2011, Akeson et al., 2007). Applying this to models such as the HBM, this means that viewing their FA as less severe, may lead to less health promoting behaviour. For those who were concerned, this was mostly due to a more recent diagnosis, which is an interesting factor that has not been considered in detail by previous research. This may be due to their susceptibility being challenged, influencing them to consider the condition and their health behaviour more seriously. If applied instead to the CS-SRM, this is more in line with the consequences component, of which trying potentially risky foods was considered to have minor consequences by the majority of participants. In terms of risk due to labelling, the adolescents supported findings of previous research (Monks et al., 2010) in that they did not view the 'may contain' labels as particularly accurate, especially in the case of nut warnings.

The participants in this study did not focus too much on whether their FA was a part of them, thinking about it only if they were likely to come into contact with their allergen. A minority even saw their FA diagnosis in a positive light as they then knew how to keep themselves safe and what to do to avoid symptoms. A key finding in this theme, supported by findings in the systematic review in Chapter 3, was the belief that their symptoms could be worse, and there is a hierarchy of severity for FA, where multiple nut allergies were seen as more severe and then contact and airborne allergies as the most severe.

The second theme supports and expands upon previous findings regarding beliefs about using the AAI and fear of needles (Monks et al., 2010; Macadam et al., 2012). There were varying levels of concern dependent on whether the AAI had been used before or not; some participants believed that not knowing was scary, whereas others felt that ignorance is bliss. The participant who was playing with their AAI and then saw the needle emerge was an interesting juxtaposition of both as they now knew more about the needle and how it worked which changed their beliefs, but not how it would actually feel when used correctly. A recent study by Leach, Smith, Brown, Davies & Jones (2018) suggests that young people aged 13-18 years were conscious about the following factors in AAIs: safety, speed of administration, accessibility and carriage, comprehensive instructions, indication of correct administration, visibility and precise drug delivery. AAI size and needle phobia were also important in this sample, mirroring the beliefs expressed by some of the adolescents in this empirical study.

Overall, adolescents in this study supported the belief that AAI carriage was annoying due to the size of the device (MacKenzie et al., 2010; Gallagher et al., 2011), as found in the systematic review (Chapter 3). Main frustrations related to inconvenience of carriage (MacKenzie et al., 2010; Gallagher et al., 2011) and having to take a large bag out with them where they did not believe it was necessary. Others who did carry an AAI were content with leaving it in their bag or with an adult if they had a more external locus of control. There were also similarities expressed regarding concerns about using an AAI correctly (Gallagher et al., 2011; Saleh-Langenberg et al., 2016; Macadam et al., 2012) where participants were reluctant to use their AAIs (Stensgaard et al. 2017), suggesting low self-efficacy in AAI administration. Discrete carriage and the contrast of a device being recognisable have been a source of conflict in previous research (Leach et al., 2018), however these participants were more concerned with inconvenience rather than discretion.

In previous research, Sampson et al. (2006) reported that 54% of their sample aged between 13 and 21 years purposely ate potentially unsafe food while 29% did not always carry their AAI. Trying unsafe foods due to perceptions of FA severity was also found in participants in the present study. Although most did report that they generally carried their AAI with them. Contrary to the findings of the systematic review, this study did not find that males were more affected by AAI carriage challenges and females also believed that that the AAI was big, bulky and inconvenient. Other adolescents in this study, both males and females, felt that the AAI was small enough to be easy to carry.

Those who had previously used an AAI were more positive and expressed less fear than adolescents who had not. Therefore, it is apparent that past experience shapes beliefs and these adolescents were able to more accurately judge the level of pain from administering an AAI and felt more capable to use it themselves, demonstrating higher self-efficacy and locus of control, compared to the participants who had not previously experienced using their AAIs. From a behavioural perspective, a graded exposure technique may be beneficial in allergy clinics, where a tester AAI with a real needle may reduce the fear of administration. Graded exposure therapy for needle anxiety is recommended in person where possible (McMurtry et al., 2015; McMurtry et al., 2016) and that this technique may lead to better healthcare compliance. An allergy clinic with a nurse (Orenius et al., 2018) or psychologist to support may be most beneficial for this approach. Focusing on the emotional and psychological aspect of AAI training, including perception of pain from the needle, as well as providing training pens for physical practice, may be useful in clinic, with a graded exposure approach to address beliefs that AAIs are very scary and painful.

AAIs were highlighted as a marker of severity both in adolescents with FA and their peers. Peers recognising the AAI as a sign of a serious FA has not been seen in previous literature considered in the introduction or systematic review. Contrary to findings in the male diabetic sample in Helgeson et al.'s study (2007), the male participants in this study were less interested in social support and preferred to not discuss their FA with their friends or chose to adopt a more teasing relationship.

Interestingly, while peer support was mostly appreciated in females in this study, suggesting support for the previous notion that supportive female friends may reduce risk-taking (Warren et al., 2016), for males in this study, they either preferred to not talk about it or use 'banter' as a coping mechanism. The idea of teasing was a new consideration and sees interaction that was previously considered only negatively in a new light, with previous research considering teasing from classmates as 'mean-spirited' (Dean et al., 2016). Furthermore, a desire to not draw attention was emphasised by some of the adolescents which has been reported in past research with adolescents preferring to confide only in close friends (DunnGalvin et al., 2009). This is supported by research by Stjerna (2015) which found adolescents were frustrated by a focus on limitations of their condition or identifying them as different.

In this sample, parental beliefs were not considered to have an impact on the participants own beliefs. This may be due to a good relationship with their parents in this sample, a reluctance to discuss the topic in the family home where the parents may overhear, or a lack of insight that their beliefs may be shaped by their parents’. Also contrary to previous research, (e.g. Stjerna, 2015; Macadam et al., 2012; Akeson et al., 2007; Sommer et al., 2014) this may reflect the newer generation of adolescents becoming more independent with the support of technology and this should be explored in more depth to see how it might be integrated into interventions.

This study uniquely identified six adolescents who had been diagnosed within a year of being interviewed, all when they were over the age of 10. Five further adolescents were diagnosed much earlier but over the age of 5 years. Participants diagnosed at an older age expressed that they wished they had found out about their FA at a younger age as they believed it would be easier to manage and that previous reactions may have potentially been avoided. DunnGalvin et al. (2009) suggested that up to the age of 8 years children tend to rely on parents but after this age they become more aware of the difficulties of managing FA and can report greater anxiety. DunnGalvin et al. (2009) also found that the shift at age 8 encompasses a shift in identity in relation to their condition, from different in a ‘special’ way to becoming sceptical and beginning to directly compare to others. Having a diagnosis of FA at a much older age and how beliefs about this impact upon management needs further investigation.

Later diagnosis was also considered to be more difficult if you had to stop eating foods you were previously able to eat and enjoy. One of the participants diagnosed at an early age to egg and milk believed that it was easy to adapt to alternatives such as egg-less cakes as she had experienced this from a young age. All participants with a late diagnosis had developed a nut FA and thus viewed the impact on their lives to be low through excluding a food they already did not like. It may be interesting to see if beliefs are different in adolescents diagnosed with other allergens, however this may be rare.

4.5. Strengths

This study included a sample size of 20 participants, which resulted in good saturation of data. The majority of participants spoke for around one hour in their interviews, providing rich data, which can sometimes be challenging in an adolescent sample. Participants also had a variety of symptoms, allergens, and ages of diagnosis, providing interesting insight not previously considered in this area of research. Further research could explore beliefs in these less represented groups to increase research diversity.

4.6. Limitations

As can be common with psychological research, the sample featured a majority of female participants. Furthermore, although the average spread of participant ages was balanced, ages 14 and 16 only featured one participant whereas the younger age group (11-12 years) had more representatives. Further research could explore these less reported demographics in more detail to increase research diversity. The interview schedule was developed only from the systematic review findings and not with input from the demographic of adolescents aged 11-16 years with a diagnosed FA. The inclusion of input from adolescents with FA may have strengthened the interview schedule to include questions of importance that did not emerge from the systematic review.

4.7. Implications

This study identified that demographics and perceived severity may influence FA beliefs. Participants with an adolescent diagnosis expressed more anxious beliefs regarding FA management and the risk of reactions, such as Jack when he considers management on a school trip abroad. Participants who were not prescribed an AAI or believed they were not at risk of anaphylaxis were more likely to engage in risky behaviour such as eating food with allergen warning labels. Peer relationships were especially important to female participants, who valued supportive friendships and felt safer when their friends knew what to do in a reaction. For males, they preferred not to discuss their FA with friends or use banter as a coping mechanism. Graded exposure may be a beneficial therapy technique for adolescents who are afraid to administer their AAIs by addressing the fearful beliefs associated with them.

4.8. Recommendations for future research

This data presented interesting findings, particularly where beliefs differ between age of diagnosis and the different experiences based on what foods the adolescents were allergic to. Further research into the effects of various symptoms, allergens and ages of diagnosis on beliefs of adolescents with FA may be beneficial. Furthermore, although already considered a time of transition, beliefs of adolescents of different ages and genders could be further explored. While the systematic review included studies with participants sampled in different countries, there is currently not known to be research comparing cultural differences in FA beliefs which warrants further investigation. There were also interesting responses from those who did not consider themselves at risk of anaphylaxis, where beliefs about risk were very different and that FA should be treated when necessary, rather than avoiding foods they are allergic to.

4.9. Conclusion

Adolescents with FA showed varying beliefs dependent on age, gender, allergen allergic to, severity of FA and age of diagnosis. Concerns around AAIs and dismissal of allergen labels support previous research, while beliefs around different allergens and differences in beliefs dependent on age of diagnosis warrant further investigation.

Similar to findings in the systematic review (Chapter 3), lack of education and understanding by peers and the wider community (Fenton et al., 2011; DunnGalvin et al., 2009; Stjerna, 2015; MacKenzie et al., 2010; Marklund et al., 2007) was considered the biggest barrier to FA management. All adolescents felt that further education would be beneficial, whether this was about different allergens, what a reaction looked like and what to do, what an AAI was and how it was used, and challenges they manage such as checking ingredients. In Sampson et al.'s (2006) study, the desire for peer education was highlighted but was difficult for adolescents to deliver themselves and so a third party such as a school nurse was recommended. It was thought that this might improve issues such as teasing, bullying and general safety. As adolescents with FA identify the importance of support from peers and as peers can be influential in influencing behaviour, particularly risk-taking behaviour, it is important to understand their beliefs regarding FA. No published study has explored this before and so the study reported in the next chapter aims to explore beliefs regarding FA in adolescents without FA.

Chapter 5: An exploration of beliefs towards food allergy in adolescents aged 11-16 years with no clinical history of food allergy

This chapter explores the beliefs about FA of adolescent peers aged 11-16 years who do not have FA. Previous research has highlighted peer beliefs as important in adolescence, both in regard to FA and in general, but has not directly explored the beliefs of these peers.

5.1. Introduction

Adolescents with FA may be influenced by peers, with some suggesting that they consume their allergens due to peer pressure (Sampson et al., 2006). In Sampson et al.'s (2006) study, the desire for peer education was highlighted by the participants and was believed to improve issues such as teasing, bullying and general safety, but was difficult for adolescents to deliver themselves. The sensitivity of social relationships and personal development in the adolescent period can have a negative impact on quality of life (Morou et al., 2014; Cummings et al., 2010; Marklund et al., 2004) as events including visiting friend's houses, sleepovers, parties, field trips, and also family social events are more difficult for those with FA (Bollinger et al., 2006).

Sommer et al. (2014) is the only known paper to compare adolescents with and without FA in relation to food choice. The main difference between the groups was that adolescents with FA found parental control protective, while those without FA felt the opposite and looked forward to their independence when making food choices. Interestingly, participants without FA in this study did not think it would be difficult to find safe food at a party. The groups also showed slight differences in knowledge about food such as healthy eating conveyed by the mass media.

A quantitative study by Valentine and Knibb (2011) also explored differences in QoL between families with a child aged 8-12 years with FA, and families who did not have a child with FA. While the parents of a child with FA had significantly lower QoL, in this sample, children with FA had similar or higher QoL than controls. This may support the suggestion by DunnGalvin et al. (2009) that there is a shift at approximately 12 years of age where adolescents experience more stress while increasing their autonomy.

In the systematic review (Chapter 3), peers are considered in detail, especially under the fourth theme 'behaviour and understanding of others' which highlighted how lack of knowledge about FA can make relationships difficult. Concerns about being left out from experiences such as eating out at restaurants with friends and school trips were difficult for adolescents with FA as they were treated differently from their peers (Stensgaard et al., 2017; Dean et al., 2016). Adolescents found both feeling excluded and being treated specially as difficult, whether this was being unable to attend camping trips or having special measures put in place to preserve safety. Adolescents also internalised fears of burdening their peers with their FA, worrying they may also be excluded due to forcing others to adapt and restricting their peers' food choices (Stjerna, 2015).

Issues such as discrimination and their classmates being mean-spirited (Dean et al., 2016) and frustration that peers tended to focus on the limitations of their FA and identifying them as different (Sterjna, 2015) were highlighted. Some adolescents also experienced bullying, from verbal threats to having their allergens thrown at them (Stensgaard et al., 2017; Fenton et al., 2013). This is especially dangerous due to the serious nature of FA. The tragic fatality of a thirteen-year-old in London an example of the dangers of bullying, where allegedly cheese was placed down the boy's shirt, triggering anaphylaxis (Davies, 2018).

To avoid being excluded, some adolescents purposely did not tell their peers about their FA as they felt they would not understand, only confiding in close friends (DunnGalvin et al., 2009). Classmates in particular were highlighted as needing more education and information to increase understanding (Monks et al., 2010). Lack of understanding around AAIs from peers also reduced the likelihood of carrying them due to embarrassment, feeling different or frustration at having to explain about the AAI (Gallagher et al., 2011). Reluctance to carry an AAI is an issue as an AAI is the only treatment for anaphylaxis and is essential in the event of a serious reaction and so it is recommended to be carried at all times. The lack of education and awareness of others was believed to be the greatest barrier to adolescents with FA being understood, accepted, and becoming independent (Fenton et al., 2011), an essential component to not only development into adulthood but to good mental health.

Adolescents with FA compared themselves to their classmates and peers of the same age and highlighted how they felt they were different from their peers. Risks such as reluctance to carry an AAI (Gallagher et al., 2011) or eating foods labelled with the adolescent's allergens in order to fit in (Fenton et al., 2013) were worrying findings from the systematic review (Chapter 3), emphasising the importance of the effect of peers in adolescent beliefs and behaviours. Addressing the beliefs of peers through education could improve the beliefs and behaviours of the individuals with FA and therefore reduce risky behaviour. Participants from studies included in the systematic review (Chapter 3) also considered knowledge of FA in adults such as family members and school staff and how this could also be improved, suggesting that educating the wider community beyond immediate peers is also important. Furthermore, peers and friends of adolescents with FA may provide protective support and be able to reduce risk-taking behaviour, or administer medication in the event of a reaction, as previously seen in Elise Hubbard, who was saved by her friend Laura using an AAI and contacting Elise's mother and emergency services (Abi, 2018).

5.1.1. Views from the qualitative study of adolescents with FA

Further to the systematic review findings, the thematic analysis of adolescents with FA (Chapter 4) also found that peers were important in supporting those with FA. Participants felt supported by their friends when they wanted to be supported or were happy to not talk about their FA. However, they did believe that knowledge of FA as a condition and understanding of severity could be improved. Participants reported a lack of understanding of peers in the transition to secondary school. Some remarked that they felt excluded at times, reflecting concerns raised in previous research discussed in the systematic review (Chapter 3). Further to exclusion from peers, school staff were believed not to understand FA and to lead to exclusion in events such as school trips.

Male participants especially discussed that they would prefer not to have added attention due to their allergies and preferred making light of the situation, refusing to speak about their condition or using 'banter'. Teasing had not been considered in a positive light in previous research, suggesting that it depends on the nature of the teasing and whether it is wanted and seen as something helpful or something that is negative and perceived as bullying. Some female participants preferred that their friends were aware of their condition but otherwise treated them as normal.

Support can differ depending on the gender of the adolescent. Male friends of female participants were also seen as less interested than their female friends, and this can be important as Warren et al.'s (2016) work showed that only supportive female friends reduced risk-taking behaviour. In Chapter 4 it was seen that female friends took the situation more seriously, sometimes to the point of being considered overprotective. Some female participants were also worried that their friends would feel anxious or scared if they were to use an AAI or if they had a reaction, whereas other participants had friends arguing over who would get to 'save' them, or 'stab them' with the needle. These peer gender differences were not found in the papers included in the systematic review (Chapter 3), suggesting a gap in research that needs to be further explored.

Overall, participants in Chapter 4 reported being happy with their social peer relationships and the way their FA was managed among them with limited negative experiences. Only two male participants recalled a sole instance of bullying, but the majority found only general misunderstanding in some peers. For some, a coping strategy of ‘banter’ with light-hearted teasing was preferred rather than dwelling on the FA or having extra attention due to their condition. This was of coping with their FA with their peers has not been seen in previous research.

As peer beliefs are important in adolescence and may have an impact on beliefs behaviour of adolescents with FA, this study aimed to explore beliefs of adolescents without a diagnosis of FA. Combined with the findings in Chapter 4, this should give a clearer indication of how best to support adolescents with FA and their peers.

5.1.2. Rationale

The results of the systematic review (Chapter 3) and the thematic analysis of adolescents with FA (Chapter 4) have shown that adolescents feel that the beliefs and understanding of their peers is important in helping them manage their FA and not feel different. They also feel that education of their peers is important, and management would be easier if they had help and understanding from their friends and classmates. Therefore, this study aimed to conduct interviews with adolescents without a diagnosed FA in order to explore their beliefs and understanding of this condition directly rather than secondarily as interpreted by adolescents with FA, to gain clearer understanding of peer beliefs.

5.2. Method

5.2.1. Study design

This was a qualitative study, using semi-structured interviews. Ethical approval was granted by Aston University’s School of Life and Health Sciences Research Ethics Committee (ID: 1039, 26/1/2017) and can be found in Appendix 3.1 and the amendment may be found in Appendix 3.2.

5.2.2. Study setting

Semi-structured interviews were conducted with adolescents aged 11-16 years, who were living in the East or West Midlands, UK, either via phone call (n = 8), face-to-face at Aston University (n = 7), or via Skype video call (n = 1) depending on the participant and their parents or guardians' preferences.

5.2.3. Participants

Sixteen adolescents aged 11-16 years from the Midlands, UK, participated in this study. Across this study were eleven females and five males. Participant demographics may be found below in Table 12.

Table 12: Participant demographics of the sample without FA

Participant	Pseudonym	Gender	Age
1	Mandeep	Male	11
2	Niraj	Male	14
3	Callie	Female	11
4	Keeley	Female	11
5	Dora	Female	15
6	Kirsty	Female	11
7	Paul	Male	14
8	Leona	Female	12
9	Kerry	Female	15
10	Ethan	Male	13
11	Lizzie	Female	14
12	Lyra	Female	15
13	Nala	Female	16
14	Juhi	Female	11
15	Jasal	Male	15
16	Aliyah	Female	13

The mean age of participants was 13.1, SD = 1.7 (age range = 11 to 16 years). Of these, two were recruited from schools and 14 were recruited via social media from Facebook, Twitter, and Aston University's staff newsletter 'Aspects'. Participants were included only if they had no current diagnosis or personal history of FA. Participants who had outgrown FA previously or had a potential FA, whether this was previously diagnosed, suspected, or unsure if an intolerance, were to be removed from the study, however no participants met these criteria. All participants knew someone with FA whether this was a classmate or close friend, and Kirsty had a younger brother with a diagnosed FA. Participant characteristics can be seen in Table 12. All names are pseudonyms.

5.2.4. Data collection

Semi-structured qualitative interviews were used to collect data. Interviews were undertaken because of their flexibility in allowing the participant to contribute to the research agenda (Pope et al., 2002). The interviews explored participant beliefs about FA as a condition and how it may affect those who have the condition. Throughout the interview, participants were also invited to think of themselves in situations where food was present and to think about what it would be like if they had a FA. The interview schedule (Appendix 3.9) was developed as a topic guide and was based on findings from previous research of adolescents with FA discussed in the systematic review (Chapter 3). If the participants were unsure of a term, for example 'anaphylaxis' or 'adrenaline auto-injector', a brief explanation was given of the term before continuing. If interviews were not conducted in person, consent forms were posted out, signed and returned by post, or scanned and emailed back.

5.2.5. Procedure

Schools in the East and West Midlands, UK, were asked if they would be willing to advertise the study through a letter to students' parents (Appendix 3.2). The study was advertised in three consenting schools and online via social media channels Twitter and Facebook (Appendix 3.3). Interested participants (or their parent/guardian) were invited to contact the researcher via email. Following email contact, participants and parents or guardians were provided with parent and adolescent versions of information sheets (Appendix 3.4 and 3.5), consent forms (Appendix 3.6 and 3.7) and demographics forms (Appendix 3.8). Information sheets and consent forms highlighted participants' ethical rights such as the need for informed consent and the right to withdraw, and also explained the procedure of the study.

Upon return of consent forms from both parent and adolescent, participant interviews were arranged based on individual participant availability.

Prior to the interview starting, participants were reminded of their ethical rights such as the confidentiality of their data and their right to withdraw before the interview and invited to ask questions. They were also asked to confirm verbally that they consented to take part in the interview and were happy for it to be audio taped. Participants were asked questions from the semi-structured interview schedule (Appendix 3.9), which was used flexibly and adapted to fit the participant's answers. Upon completion of the interview, participants were thanked, debriefed and received a £10 Love to Shop or book voucher for their time.

5.3. Data analysis

Following data collection, data was transcribed verbatim to prepare for analysis. Data was then analysed according to Braun and Clarke's (2008) six-phase approach; familiarisation, initial coding, searching for themes, reviewing themes, defining and labelling themes and producing the report. Observed themes of interest were clustered together and developed into overarching themes aiming to capture significant data for further analysis. Interpretation of themes involved further re-reading, mind-maps and theme tables to attempt an accurate reflection of the interviewed participants. Initial analysis and initial themes were developed and then discussed with the supervisory team. Themes were then revised until a consensus was agreed that the themes were an accurate reflection of the data.

5.4. Results

Through thematic analysis of the data, four overarching themes were constructed: 1) "I'd feel very worried and scared that I could have an allergic reaction anytime": Peer perceptions of living with FA; 2) "Probably stick to places I know": The burden of managing FA in safe and risky places; 3) "Think about how they would feel": Personal responsibility and supporting people with FA; and 4) "I think that other people should be aware about how bad they can be": Educating others to increase understanding.

5.4.1. Theme 1: "I'd feel very worried and scared that I could have an allergic reaction anytime": Peer perceptions of living with FA

This theme explores the beliefs of living with FA from adolescents with no clinical history of FA. Participants considered the challenges of living with FA and thought about how they would feel in these situations and how they would manage them. Participants were concerned about AAIs, reactions, and the potential of anaphylaxis. They felt that they did not have enough information about these topics and thought they would be stressful. In particular, having to use an AAI was considered to be scary. However, some participants had a more confident outlook, predicting that they would be fine in managing FA by following simple rules such as just ‘not eating it’. Often these participants had previous experience with a friend or sibling having FA or had experience of avoiding foods due to other reasons such as being vegan.

The threat of having a potential reaction at any time and the belief that daily routines would be very different concerned some participants as they believed this would be difficult to deal with.

> *If I had to react to food, I’d feel very worried and scared that I could have an allergic reaction anytime – Mandeep, M11*
>
> *Not particularly scared just a bit like upset because milk is in quite a lot of things and you have to kind of like change your routine and everything would be different – Keeley, F11*

These quotes illustrate that the participants understand that living with FA means that life is different and involves more conscious thought about food choices and risks. The participants believed that reactions would be scary and felt that they would be worried about having a reaction at any time, especially an anaphylactic reaction. When they thought about having to remove a food from their diet, some participants thought this would be fine due to alternatives (e.g. dairy free) and the increase of selective diets (e.g. vegan) whereas others felt unhappy at having to change their routine to having to check foods and manage these risks.

Participants were also very unsure of AAIs, feeling scared of using the needle where people could see and instead stating that they would rather use it somewhere that was private.

> *Probably a bit embarrassed and like keep it in my bag all the time and I’d probably only use it um in like a private place – Keeley, F11*
>
> *Don’t know, scared that like something’s going to happen and you’re just stuck stabbing yourself with a needle – Callie, F11*

This view of AAIs may lead to difficulties in managing a reaction properly. Participants believed that they would not know what to do, whether it was themselves or someone they knew having a reaction, and this made them feel helpless. There was concern about the use of a needle which made the participants feel uncomfortable, seeing the AAI as something scary and something that they did not want to use unless they absolutely had to. They also believed they would want to avoid causing a scene so stated they would try their best to be discrete with AAIs and in the event of a reaction, some said that they would rather take themselves somewhere more private. They also believed that those having a reaction would want space and privacy rather than everyone observing and desired to be supportive of this.

Outside of AAIs and reactions, the participants believed that having FA would not affect their lives too much and remarked they would want to continue on with as normal a life as possible.

> *Wouldn't really bother me, I'd just think "oh, they've just got food which I could have at home, just nicer than whatever they've got" – Kirsty, F11*

As FA is a condition where symptoms are only present in the event of interaction with an allergen, it was believed that having a normal life would be manageable as they would not generally appear or behave differently to others and would still be able to take part in social and academic activities. It was also believed that with the increase of allergen-free options, it would be easier to adapt by buying alternatives or bringing food from home.

However, it was sometimes difficult for participants to imagine life with FA when they had not experienced it themselves, especially when they were discussing a food that they really enjoyed. In scenarios where the adolescent considered not being able to consume their favourite food, they found this hard to accept.

> *When I found out my friend had nut allergy, I was just like, "what about Nutella?!" because I love Nutella and I couldn't imagine life without it because it tastes so good – Leona, F12*

Participants believed that allergen-free options were important for giving more choice to those with FA.

> *They [allergy-free options] should be available everywhere because they are still people at the end of the day and they need feeding as well – Lyra, F15*

While it was acknowledged that there was more choice, and supermarkets and cafes were catering more for people with FA, it was believed that these options should be more widely available as it was not detrimental to those without FA but important for those with FA.

Overall, participants felt that some aspects of having FA would be difficult to manage and believed that AAIs and the potential for reactions were scary. However, this may be due to the lack of understanding surrounding these, as participants were concerned that they would not know what to do if a reaction or the need to use an AAI occurred. However, it was widely believed that having FA would not deter from having a normal life and could be managed by buying alternatives or bringing food from home. The food restrictions were seen to be difficult, especially for favoured treats but allergen-free options were regarded positively.

5.4.2. Theme 2: "Probably stick to places I know": *The burden of managing FA in safe and risky places*

Participants considered various scenarios and places that may be challenging for those with FA and thought about how the person with FA would feel, and also how they themselves would feel in these situations. Participants considered how it would feel to eat outside of the home in different settings with the need to check menus and ingredients and felt that it would be necessary but frustrating. They believed that the family home would be much more comfortable with the support of parents and the familiarity of knowing what food was in the house. In contrast, being on holiday was perceived to be difficult with challenges such as language barriers, unfamiliar dishes, and different cultures, mirroring beliefs of those with FA found both in the systematic review (Chapter 3) and in the interviews with participants with FA (Chapter 4).

Home was considered the safest place, whereas increased distance from home was perceived to have increased risk.

> *I think they feel much safer because they're used to being at home so they know what they can do and can't do – Nala, F16*

When thinking about the home environment, all participants all believed that they would feel safe and secure in the family home with their parents checking the ingredients and making sure their food was safe. They would know what food they could eat and have familiar brands that they knew were likely to be safe. They believed that the risk of a reaction was far lower at home and there was a feeling of having more control.

With eating outside of the home, planning ahead was considered important when eating locally as it reduced the likelihood of being unable to eat at the chosen place. It was also believed that as these places were known to be safe, there was less chance of having a reaction and being judged by others. Therefore, they preferred the idea of going to places they were familiar with which were considered safer.

> *I'd hope that nobody would like judge me for it but then a bit I'd just be I'd probably like stick to places I know where they wouldn't have nuts – Leona, F12*

Alternative menus (e.g. gluten free) when eating outside of the home and in new places were perceived positively as they allowed people to make a choice about whether the food was suitable and take control of what they eat and the associated risks. They believed this would help them to consider where was safe to eat if they had FA.

> *They're good because people who do want to eat it and they might have an allergy, they have to, they can just look at that and think "do I risk it or don't I risk it?" – Kirsty, F11*

However, while the participants explained that they saw symbols on certain menus which related to the ingredients (e.g. gluten free, nut free, vegetarian or vegan) which may help manage eating outside of the home, they explained that these symbols were discrete, so this was not always obvious and may be missed. Therefore, it was felt that while there were options, there was room for improvement.

Checking menus and labels was seen as something that would be a nuisance as this would result in taking longer to order and therefore longer to get their food. The pressure of having to check ingredients in foods was thought to be frustrating as ingredients were not always clear. 'May contain' labels were judged especially harshly as participants believed that they should be more precise, especially in the case of nut warning labels. The lack of clarity on labelling could result in increased risk when eating outside of the home.

> *I find them annoying because they should either contain nuts or they shouldn't contain nuts – Lyra, F15*

> *If I had one, I would be quite annoyed 'cause you have to check the wrapper and then if your friends- your friends won't go out to eat it in case you have a reaction to it as well – Kerry, F15*

The participants believed that companies were negligent for not being more secure in their food processes and should clarify in ‘may contain ‘labels whether the contamination could have occurred in the production or if the allergen was present in another part of the company altogether. They believed companies were only concerned with avoiding lawsuits and were not as concerned with their consumers. Some of the participants explained that the uncertainty of the presence of allergens would make them more likely to try a bit of the food to see what happened and eat the rest if they did not experience a reaction.

Outside of the home, holidays abroad were believed to be the most challenging places with different customs and potential language barriers in both speech and labelling. They considered that some places would be particularly unsafe, such as seaside towns if you had an allergy to fish, or Asia, as nuts were common in traditional Asian dishes. All-inclusive and catered holidays were also thought to be very difficult for adolescents with FA to manage and a situation that the participants felt they would find difficult as they had previously tried various, unknown foods without concern.

> *You don’t know what’s in the food and you might not know how to speak the language. But, then- then again, you might be able to, like, know what nut is or something and free and [laughs] basic words in that language and say it to them and they might understand that you have an allergy – Phillip, M14*

> *They have to be very careful of what they order. So, if they were allergic to fish or something and they went to, I don’t know, somewhere near like the ocean, where there’s loads of seafood, they’d feel like very left out because everyone in their- well- whoever they’re going with, is going to order fish and they can’t have any - Aliyah, F13*

Although some participants such as Mandeep felt that going on holiday would be daunting, others such as Phillip were more positive and believed that difficulties could be overcome. Some younger participants considered that having their parents with them would be reassuring. Most felt that they could overcome the barriers of eating on holidays by researching and preparing ahead of the trip or learning basic vocabulary for the country they were visiting in order to safely enquire about ingredients and finding restaurants that would be safe. Participants discussed the usefulness of modern technology, with features such as an online translator, as mobile phones are becoming easier to use abroad.

Checking ingredients overall was believed to be annoying as they wanted to start eating as soon as possible without the pressure of reading through all the ingredients whether in a restaurant or buying food from a shop. On the other hand, worries over being careful and being left out or judged were also highly concerning for the participants.

5.4.3. Theme 3: "Think about how they would feel": Personal responsibility and supporting people with FA

The participants explained that they wanted to understand how having FA affects people and also what they themselves could do to help. They discussed a need to support those with FA to ensure that they felt as safe as possible. Some participants expanded on how adolescents with FA were treated unfairly and felt that FA did not warrant a difference in treatment or exclusion from activities. They believed that situations such as being left out of school trips or activities were unfair as there are alternative food options and food only takes up a small part of the trips and activities. In other situations, being given a poor replacement such as a small bag of sweets rather than a large Easter egg as a prize was not seen as appropriate, and having FA should not mean that you should accept a poor substitute. It was believed that those with FA should not be treated differently because of their FA.

> *They won a prize and the Easter eggs are like that big [gestures large Easter egg size] so they got a little mini packet of Haribo's instead of getting the Easter egg and I felt bad for them – Leona, F12*

However, these views may suggest that some participants do not understand the seriousness of FA. While having any health condition should not warrant exclusionary behaviour, adolescents with FA would still need to be careful to manage their risks.

There was also a concern that asking their friends about their FA could be seen as invasive and may annoy them. The person with FA may feel embarrassed or they may want to get away from talking about it.

> *I guess the person doesn't want to keep talking about it if they have to talk about it at home, check the labels and so on – Lyra, F15*

Some participants were therefore hesitant to ask about FA, despite wanting to know more. They wanted their peers with FA to feel comfortable around them and so decided that they would wait until the person with FA wanted to talk to them.

On the other hand, Leona who had a friend with FA expressed that she felt guilty she did not know about the FA and wished she had known sooner.

> *I had a friend who has had a nut allergy and I always used to bring in snickers and she told me in year six and we we'd been friends since year one […] I wish she told- she had told me sooner because she felt like she could open up to me once she told me but she'd told me sooner, I would've felt better and then I feel guilty, like, bringing in the like nut bars and everything – Leona, F12*

The desire to know about the allergies in order to support their friends was important, especially to the female participants. Leona identified that a barrier had been lifted once the FA had been disclosed and she was able to better support her friend with FA. Interpersonally, inclusion and kindness were highlighted as essential to improving attitudes and understanding of FA, as well as supporting them.

> *Be more considerate about them and kind of think about how they would feel and not just about what they think – Callie, F11*

The participants considered emotional support and considering how someone would feel about their FA, and felt it was important to be considerate of these feelings and how best to support them, especially for their friends. They discussed how they would feel in certain situations, whether they would feel worried or embarrassed, for example about reactions, or sad if they were to feel left out.

The girls in particular also wanted to offer active support to help their friends with FA feel safer, whether this was not eating the allergen in their presence, finding foods that were safe for them to eat, or learning about how to help if a reaction occurred. These beliefs were less evident in the boys' accounts, who were more reserved.

> *Not eat around them because then they'll feel like they're left out and I would want them to know that I know what to do if they have a reaction so then they feel a bit safer, knowing that I can help them if they did – Lizzie, F14*
>
> *You, er, might know of a couple of things that they could eat so like they could help them like research things they might be able to eat – Kirsty, F11*

Support groups and changes to school and restaurant policy were also discussed as areas that could provide more support to people with FA.

> *One on one kind of meetings, like for- like some kind of, um, routine thing. Like, maybe it could be like every month or- or every other week but they just kind of have like spend li- like a morning just talking about food allergy and just, um, just giving them support – Keeley, F11*

> *The school I'm at should definitely, ha, definitely not have nuts and 'cause nuts are very common and I feel like most restaurants and places should have, like how there's a vegan option, they should have like a allergy option – Leona, F12*

Overall, participants in the sample were compassionate, especially when they had a close friend with a FA. They suggested a variety of ways to support people with FA and make them feel more confident and comfortable, ranging from not eating the allergen around them, carrying their medication, reading labels and double-checking ingredients. There was a clear desire to support those close to them, help with FA management, and take a more proactive role with their friends, in addition to seeking further education.

5.4.4. Theme 4: "*I think that other people should be aware about how bad they can be*": *Educating others to increase understanding*

The participants in this study were aware that they had limited knowledge and a lack of understanding about FA, but all expressed that they wanted to rectify this by learning more through increased education. They felt that education could be provided in secondary schools where there were more students with FA.

Participants were mostly aware of allergies to pollen and nuts but were less confident about other foods people could be allergic to, unless they knew of someone personally with that FA. Eggs, gluten and milk were also sometimes considered as foods that people could be allergic to and participants talked about how this may affect them, for example how a FA to cow's milk may be very restrictive as milk is a common ingredient in many foods such as baked goods, dairy products and condiments. Other foods that are in the 'top 14' for most common allergens such as fish, shellfish, and soy were rarely mentioned.

> *Milk is in quite a lot of things and you have to kind of like change your routine and everything would be different – Keeley, F11*

The majority of participants also had a lack of understanding of the difference between FA and intolerance, what anaphylaxis is, and what medication someone with FA uses.

> *I didn't really know that people could suffer that much from just like food - Aliyah, F13*

Even those who believed themselves to have a good understanding of FA whether this was from knowing someone personally with FA or from being told about it by a parent, felt they and their peers would benefit from further education.

> *I feel like it should be more aware because so many people-, because you, in secondary school you mix with so much more people. Like there's so many forms and everything and so many people that I know now have food allergy – Leona, F12*

To improve beliefs and attitudes through education, the majority suggested an information event held at their school would be useful, whether this was a class in Personal, Social, Health and Economic Education (PSHE), an assembly, information leaflets or a stand-alone seminar similar to how they receive sex education.

> *I think you should just be like aware and like um in secondary school where you have sex education, you should also have like allergy education and stuff so that people know like the downsides and the upsides of allergies – Phillip, M14*

> *They [school] could promote it more so we understand the different types because only if you, like, I think we only really know of a nut allergy but I don't think we know of any other ones in specific – Callie, F11*

Participants highlighted that they wanted to understand more about what FA was and how the AAI worked, but also expressed that more awareness was needed for how prevalent FA was and how serious they could be. Participants were unsure of these things even if they knew someone with FA and were shocked when discussing the severity of anaphylaxis and how many foods people can be allergic to, most being aware of only nuts unless they knew someone specifically with another FA.

> *I think that other people should be aware about some allergies and how bad they can be because certain allergies could be like really, really bad – Kirsty, F11*

Education may reduce the concern and misunderstanding surrounding AAIs and reactions, leading FA to be acknowledged as a serious condition and for participants to feel more confident in supporting peers with FA. Improved understanding and empathy in peers without FA may result in adolescents with FA feeling better able to manage their FA with informed support and help from their friends.

5.5. Discussion

This is the first known study to explore beliefs of FA in adolescents who do not have this condition. The only previous study to compare adolescents with FA and without FA was Sommer et al. (2014), who qualitatively compared food choice. No studies have explored FA beliefs. This study was conducted because the systematic review (Chapter 3) and interviews with adolescents with FA (Chapter 4) suggested that the beliefs of peers are important in how adolescents perceive and manage their FA, yet there is no current research which looks at the beliefs of these peers. Analysis of the data revealed four themes regarding the beliefs of adolescents without FA: 1) “I’d feel very worried and scared that I could have an allergic reaction anytime”: Peer perceptions of living with a FA; 2) “Probably stick to places I know”: The burden of managing FA in safe and risky places; 3) “Think about how they would feel”: Personal responsibility and supporting people with allergy; and 4) “I think that other people should be aware about how bad they can be”: Educating others to increase understanding.

In the first theme, ‘“I’d feel very worried and scared that I could have an allergic reaction anytime”: Peer perceptions of living with a FA,’ adolescents showed great concern for anaphylaxis and use of AAIs, which they believed would be scary and may lead to judgement from peers, this is also found in the previous study of adolescents with FA, showing empathy. In scenarios where the adolescents imagined themselves in a challenging situation such as having a reaction, they wanted to be discrete and not draw what they perceived as unnecessary attention to themselves or their hypothetical FA. When considering others who may have FA the adolescents were supportive and empathetic, yet when thinking of themselves with FA they wanted to avoid attention where possible. These beliefs about AAIs being scary and empathy of worries about judgement show that adolescent peers are able to understand components of living with FA and take them seriously. Addressing beliefs about AAIs being scary is important, as reluctance to use an AAI if their friend is having an anaphylactic reaction may be fatal. Improving self-efficacy of friends of adolescents with FA, may have strong protective qualities as seen in Elise Hubbard, a 13 year old who was saved in a severe reaction by her friend Laura, who administered an AAI and called an ambulance, saving Elise’s life (Abi, 2018).

There were also worries about missing out on experiences compared to others if they were not able to eat the same foods and frustration at being treated unfairly, which was also seen in Chapter 4 in the participants with FA. This supports the findings of previous research with adolescents with FA discussed in the systematic review in Chapter 3 (Gallagher et al., 2011; Fenton et al., 2013; Stjerna, 2015; Akeson et al., 2007), where adolescents felt they were missing out in places that were more challenging for allergen management such as restaurants and school trips (Stensgaard et al., 2017). They also felt left out in their relationships where they may miss experiences with popular foods that their friends enjoyed, such as chocolate (Stjerna, 2014). This suggests that adolescents without FA are able to empathise and understand feelings associated with FA and the challenges adolescents face when trying to manage their FA. While previous research has considered that adolescents with FA do not want to cause a fuss as they believed themselves a minority, that peers understand that treating people differently to the point of exclusion is unfair highlights that suitable alternatives may be more readily accepted. This could inform schools in school trips and catering and encourage school policies to reduce stigma as it is noticed by others.

There were also the similar beliefs between adolescents with and without FA regarding food labelling. The beliefs around labelling are very similar to the beliefs expressed by those with FA discussed in Chapter 4, with the desire for clearer labelling such as which nut the product may contain, and the frustration associated with checking. In the present study, adolescents without FA felt that ‘may contain’ labels needed to be more accurate and that labels were sometimes only applied to prevent companies from being sued. This was also discussed in the systematic review (Chapter 3), where adolescents with FA were dismissive of food allergen warning labels and consumed the food anyway, as found in studies such as Monks et al. (2010) and Mackenzie et al. (2010). Participants in both this study and in Monks et al. (2010), felt that less use of warnings where risk was low as well as clearer and more consistent allergy warnings may improve allergen avoidance as labels may be more trusted. This suggests that greater transparency in food labelling procedures would be beneficial and that food production companies should consider clearly expressing how they determine whether to include a label, and which specific ingredient is included. This would allow friends of those with FA to more easily support them if they wish to check labels or to be considerate of what they bring into school from home.

In the second theme, ‘“Probably stick to places I know”: The burden of managing FA in safe and risky places,’ adolescents considered that home would be the safest place with holidays being the place with the most perceived risk for someone with FA, supporting findings from the sample of adolescents with FA in the previous chapter (Chapter 4). In a similar theme from the systematic review (Chapter 3), familiarity, predictability and distance from external help affected participant beliefs around place, suggesting the ecological systems theory may also apply well to the hypothetical considerations of FA. The presence of a parent helped to reduce this perceived risk, fitting with a more external locus of control, with the family home in the microsystem being considered the safest place for managing FA (Fenton et al., 2013; Stjerna, 2015; Marklund et al., 2007). The adolescents without FA expressed that they would probably only go to places they knew were safe and had attended frequently to reduce risk of consuming an allergen. This was also found in the systematic review (Chapter 3), with previous research reporting that food prepared outside of the home in places such as restaurants worried adolescents with FA (MacKenzie et al., 2010; Marklund et al., 2007).

Participants in the present study considered that restaurants and school trips could be annoying, similar to findings from the systematic review (Chapter 3) about feeling excluded from experiences (Stensgaard et al., 2017). Participants without FA in the present study also considered that asking about allergens may be frustrating. If adolescents with FA knew that peers had the potential to understand this frustration, they may feel more comfortable asking. There was less concern about schools from participants and trust of teachers was not mentioned. This is different from research with adolescents with FA who sometimes experienced conflict in schools due to a lack of understanding and support from teachers (Marklund et al., 2007; Stjerna, 2015). Adolescents without FA may expect teachers to have the needed knowledge and resources to effectively support those with FA and therefore did not consider how misinformed teachers may be a barrier. This highlights how adolescents with FA must be more sceptical of those outside their microsystem, and that they may need to have a more internal locus of control as they feel teachers and other adults may not be trustworthy to keep them safe in regard to their FA. Participants in the present study did not really consider aspects such as having to sit alone or being excluded from school trips (Fenton et al., 2011; Dean et al., 2016) as they felt that FA did not warrant exclusion, this may mean that they do not understand the severity of FA and this needs to be addressed, or that school policies that implement this are unsatisfactory and need to be reviewed. The majority also believed that FA should not be a source of bullying or mark people as different, which previous research (Stensgaard et al., 2017; Fenton et al., 2013) reported as an issue but was not experienced by the majority of the interviews with participants with FA (Chapter 4). This belief that stigma is unwarranted, may support ideas for school-based interventions as the participants interviewed were supportive of FA. This suggests bullying may be rarer than feared, and that adolescents with FA may be able to be included more safely in schools. This may also lead to protective support, where peers may be able to intervene in bullying and reduce it.

In the third theme, '"Think about how they would feel": Personal responsibility and supporting people with FA,' strong suggestions of compassion were also apparent from the data as participants wanted to support and help their friends with FA. It has not been previously suggested that adolescents with FA rely on friends, instead mentioning parents or trusted adults suggesting a more external locus of control in trusted adults. The adolescent females in the sample were sympathetic and more interested in actively supporting their friends with FA, supporting Warren et al.'s (2016) study highlighting supportive female friends as a protective factor against engaging in risk and not males. In previous research, females have reported stronger friendships than males, yet also experience more stress with these friendships due to the added responsibility (Thomas & Daubman, 2001; Belle 1987). A peer-led programme for asthma has shown a greater effect in female participants (Shah et al., 2001), suggesting that female adolescents may benefit more from social support, which could be considered in future interventions for FA.

This offer of peer support may increase confidence and risk management in those with FA. Previous research by Jones, Sommereux and Smith (2018) found that support groups for young people with FA resulted in improved self-esteem, and confidence both generally, and when managing their FA. These groups helped adolescents feel included and share experiences with people who also had FA, which was highly valued. This study argued that young people with FA desired more availability of these support groups, highlighting the importance of peer support. That adolescent peers without FA also acknowledge that support groups is a useful resource, shows empathy and the potential for peer support from peers without FA. Another novel finding in this study was the concern of those without FA feeling as if they would 'bother' those with FA by asking them about it. This suggests that opening conversations about FA among adolescents may be a way to improve perceived support and that a peer-led intervention may be successful in the adolescent FA population not only with peers with the same condition but also friends willing to learn and support with boosted self-efficacy and a more open dialoge about FA.

In the fourth theme, '"I think that other people should be aware about how bad they can be": Educating others to increase understanding,' there was a clear call for further education to increase understanding about FA and that schools would be the best place to implement this. Previous research adolescents with FA has also reported such findings. Sampson et al.'s (2006) study suggested education would reduce peer pressure and negative peer behaviour such as teasing and bullying. This is also highlighted in other research (Stensgaard et al., 2017; Monks et al., 2010; Stjerna, 2015; Marklund et al., 2007) where adolescents with FA wished that others knew how severe an FA can be and how situations made them feel. This desire from adolescents without FA to learn and understand aligns with the desire for more understanding from those with FA, suggesting that an intervention involving adolescents with and without FA may be beneficial for both.

5.6. Strengths

This study is the first known study to explore the beliefs of adolescents without FA. At an age where peer beliefs and attitudes are highly influential, it is essential to improve understanding of peer beliefs if community or education-based interventions are to be implemented. The data was representative of participants from across the adolescent age range and views of both males and females were explored. This data suggests that peer-led and school-based interventions may be well received by peers without FA. Especially in cases where they knew someone with FA, the participants wished to support and be properly educated about FA. A barrier to this was that participants were reluctant to pry, whereas previous research suggests a reluctance from adolescents with FA to reach out as they fear being stigmatised. If an intervention was to open this conversation, increase self-efficacy, and educate on how to best support those with FA, this may further reduce cases of bullying so that reactions to food and anaphylactic deaths in schools (Davies, 2018) may be reduced, and instances where friends are able to save lives in the case of a reaction increase (Abi, 2018).

5.7. Limitations

As with the previous study, more females (n=11) took part in the study than males (n=5). This is common in psychological research, and further research into male beliefs may be beneficial. Due to the preferences of the adolescents, ten interviews were conducted over the telephone rather than face-to-face. It was sometimes more challenging to engage adolescents to discuss beliefs over the phone and these participants needed further encouragement from the interviewer. Interviews in person or over Skype elicited a greater depth and flow of discussion, potentially due to the added encouragement from body language and facial expressions, and the arguable added ease of building rapport with someone you can see. Furthermore, as all participants knew someone with FA, whether this was a family member, friend, or classmate, this may have affected their beliefs. Further research into adolescents who do not know someone with FA may add a different perspective to these findings. Finally, similar to the previous study of adolescents with FA, this interview schedule was also not developed with input from the demographic of adolescents aged 11-16 years without a diagnosed FA. The inclusion of input from adolescents may have strengthened the interview schedule to include questions of importance that did not emerge from the systematic review, however may have been difficult if the adolescents approached had no prior knowledge of FA.

5.8. Implications

This research highlights that peers may understand more than believed by adolescents with FA and show a willingness to help that was not considered in previous research. Further research could explore the effect of an educational intervention to address and inform adolescents without FA on areas they feel are intimidating such as reactions and AAIs, as well as informing them what FA is and what happens during a reaction. This may improve the adolescents' confidence in supporting their peers with FA provide further support by knowing what to do if a reaction occurred. With this education and addressing of misinformed beliefs, better support and reduced stigma in their friends and classmates with FA may result.

5.9. Conclusion

Overall participants in this sample, especially the females, were sympathetic and compassionate towards those with FA. Checking food labels and menus was perceived to be frustrating, especially in places far from home. Knowledge and understanding were highlighted as an area that needed improvement, which participants suggested could be addressed in schools through PSHE classes or assemblies. There were concerns over how to manage a reaction if one was to occur and apprehension around the needle in an AAI, which could be addressed in school-based interventions. The concerns of others were also highly influential in the adolescents' beliefs and their predicted behaviour, whether this was being secretive when using AAIs or feeling anxious when ordering foods in restaurants. This suggests that peer influence may also have an effect on those with FA.

The ability to gather information on beliefs and the strength of those beliefs in adolescents with and without FA would be useful in order to inform both individual and group interventions. The next chapter describes the development and initial testing of a scale to measure beliefs about FA in adolescents.

Chapter 6: Scale Development: The development of the Adolescent Food Allergy Beliefs scale: FA Questionnaire (AFAB) and Peers Without FA Questionnaire (AFAB-P)

6.1. Introduction

This study aimed to develop a quantifiable measure for strength of beliefs around FA in children and adolescents aged 11-16 years both with and without a diagnosed FA. A scale for adolescents with FA was developed as information about beliefs may provide insight into why adolescents are the age range most at risk to experience an anaphylactic reaction. A scale for adolescents without FA was developed as the qualitative studies highlighted that peers have the potential to be empathetic and have a desire to learn about FA but have significant gaps in knowledge about seriousness of FA. There was also anxiety about getting involved in management (e.g. assisting during a reaction), where they may be the only person available. Previous research has also highlighted that bullying and misunderstanding from peers (DunnGalvin et al., 2009; Sampson et al., 2006; Stensgaard et al., 2017; Fenton et al., 2013) can be issues in adolescents with FA, in extreme cases leading to deaths in schools (Davies, 2018). Understanding and addressing misinformed beliefs, such as that FA is not severe, may reduce the risk of bullying and stigma in adolescent peers. These scales therefore aim to measure adolescent beliefs about FA, providing experiential condition beliefs of adolescents with FA and beliefs of their peers without FA.

Currently no scales exist that measure adolescent beliefs of FA. Existing scales such as the Illness Perception Questionnaire (IPQ) consider illness beliefs but is generic and was not developed specifically for adolescents. The vocabulary and phrasing may therefore not be suitable. Scales specifically for FA mainly measure QoL or coping, such as the Food Allergy Quality of Life Questionnaire – Child and Teenager Forms (Flokstra de Blok, 2014) and the Food Allergy Management and Adaptation Scale (Klinnert et al., 2015). DunnGalvin et al. (2018) have developed a coping and emotions scale for 6-23-year olds, however this also mainly focuses on coping rather than beliefs about FA. At present, there are no FA specific scales dedicated to the age group of interest, despite being the age range most at risk of fatal allergic reactions. Previous research has indicated that there is a shift in beliefs when transitioning into secondary school (Fenton et al., 2011), in a new environment and as a developing adolescent. DunnGalvin et al. (2009) also suggested a shift in beliefs around 12 years of age due to increasing independence in the child. Therefore, the study of FA beliefs in those aged 11 and above attending secondary school is important for further understanding to inform future research and interventions.

No scale that considers the beliefs of adolescents without FA exists either, despite studies such as Monks et al. (2010) highlighting the desire of adolescents with FA to include these peers in school-based interventions designed to improve FA management. Such a scale may be useful to understand beliefs of peers in an age range where peer perceptions are considered important (Ary et al., 1999; Allen et al., 2005; Thomas and Daubmann, 2001), especially by adolescents with FA (DunnGalvin et al., 2009, Warren et al., 2016; Sampson et al., 2006).

This chapter describes the development and validation of two scales, one to measure beliefs of adolescents with FA, the Adolescent Food Allergy Beliefs Questionnaire (AFAB); and one to measure beliefs in adolescents with no FA, the Adolescent Food Allergy Beliefs Questionnaire for Peers (AFAB-P).

6.2. Method

The Health Research Authority (HRA) and Leicester Hospitals NHS Trust provided ethical approval for this study (IRAS ID: 226560, 26/01/2018). The scale was developed based on recommendations about patient-recorded outcome measures from U.S. Department of Health and Human Services FDA Center for Drug Evaluation and Research, U.S. Department of Health and Human Services FDA Center for Biologics Evaluation and Research and U.S. Department of Health and Human Services FDA Center for Devices and Radiological Health (2006). The recommendations for development and modification involve a four-step process; 1) identify concepts and develop conceptual framework, 2) create instrument, 3) assess instrument, and 4) modify instrument.

6.2.1. Item generation

Generation of items can be from a range of sources such as a systematic review or previous studies (U.S. Department of Health and Human Services FDA Center for Drug Evaluation and Research et al., 2006). Data from the studies discussed in the systematic review and the two qualitative studies (Chapters 3, 4 and 5) were used to develop items for the two versions of the AFAB, one for those with FA and one for those without. Highlighted areas of importance for items included place, AAIs, reactions, labels, school, relationships, perceived severity of FA, and understanding of FA. In the FA sample, qualitative findings suggested adolescents believed nut allergies were the most serious allergen and age of diagnosis o be important factors, so these were also included. Items were phrased as statements with a 5-point Likert-scale layout. Adolescent participants from the previous qualitative studies (Chapter 4 and Chapter 5) were asked if they were happy with the 5-point format, or if they would like more or less options (e.g. a 7-point format) and they preferred the original 5-point format (see section 6.2.2 below on item review). Previous research has not suggested a difference between 5 and 7-point scales (Hartley, 2014), though removing the mid-point can force an opinion. Having a mid-point allows for a neutral option, which adolescents wanted included but has previously been suggested to be used as an option when adolescents are not sure how to answer (Raaijakers, van Hoof, Hart, Verbogt & Vollebergh, 2000).

Both the scale for those with FA and the scale for those without FA comprised of 43 identical items. For each version of the AFAB, item wording was adjusted as appropriate, for example in the FA scale questions were focused around ‘my allergy’ and in the scale designed for those without FA, questions were instead framed hypothetically ‘if I had a FA’ or ‘people with FA’. A full list of questions for the two versions of the AFAB may be found in the appendix (6.1 and 7.1). All questions in the AFAB were required to be answered and the Qualtrics tool of ‘forced response’ was used to ensure this.

6.2.2. Item review: piloting the measures with adolescents

Eleven participants who had taken part in the interviews, 6 with FA (age range 11-16, 2 males) and 5 without (age range 12-16, 1 male), agreed to pilot and review the relevant AFAB version (as recommended by the U.S. Department of Health and Human Services FDA Center for Drug Evaluation and Research et al., 2006). Question and response wording were checked to be accessible to the age range, clearly understandable, and to follow a clear structure for ease of completion. The scale versions were then refined based on this feedback.

The adolescents were overall very happy with the scale and the representation of their views, remarking that it was ‘very good’. However, they also discussed how the wording on certain questions may be changed to be clearer with the younger participants in mind. They also considered that a couple of questions were quite similar as ‘Does your FA make you feel scared?’ and ‘Does your FA make you feel anxious?’ could be answered in the same way. The statement ‘I would feel confident using an AAI’ was removed as the sample without FA and the majority of the sample with FA were unlikely to have used one and confidence was not considered important. Instead the statement ‘I would not use an AAI if I had a reaction because I do not like needles’ was kept, as this considered AAI usage. and as a minority of the qualitative participants mentioned death, it was considered acceptable to include the item that FA was ‘life threatening’. All who reviewed the scale felt that no items were missing. A statement about obscure allergies was considered (as some of the participants had less-common allergens) but it was felt that the statement about whether allergies were understood covered this appropriately. Wording on some items were changed for comprehension for the youngest participants. As such, ‘severity’ was changed to ‘seriousness’, identity was changed to ‘part of who I am’ and some terms were defined or given examples in brackets such as ‘unpredictable (you don’t know when a reaction could happen)’.

For layout, one suggested the use of page numbers or question numbers to make the scale easier to follow. All were happy with the five points and agree to disagree Likert scale, though one without FA considered some of these Likert scale questions could be yes or no. However, as the majority of 10 participants preferred the Likert scale, this was chosen, and items were reviewed.

Feedback was also provided from two certified paediatric allergists at Leicester Royal Infirmary. They felt the scale was very long but were reassured that this was just a prototype scale and the final one would be shorter.

6.2.3. Participant recruitment for reliability and validity analysis of the scales

To take part, participants were required to be living in the United Kingdom and to be between 11 and 16 years of age. Participants were recruited through the allergy clinic at Leicester Royal Infirmary (Appendix 5.1), social media (Appendix 5.2), an advert from Allergy UK (Appendix 5.2), allergy newsletters (e.g. British Society of Allergy and Clinical Immunology) (Appendix 5.2), and through a Qualtrics participant panel. Participants were able to complete the questionnaire at home in their own time.

A total of 200 study packs were posted to adolescents with FA registered at Leicester Royal Infirmary (LRI) who had not taken part in the previous study. In the study pack, a link was included for participants to complete the questionnaire online should they wish to. Questionnaires were also uploaded to an online survey platform called Qualtrics, which can be used on computers, tablets and mobile phones. The study, along with a link to the questionnaires, was advertised online via social media channels Facebook and Twitter, as well as the Aston University newsletter ‘Aspects’. Allergy newsletters such as Midlands Asthma and Allergy Research Association (MAARA), British Society of Allergy and Clinical Immunology (BSACI), and the Allergy UK website also included adverts for this study. A participant panel affiliated with the Qualtrics software company was also used to recruit participants with and without FA.

6.2.4. Procedure for reliability and validity analysis

The study pack included an information sheet for parents and adolescents (Appendix 5.3 and 5.4) explaining the nature and purpose of the study, an informed consent form for 16 year olds to give their own consent (Appendix 5.5), an assent form for adolescents aged 11-15 (Appendix 5.6) and a parental consent form for adult permission (Appendix 5.7). A demographic questionnaire (Appendix 5.9) was included for information about the participant such as age, gender and history of comorbid conditions such as asthma and eczema. A FA-specific demographic questionnaire was also included with questions about the condition history such as allergens, medication, age of diagnosis and outgrown allergies (Appendix 5.8). Those with FA completed the AFAB; the beliefs prototype scale for those with FA (Appendix 6.1), while those with no current diagnosis of FA completed the AFAB-P; the beliefs prototype scale for those without a current diagnosed FA (Appendix 7.1). Both sets of participants also completed the four validation scales (Appendix 5.10, 5.11, 5.12 and 5.13). Where appropriate, additional instructions for adolescents without FA were included at the top of these validation scales for coherence (Appendix 7.2 and 7.3).

The demographic questions, the scale, and the validation scales took approximately 30 minutes to complete. With each new question format (e.g. a slider or matrix), clear instructions were given on how to answer the questions. The scale was formatted so answering was made as easy and clear as possible, however participants were encouraged to ask a parent or guardian for clarification if needed. Participants were able to submit an email address if they wished to be entered for a prize draw for Love2Shop vouchers, but this was not mandatory. A data protection statement (Appendix 5.14) was included at the end of the scales.

6.2.5. Construct validity

Construct validity, or whether a measure is measuring the phenomenon of interest (Pseudovs et al., 2007), was assessed by correlating the scales with another tool that measures a similar construct. As there is no suitable closely related scale to measure adolescent beliefs about FA, questionnaires measuring illness perceptions (BIPQ), stress and coping (Kidcope), health locus of control (MHLC-B), and attitudes to risk (ARQ-P) were used. These measures are described below:

- **Brief Illness Perception Questionnaire (BIPQ)**

The Brief Illness Perception Questionnaire (BIPQ) (Broadbent, Petrie, Main & Weinman, 2006) is a 9-item scale (Appendix 5.10) that considers beliefs about any illness and may be applied to any age. It has a 11-point Likert-scale that assesses emotional and cognitive representations of illness. The authors did not report the Cronbach's alpha, however concurrent validity with IPQ-R (Revised Illness Perception Questionnaire) is appropriate with correlations from .32 to .63. In this study, the Cronbach's alpha for the BIPQ was .61 in the sample with FA and .81 in the sample with no FA. .61 was a surprisingly low alpha score and may suggest that the AFAB measures different beliefs than the BIPQ for adolescents with FA. It may be higher in the sample without FA, as their beliefs may not be as strong as adolescents with lived experience of FA.

The BIPQ is also able to distinguish between different illnesses, supporting its discriminant validity. Based on work on illness representations from Leventhal et al. (1984), with sub-scales of cause, consequences, timeline, personal control, treatment control, identity, coherence, emotional representation, and illness concern, this scale was very relevant to beliefs, the construct of interest. However, the BIPQ differs from the AFAB as the AFAB aims to capture beliefs specific to an adolescent population with factors such as school and reliance on parents, which are not included in the more general BIPQ.

The BIPQ was chosen over the original Illness Perception Questionnaire (IPQ) or the Illness Perception Questionnaire Revised (IPQ-R) primarily due to its shorter length to reduce fatigue effects for the adolescent participants. For adolescents without FA, there was a short instruction at the top of this scale which asked them to consider how they would feel if they had a FA, similar to the AFAB questions, rather than a general illness, as the BIPQ does not define an illness. The BIPQ questions are very general and can be applied to FA. It was expected that the BIPQ would be correlated with the FA belief scales as it measures general illness beliefs. In particular correlations were expected in cyclical timeline beliefs, emotional representations and illness identity, as these factors were previously shown to be important in research by Jones et al. (2014).

- **Multidimensional Health Locus of Control (MHLC-B)**

The Multidimensional Health Locus of Control (MHLC-B) (Wallston, Wallston & DeVellis, 1978) comprises of 18 items (Appendix 5.11) regarding beliefs about locus of control in a medical condition. Wallston (1992) argues that beliefs are not mediated for those with an internal health locus of control, but that beliefs may moderate the relationship between behaviour potential and expectancy measures such as self-efficacy beliefs. This means health locus of control may have a positive effect through moderating health beliefs but may not completely change them.

The authors report an alpha reliability score in the MHLC subscales of .67 to .77. In three college samples where the MHLC-B was applied, the subscales had the following range of alpha scores; internal = .66 to .80, chance = .68 to .83, and powerful others = .73 to .75. When forms A & B were both used, the alpha was slightly higher (.82 to .86), however only form B was used in the current study to reduce fatigue effects. The Cronbach's alpha in the FA sample was .81 and in the sample without FA is was .80. For the subscales, in the FA sample, alphas scores for the subscales were: internal .69, chance .64, and powerful others .75. In the sample without FA, subscale alphas were internal = .71, chance = .67, powerful others = .74.

Items are rated with a six-point Likert-scale from strongly disagree to strongly agree. The MHLC-B is scored based on three sub-scales regarding their locus of control: internality, chance externality, and powerful others externality. The MHLC-B may be applied as an independent variable in combination with relevant belief and attitude variables to predict health behaviour, fitting well as a validation scale for this scale. Form B was written in the most accessible way for the adolescent sample and was the easiest to understand. It was also shorter than the 40-item Nowicki and Strickland Locus of Control Scale for Children (1973) and so would reduce fatigue effects. This scale was used as beliefs may be correlated with sub-scales of the MHLC-B (Wallston et al., 1978).

- **KIDCOPE**

Kidcope (Spirito, Stark & Williams, 1988), is a brief scale (Appendix 5.12) that considers coping in children and adolescents. Kidcope comprises of ten items. Cronbach's alpha of the Kidcope in this study was .85 in the FA sample and .82 in the sample without FA. As each subscale comprises of one item, post-hoc power analysis will be assessed with G*Power.

There are two parts to the Kidcope: the first part asks an open question asking the participant to explain a problem that bothered them and then asks them to rate how they felt about it. The second part considers coping mechanisms, and the participants rated the frequency and usefulness of these behaviours. The older version (13-18 years) was used as the phrasing was found to be appropriate and it considers frequency as well as usefulness of the coping behaviour. Each item refers to a different coping mechanism, except emotional regulation, where two items are related to this strategy. Kidcope was chosen because it is able to consider stress and coping in general and gave an overall indication as to how the adolescents dealt with stress. Coping was expected to be correlated with the beliefs scale as previous work by DunnGalvin et al. (2009) suggested that FA beliefs were important to coping.

- **Adolescent Risk-Taking Questionnaire - Risk Beliefs Questionnaire (ARQ-P)**

The Adolescent Risk-taking Questionnaire (Gullone, Moore, Moss & Boyd, 2000), comprises of two 22-item parts; a risk behaviour scale (ARQ-B) and a risk judgements scale (ARQ-P) (Appendix 5.13). The authors ran Cronbach's alpha on each subscale, and on females, males, older adolescents, younger adolescents, and the full sample. Only two factors were below .7; perceptions in older adolescents (.67) and antisocial behaviours in girls (.66). Most subscales exceeded .8, except the antisocial subscales, which ranged from .70- to .79. In the FA sample, the Cronbach's alpha was .85 and in the sample without FA it was .86. For the AFAB subscales, in the FA sample, alpha scores were thrill-seeking .80, rebellious .63, reckless .74, and antisocial .70. In the sample without FA, thrill seeking was .72, rebellious was .66, reckless was .78, and antisocial was .69.

The ARQ-P and the two AFAB scales should negatively correlate, the riskier an action is perceived to be, the less likely the adolescent is to engage in the behaviour. The ARQ-P measures how risky adolescent believe the 22 included behaviours to be. The scale fit into a four-factor structure of thrill-seeking items, rebellious items, reckless items and antisocial items. The ARQ-P was chosen as it was relevant to the age range. The belief questionnaire (ARQ-P) was used and not the behaviour questionnaire (ARQ-B) as only beliefs were explored. The ARQ-P was expected to be correlated with the beliefs scale as strength of beliefs about risky behaviour was predicted to be related to strength of condition beliefs about FA.

6.2.6. Ethics

An information sheet was included as the first page of the questionnaire both in the hard copies and online versions, detailing the study motivation, procedure and the ethical rights of the participants. Participants were reminded that their answers were anonymous and confidential, that they had the right to withdraw at any time and were provided contact details if they had any questions or complaints. In case of future withdrawal, participants were asked to make a code of their initials and three numbers to cite in contacting the main researcher. Participants were not expected to feel upset during completion of the questionnaire, but participants were made aware that it was a possibility, with contact details for complaints and the right to withdraw at any time emphasised. Following the declaration of ethical rights, an informed consent form for adolescents and for adolescent parents if the adolescent was under 16 years of age was provided. These consent forms were required to be signed before completion of the study. Following the questionnaire was a privacy statement, again informing the participants of the use of their data.

6.3. Data analysis

For each scale, principal components analysis (PCA) with varimax rotation was used to assess the internal factor structure for each scale. The Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy and the Bartlett's Test of Sphericity is stated. Eigenvalues and scree plots were used to identify the number of components and grouping of subscales. Cronbach's alpha was calculated for each scale and all sub-scales and items. Cross-sectional validity was measured using Pearson's correlational analysis. Discriminative validity was assessed using correlations and ANOVAs as appropriate.

6.4. Results

The results detail the descriptive statistics and demographic data of both the participants with FA (AFAB) and participants without FA (AFAB-P). Reliability and validity analysis was conducted on each scale separately.

6.4.1. Descriptive statistics

A total of 294 participants completed the demographic information and relevant AFAB scale but only 280 participants completed the AFAB or AFAB-P and all validation scales. A total of 9 participants returned hard copies of the scale from Leicester Royal Infirmary; all other participants were recruited online. N=152 (51.7%) had a diagnosed FA while n=117 (39.8%) did not have a FA. N=25 (8.5%) participants had grown out of their FA, and so were included in the scale for adolescents without a current diagnosed FA, as previous research suggests that the majority of adolescents who grow out of FA do so in infancy (Sicherer & Sampson, 2014) and so may not have recent memory of living with FA. N=138 (46.9%) participants were male and n=154 (52.4%) were female; 2 (0.7%) participants preferred not to disclose their gender.

The majority of the participants were British (79.6%), 10.9% were White European, and the other ethnicities varied between 0.3 to 3.7%. The mean age of participants was 13.98 years with a standard deviation (SD) of 1.792, though the proportion of participants aged 16-years was highest at 31.3% of the total sample. Participants lived in various areas of the UK, the majority living in England (83.7%), while other participants resided in Wales (7.5%), Scotland (6.15%), and Northern Ireland (2.7%), with 1.7% preferring not to say.

Some participants had previously had treatment for asthma (45.5%), eczema (45.6%) or hay fever (60.1%). Some also had family members who also had FA whether this was a parent (36.1%), sibling (22.1%), grandparent (11.9%), aunt or uncle (12.2%), cousin (15%) or other relative (2.7%). 41.5% stated they did not know of any family member with FA. Table 13 details the demographics of the AFAB and AFAB-P samples. Further FA group specific demographics are available in Table 14.

Table 13: Demographics of the AFAB and AFAB-P samples

Variable	**FA** (N=152)		**No FA** (N=142)		**Total** (N=294)	
Age	Mean	14.09	Mean	13.87	Mean	13.98
	SD	1.81	SD	1.77	SD	1.792
	Min	11	Min	11	Min	11
	Max	16	Max	16	Max	16
Gender	**N**	**%**	**N**	**%**	**N**	**%**
Male	72	47.4	66	46.5	138	46.9
Female	78	51.3	76	53.5	154	52.4
Prefer not to say	2	1.3	0	0		
Ethnicity	**N**	**%**	**N**	**%**	**N**	**%**
British	116	76.8	118	83.1	234	79.6
White European	20	13.2	12	8.5	32	10.9
Indian	1	0.7	1	.7	2	.7
Pakistani	4	2.6	2	1.4	6	2.0
Bangladeshi	2	1.3	1	.7	3	1.0
Chinese	0	0	1	.7	1	.3
Black African	2	1.3	1	.7	3	1.0
Black Caribbean	0	0	1	.7	1	.3
Other Black background	1	0.7	0	0	1	.3
Other/mixed ethnic group	6	3.9	5	3.5	11	3.7
Outgrown at least one FA	**N**	**%**	**N**	**%**	**N**	**%**
	50	32.9	30	21.1	80	27.2
Other atopic conditions	**N**	**%**	**N**	**%**	**N**	**%**
Asthma	96	63.2	35	24.6	131	44.6
Eczema	87	57.2	44	31	131	44.6

Hay fever	111	73	64	45.1	175	59.5

Relative with FA	**N**	**%**	**N**	**%**	**N**	**%**
Parent	68	44.7	38	26.8	106	36.1
Sibling	37	24.3	28	19.7	65	22.1
Grandparent	23	15.1	12	8.5	35	11.9
Aunt/uncle	22	14.5	14	9.9	36	12.2
Cousin	27	17.8	17	12	44	15
Other	4	2.6	4	2.8	8	2.7
None	46	30.3	76	53.5	122	41.5

Region of residence	**N**	**%**	**N**	**%**	**N**	**%**
East Midlands	26	17.1	10	7.0	36	12.2
East of England	16	10.5	11	7.7	27	9.2
London	12	7.9	10	7.0	22	7.5
North East England	8	5.3	10	7.0	18	6.1
North West England	17	11.2	20	14.1	37	12.6
Northern Ireland	4	2.6	4	2.8	8	2.7
Scotland	7	4.6	11	7.7	18	6.1
South East England	24	15.8	10	7.0	34	11.6
South West England	3	2	5	3.5	8	2.7
Wales	10	6.6	12	8.5	22	7.5
West Midlands	10	6.6	25	17.6	35	11.9
Yorkshire and the Humber	11	7.2	13	9.2	24	8.2
Prefer not to say	4	2.6	1	0.7	5	1.7

Table 14: FA specific demographics

Variable		
Age of first reaction	**Mean**	**SD**
	4.84	4.06
Age of diagnosis	**Mean**	**SD**
	5.6	4.28
Allergen	**N**	**%**
Peanut	90	30.6
Other nut	59	20.1
Sesame seeds	13	4.4
Cow’s milk	30	10.2
Egg	25	8.5
Soya	18	6.1
Fish	14	4.8
Shellfish	20	6.8
Latex	7	2.4
Tree pollen	44	15
Grass pollen	55	18.7
Other	36	12.2
N of FA	**N**	**%**
1	64	42.1
2	32	21.1
3+	56	63.2
Method of diagnosis	**N**	**%**
Skin prick test	99	65.1
Food challenge	39	25.7
Blood test	75	49.3
History	38	25
Other	9	5.9
Don’t know	8	5.3

Prescription	**N**	**%**
AAI	98	64.5
Antihistamines	103	67.8
Other	19	12.5
Hospital due to FA	**N**	**%**
	81	53.3
Anaphylactic reaction	**N**	**%**
	59	38.8
Symptoms of worst reaction	**N**	**%**
Vomiting	69	45.4
Abdominal pain	52	34.2
Rash	87	57.2
Face swelling	57	37.5
Tingling/sore mouth	71	46.7
Swelling of lips or tongue	59	38.8
Throat tightening/ difficulty swallowing	82	53.9
Breathing difficulties	68	44.7
Wheeze	58	38.2
Collapse/faint	11	7.2
Other	22	14.5
Treatment of worst reaction	**N**	**%**
Antihistamines	104	68.4
Painkillers	41	27
AAI	39	25.7
Nothing	14	9.2
Other	21	13.8

6.4.2. Adolescent Food Allergy Beliefs Scale: Food Allergy Questionnaire (AFAB)

6.4.2.1. Initial internal reliability checks of AFAB

To ensure ease of interpretation, the entire scale was reverse scored so that a higher score related to a greater belief in that item. The Cronbach's Alpha for the full 43-item FA version of the AFAB scale was .848. This is a high internal validity with low risk of item redundancy (Pallant, 2011). Cronbach's Alpha if item deleted varied from .838 to .851 and so no items were removed at this stage. Multicolinearity checks were made to assess for item redundancy, in a correlation matrix of all items, any above .800 would be removed from the scale but none were (highest r score observed .678).

6.4.2.2. Factor analysis of AFAB

Principal components analysis (PCA) with varimax rotation was run. The Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy is recommended to be .600 or above. The KMO of the FA scale was .788 and the Bartlett's Test of Sphericity was significant ($\chi 2$ (903) = 3006.99, $p < .001$) so the scale was satisfactory for analysis. Initially, 12 items had eigenvalues over 1 with a variance of 67.97%. The point of inflection on the scree plot was 3 (Figure 7) and so factor analysis was run forcing 2 components.

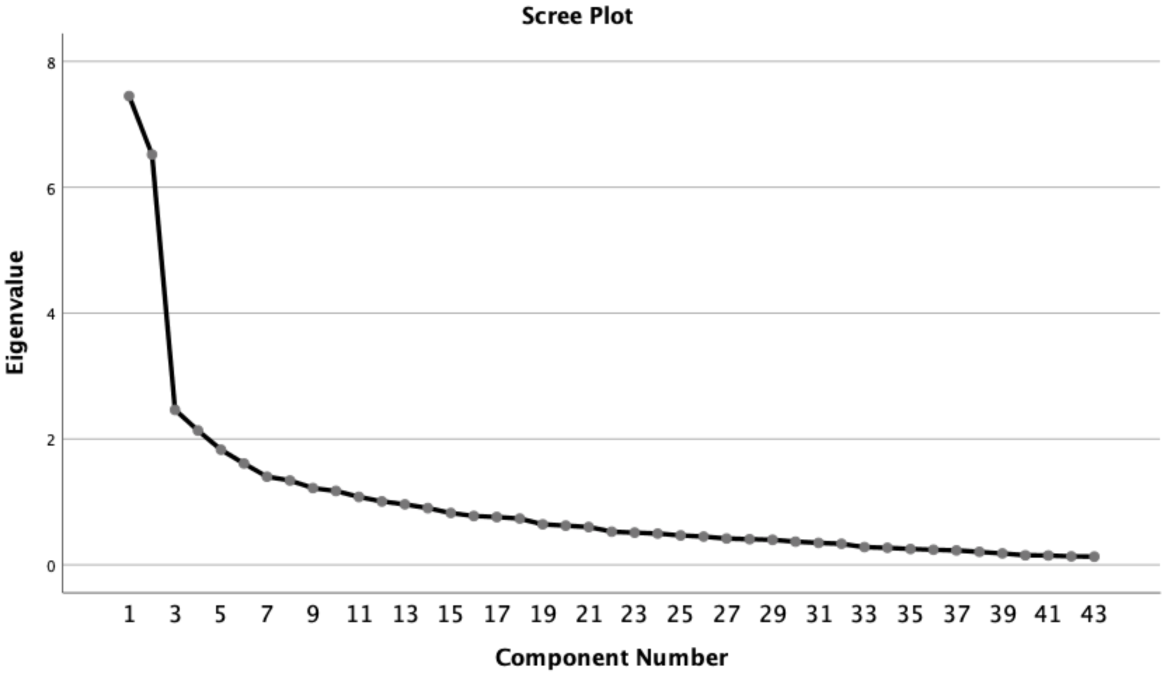


Figure 7: Scree plot of AFAB

Factor Analysis with 2 components explained 32.48% total variance. Items with factor loadings of less than 0.3 were removed. This left 23 items (Table 15) and increased total variance to 51.44% and KMO to .872. Component 1 explained 27.22% of variance and Component 2 explained 24.22%. The item ‘My food allergy is annoying’ was removed as it loaded onto both factors. Items removed may be found in Table 16. The two components were named:

FA1) ‘Low severity and burden’
FA2) ‘High impact of food allergy’

Table 15: Components 1 and 2 in the reduced AFAB

Rotated Component Matrix^a

	Component	
	1	2
I think food allergy seriousness is exaggerated.	.848	
My treatment will cure my food allergies.	.761	
I think life is easy with a food allergy.	.730	
I think all restaurants understand food allergies well.	.708	
My food allergy would not affect any holidays I have abroad.	.697	
Symptoms of a food allergy are mild, like a rash or an upset stomach.	.690	
Food allergies and food intolerances are the same thing.	.655	
I think ‘may contain’ labels are always accurate.	.620	
It’s better to let my parent take responsibility for my food allergy (e.g. check labels and carry my adrenaline-pen).	.612	
I think there are enough allergy-free/alternative options (e.g. dairy free milks like almond milk).	.604	
I’m not worried about my food allergy.	.601	
Living with a food allergy gets easier as you get older.	.577	
I would not use an adrenaline pen (e.g. Epi-Pen/JEXT) if I had a reaction because I do not like needles.	.574	

Having a food allergy has changed my social life.		.827
I think my food allergy makes school difficult.		.779
My food allergy makes me feel sad.		.745
I think food allergies make new friendships difficult.		.740
I think food allergies make romantic relationships (having a boyfriend or girlfriend) difficult.		.730
School trips are hard with a food allergy.		.728
My food allergy is scary.		.672
My food allergy is unpredictable (I don't know when I could have a reaction).		.670
My food allergy has a big impact on my life.		.594
My food allergy is annoying.	-.422	.460
Eigenvalues	7.43	6.54
% variance explained	27.22	24.22

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.

a. Rotation converged in 3 iterations.

Component 1 was labelled ‘Low severity and burden’ as these items reflected a belief that living with FA was not a burden and did not have a large impact on their life. Component 2 was labelled ‘High impact of FA’, as this component included items that related to a belief that FA had a stronger impact on the life of adolescents with FA, emotionally through being sad or scared, socially when engaging with friends, and in the school setting.

Table 16: Items removed from AFAB

Items removed from AFAB
A food allergy is a serious condition
Food allergies and food intolerances are the same thing.
A food allergy is a life-threatening condition.
Food allergies are common.
You can grow out of food-allergies.
I will have my food allergy for the rest of my life.
Primary school was easier than secondary school for managing my food allergy. (If you did not find out you had an allergy until secondary school, put whether you think it would have been easier in primary school).
If I had a reaction to food, I could handle the situation.
My actions (e.g. checking ingredients) affect how serious my food allergy is.
I should always check ingredients in food.
I think schools could do more for people with a food allergy.
Some places are more difficult than others when trying to manage food allergy.
I can handle having my food allergy.
I think nuts should be banned in schools.
I think ‘may contain’ labels are always accurate.

6.4.2.2. Reliability analysis of the reduced scale

The Cronbach’s alpha of the reduced 22-item FA scale was .867. Cronbach’s alpha if item removed varied from .853 to .869, however the Cronbach’s alpha scores for the sub-scales would be reduced if items were removed and so no further items were removed. The sub-scale called Low severity and burden has 13 items and a Cronbach’s alpha score of .897. Cronbach’s alpha if item removed varied from .880 to .895 and so no further items were removed. The sub-scale called High Impact of FA contains 9 items and a Cronbach’s alpha score of .892. Cronbach’s alpha if item removed varied from .872 to .890. Therefore, no items were removed.

6.4.2.3. Cross-sectional validity of AFAB

Cross-sectional validity was run with the FA sample, correlating the AFAB with the four validation scales; BIPQ, MHLC-B, Kidcope and ARQ-P. Cohen (1988, pp. 79–81) suggests the following correlation sizes; r=.1 to .29 is small, r=.3 to .49 is medium and r=.5 to 1.0 is large.

The BIPQ has 8 subscales, and the total score may also be used and represents the degree to which the illness is perceived as threatening or benign. Correlations between the BIPQ and the AFAB can be seen in Table 17.

Table 17: AFAB subscales and BIPQ correlations

BIPQ	**Low severity and burden (N=147)**	**High impact of FA (N=147)**
Consequence	.036	**.209***
Timeline	**-.538****	-.093
Personal control	.081	-.045
Treatment control	**.185***	.094
Identity	**.211***	.147
Illness concern	.083	**.256****
Coherence	**-.166***	-.137
Emotional representation	.055	**.217****
BIPQ Total	.008	**.237****

****Correlation significant at 0.01 level**

***Correlation significant at 0.05 level**

The sub-scale ‘Low severity and burden’ was strongly negatively correlated with the BIPQ factor ‘timeline’. Treatment control and identity had small positive correlations with this sub-scale and coherence had a small negative correlation. This suggests that the longer an adolescent believes that their condition will continue, the higher their perceived severity and burden. A greater belief that FA is not severe was related to less understanding of their FA (coherence) and a lower belief in treatment for controlling their FA

The sub-scale High impact of FA was significantly positively correlated with illness concern, emotional representation and consequence. This indicates that a strong belief that FA has a big impact was related to higher illness concern, emotional representation of illness, and perception of consequence. The total score for the BIPQ also had a low positive correlation with subscale 2, suggesting that the higher perceived threat may increase perceived impact of FA.

Correlations between the AFAB and health locus of control can be seen in Table 18.

Table 18: AFAB subscales and MHLC-B correlations

MHLC-B	Low severity and burden, N=144	High impact of FA, N=144
Internal	.138	0.56
Chance	**.443****	**.282****
Powerful others	**.315****	**.235****

****Correlation significant at 0.01 level**

***Correlation significant at 0.05 level**

Both FA subscales had a significant positive correlation with the two external locus of control factors. Low severity and burden had a medium positive correlation with chance and powerful others. Impact of FA presented a similar trend though at a lower correlation. This suggests that a stronger belief that health is due to chance relates to greater belief that FA is not a burden. A higher belief that health is the responsibility of others such as parents and doctors may correlate to a greater belief that FA is not a burden. However, stronger beliefs in the High impact of FA was also related to stronger beliefs in chance and powerful others being in control of their health.

KIDCOPE comprises ten coping styles: distraction, social withdrawal, cognitive restructuring, self-criticism, blaming others, problem solving, emotional regulation, wishful thinking, social support and resignation. Frequency and efficacy scores were correlated with the AFAB and can be seen in Table 19. Frequency scores include all adolescents as the scale goes from do not use at all to use most of the time. Efficacy scores are only included for those who did use the strategy as they refer to how effective the adolescent thinks the strategy is. The N for each coping strategy in the table refers to the number of adolescents who said they used that strategy.

Table 19: AFAB subscales and Kidcope correlations

Kidcope	Frequency N=146		Efficacy	
	Low severity and burden	High impact of FA	Low severity and burden	High impact of FA
Distraction N=128	.050	.151	.059	.047
Social withdrawal N=113	-.049	**.237****	.088	-.009
Cognitive restructuring N=121	.111	.070	.040	.058
Self-criticism N=104	**.237****	.083	**.198***	-.052
Blaming others N=105	**.325****	**.173***	**.196***	-.116
Problem solving N=124	.142	-.027	**-.179***	.046
Emotional regulation 1 N=105	**.261****	.061	.176	.126
Emotional regulation 2 N=117	**.283****	-.019	**-.197***	.143
Wishful thinking N=122	.062	-.004	.126	-.052
Social support N=124	.096	.019	-.051	.079
Resignation N=123	.163	.063	.041	.158

***Correlation significant at 0.05 level**

****Correlation significant at the 0.01 level**

Low severity and burden was positively correlated with frequency of use of self-criticism, blaming others, and both emotional regulation strategies. High impact of FA was only significantly positively correlated with frequency of blaming others.

Strong beliefs about Low severity and burden of FA were significantly correlated with reporting that the following coping strategies were more effective: self-criticism and blaming others. Emotional regulation 2 and problem solving had small negative correlations with High impact of FA, suggesting these strategies were perceived as less effective. No efficacy scores in the coping strategies were significantly correlated with High impact of FA.

Correlations with risk-taking as measured by the ARQ-P can be found in Table 20.

Table 20: AFAB subscales and ARQ-P correlations

ARQ-P	Low severity and burden, N = 141	High impact of FA, N = 141
Thrill-seeking	**-.433****	**-.192***
Rebellious	.137	-.004
Reckless	**.278****	.003
Antisocial	-.092	-.114

****Correlation significant at 0.01 level**

***Correlation significant at 0.05 level**

Low severity and burden had a medium negative correlation with beliefs that thrill seeking is risky and a small positive correlation with reckless beliefs showing that those who did not feel these behaviours were risky, had a stronger belief in the low impact of FA. However, a strong belief in the high impact of FA also related to a belief that thrill-seeking behaviour was not risky. Rebellious and antisocial beliefs were not significantly correlated with either subscale.

6.4.2.4. Discriminative validity – AFAB

Discriminative validity was used to assess how the scales discriminated between groups that should be dissimilar (Pseudovs et al., 2007), such as gender, age, age of diagnosis and prescription of AAI. These groups were tested in particular as they were highlighted in the qualitative studies (Chapter 4 and Chapter 5) and in previous research discussed in the introduction as important.

- Gender

Two independent samples t-tests results explored gender differences for subscale 1 (Low severity and burden) and subscale 2 (High impact of FA) independently. For low severity and burden, differences between males (M=34.95, SD=11.30) and females (M=32.15, SD=11.39, t(148) = 1.513. p=.132, two-tailed) was not significant. The mean difference was 2.80 (95% CI -.858 to 6.47).

There was no significant difference between males (M=30.46, SD=7.88) and females (M=30.62, SD=8.76, t(148)= -.116, p=.908) for the scores on the High impact of FA subscale. Mean difference was .157 (95% CI= -.254 to .285). Eta-squared was very low for both analyses at 0.0.

- Age

Correlational analysis was run on age at the time of the study and the two subscales (Table 21). Low severity and burden had a small positive correlation with age at time of the study which was significantly correlated at the p=<0.5 level. This suggests that as age increases, the belief that FA has low severity and burden increases, meaning that FA is believed to be more severe in younger participants.

Table 21: Age and AFAB subscale correlations

	Low severity and burden	**High impact of FA**
Age in years	**.193***	.042

***. Correlation is significant at the 0.05 level (2-tailed).**

- Age of diagnosis

Another correlational analysis was run with age of diagnosis and the two FA subscales (Table 22). Low severity and burden had a medium positive correlation with age of diagnosis, significant at the p=<.001 level. This indicates that a higher age of diagnosis may be related to a stronger belief that FA as a condition has low severity and burden, suggesting that adolescents believe FA is less severe if they are diagnosed at an older age.

Table 22: Age of diagnosis and AFAB subscale correlations

	Low severity and burden	**High impact of FA**
Age of diagnosis	**.303****	.139

***. Correlation is significant at the 0.00 level (2-tailed).**

- Prescription of AAI

There was a difference in scores on the subscale measuring low severity and burden, depending on whether the participant had been prescribed an AAI or not. Those with an AAI had a higher score on this sub-scale (M=31.78, SD=11.54) than those who did not (M=36.63, SD=10.32, t(150)=-2.70, p=.011). The mean difference was -4.85 (95% CI = -8.58 to -1.13).

There was no difference in mean scores for the high impact of FA sub-scale between those who had been prescribed an AAI (M=30.93, SD=8.54) and those who had not (M=29.67, SD=7.80, t(150)= -.899, p=.37). Mean difference was -1.26 (95% CI =-1.51 to 4.04).

6.4.3. Adolescent Food Allergy Beliefs Scale: Peers without Food Allergy Questionnaire (AFAB-P)

6.4.3.1. Initial reliability checks of AFAB-P

The Cronbach's Alpha for the full 43 item scale in the sample without FA (AFAB-P) was .771. This also is a high internal validity with low risk of item redundancy (Pallant, 2011). Cronbach's Alpha if item deleted varied from .768 to .792 and so no items were removed at this stage. Multicolinearity checks were made to assess for item redundancy, any above .800 would be removed from the scale but none were (highest r score observed .798).

6.4.3.2. Factor analysis of AFAB-P

The initial scale comprised of 43 items. Kaiser-Meyer-Olkin Measure of Sampling Adequacy was .697 and Bartlett's Test of Sphericity was significant ($\chi 2$ (903) = 2412.53, p < .001). A total of 13 components had eigenvalues higher than 1.0, which would explain 66.96% of variance. As this was too many to extract, the scree plot was examined (Figure 8) which suggested extracting 3 components.

A 3-component solution was run but once cross-loading variables are removed, there would only be a single primary loading variable (which is a score >0.6), and so a solution was run extracting 2 components. Items with factor loadings of less than 0.3 were removed, which resulted in a reduced scale of 14 items (Table 23). This increased the KMO to .763 and variance to 52.418%. Items removed may be found in Table 24.

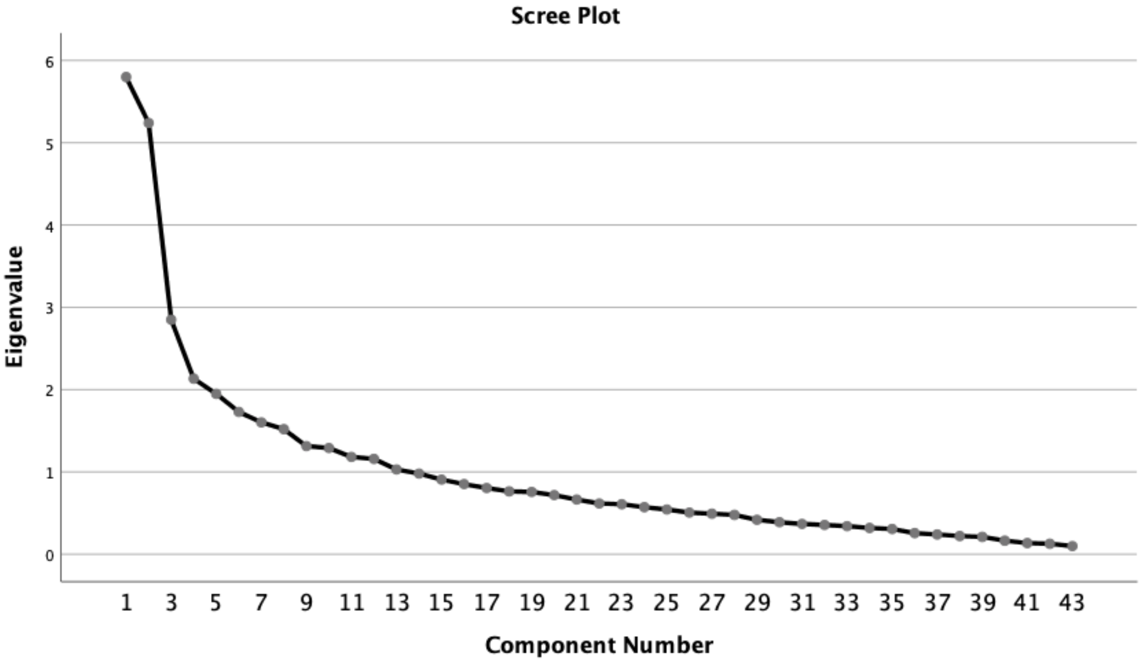


Figure 8: Scree plot of AFAB-P

Component 1 explains 30.37% of variance and Component 2 explains 22.05%. There were 8 factors in component 1, and 6 factors in component 2 and these components were labelled as follows:

NFA1) ‘Emotional and social difficulties associated with having FA’
NFA2) ‘Optimistic views of FA’.

Subscale 1 was labelled ‘Emotional and social difficulties associated with having FA’ as this component focused on the barriers in living with FA. Similar to the AFAB subscale 2 ‘High impact of FA’, this subscale focuses on beliefs regarding social issues in forming peer relationships, managing FA at school and emotional challenges such as feeling sad or scared. Subscale 2 was labelled ‘Optimistic views of FA’, as items were related to beliefs that FA does not have a high impact on a person's life. This component includes items related to beliefs that FA is easy to manage, similar to the AFAB subscale 1 'Low severity and burden'. This similarity in subscales for the AFAB and AFAB-P may suggest that adolescent beliefs may be similar across these samples.

Table 23: Components 1 and 2 in the reduced AFAB-P

Rotated Component Matrix[a]		
	Component	
	1	2
Having a food allergy would impact my social life.	.811	
I think a food allergy would make school difficult.	.746	
I think food allergies can make new friendships difficult.	.737	
School trips would be hard with a food allergy.	.729	
If I had a food allergy, I would feel sad.	.707	
If I had a food allergy, I would feel scared.	.706	
I think food allergies can make romantic relationships (having a boyfriend or girlfriend) difficult.	.705	
If I had a food allergy, I would feel annoyed.	.596	
If I had a food allergy, I would not feel worried.		.761
If someone with a food allergy ate something with a 'may contain' label on for something they were allergic to, nothing will happen.		.757
I think food allergy seriousness is exaggerated.		.708
I think life is easy with a food allergy.		.697
Treatment can cure food allergies.		.586
I think there are enough allergy-free/alternative options (e.g. dairy free milk like almond milk).		.565
Eigenvalues	4.26	3.08
% Variance explained	30.37	22.05
Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser Normalization.		
a. Rotation converged in 3 iterations.		

Table 24: Items removed form AFAB-P

Items removed from AFAB-P
A food allergy is a serious condition.
Food allergies and food intolerances are the same thing.
Symptoms of a food allergy are mild, like a rash or an upset stomach.
A food allergy is a life-threatening condition.
Food allergies are common.
You can grow out of food-allergies.
I will have my food allergy for the rest of my life.
My food allergy has a big impact on someone’s life.
Food allergies are unpredictable (I don’t know when I could have a reaction).
People with food allergies should always check ingredients in food.
Food allergy symptoms get better as you get older.
Primary school would be easier than secondary school for people with a food allergy.
Treatment can cure food allergies.
I would not use an epi-pen if I someone a reaction because I do not like needles.
If someone had a reaction to food, I could handle the situation.
Someone’s actions (e.g. checking ingredients) affect how serious their food allergy is.
If I had a food allergy, I think it would be better to let a parent take responsibility for the food allergy (e.g. check labels and carry my adrenaline-pen).
I think restaurants understand food allergies well.
I think schools could do more for people with a food allergy.
Some places are more difficult than others when trying to manage food allergy.
If I had a food allergy would not affect any holidays I have abroad.
I can handle having a food allergy.
I think nuts should be banned in schools.
I think ‘may contain’ (e.g. ‘may contain nuts’) labels are important.
I think ‘may contain’ labels are always accurate.
I do not think ‘may contain’ nuts labels need to say which nuts are included.
Nut allergies are the most serious of food allergies.

It’s easier to be born with a food allergy than find out you have it when you’re a teenager.
If I had a food allergy, it would be part of who I am.
I don’t think food allergies limit people when they are adults

---

6.4.3.3. Reliability analysis of reduced scale

The total Cronbach’s alpha for the reduced scale was .778. Cronbach’s alpha if item deleted varied from .745 to .796, however as the subscale alphas would be reduced if items were removed, all items were retained. Component 1 had a Cronbach’s alpha of .866. Cronbach’s alpha scores if item deleted ranged from .835 to .863. Component 2 had an alpha of .783. Range if items deleted were from .725 to .774.

6.4.3.4. Cross-sectional validity of AFAB-P

Similar to the reduced AFAB, the reduced AFAB-P was also validated against the four subscales BIPQ, Kidcope, MHLC-B and ARQ-P.

Correlations with illness perceptions as measured by the BIPQ can be found in Table 25.

Table 25: AFAB-P and BIPQ correlations

IPQ	**Emotional and social difficulties, N=141**	**Optimistic views of FA, N=141**
Consequence	**.541****	-.140
Timeline	**.265****	**-.313****
Personal control	-.061	**.183***
Treatment control	-.096	**.231****
Identity	**.384****	.003
Illness concern	**.438****	**-.183***
Coherence	-.058	.013
Emotional representation	**.561****	-.071
BIPQ Total	**.370****	-.058

****Correlation significant at 0.01 level**
***Correlation significant at 0.05 level**

Greater belief in Emotional and social difficulties associated with having FA was correlated with greater consequences of illness, timeline, emotional representation, identity, and illness concern. The sub-scale was also positively correlated with the BIPQ total score. Stronger Optimistic views of FA were related to a stronger belief in a shorter timeline for FA and less illness concern, a greater belief in personal control and treatment control. Most correlations were medium to large. Coherence was the only factor not significantly correlated with either subscale.

Correlations with health locus of control as measured by the MHLC-B can be found in Table 26.

Table 26: AFAB-P and MHLC-B correlations

MHLC-B	**Emotional and social difficulties, N=138**	**Optimistic views of FA, N=138**
Internal	.004	.060
Chance	.063	**.213***
Powerful others	.131	**.236****

****Correlation significant at 0.01 level**
***Correlation significant at 0.05 level**

Emotional and social difficulties associated with having FA did not correlate with any of the MHLC-B domains. More optimistic views of FA were related to a greater belief in the two external locus variables, chance and powerful others but the correlations were small.

Correlations with coping as measured by the Kidcope can be found in Table 27. As described above, the N for each coping strategy refers to the number of adolescents who said they used that strategy for efficacy.

Table 27: AFAB-P and Kidcope correlations

Kidcope	**Frequency N=137**		**Efficacy**	
	Emotional and social difficulties	**Optimistic views of FA**	**Emotional and social difficulties**	**Optimistic views of FA**
Distraction N=119	**.178***	-.122	-.154	.092
Social withdrawal N=111	.074	.146	.050	-.041
Cognitive restructuring N=117	-.051	-.001	-.116	.061
Self-criticism N=88	.084	**.220****	-.148	-.111
Blaming others N=90	.118	.163	-.043	-.085
Problem solving N=121	.031	-.051	-.041	-.016
Emotional regulation N=96	.154	.115	-.124	-.035
Emotional regulation 2 N=107	-.058	.078	.011	.027
Wishful thinking N=110	.052	.065	-.015	-.036
Social support N=126	-.096	-.109	.028	-.003
Resignation N=105	.106	.074	.175	-.059

****Correlation significant at 0.01 level**

***Correlation significant at 0.05 level**

Emotional and social difficulties had a small positive correlation with frequency of using distraction as a coping technique. Optimistic views of FA had a significant positive correlation with frequency of using self-criticism as a coping strategy. No efficacy scores for the Kidcope were significantly correlated with the subscales in the AFAB-P.

Correlations with risk-taking as measured by the ARQ-P can be found in Table 28.

Table 28: AFAB-P and ARQ-P correlations

ARQ-P	**Emotional and social difficulties, N=137**	**Optimistic views of FA, N=137**
Thrill-seeking	**-.214***	-.097
Rebellious	-.116	.115
Reckless	-.094	**.369****
Antisocial	-.156	.129

****Correlation significant at 0.01 level**

***Correlation significant at 0.05 level**

Emotional and social difficulties of living with FA had a small negative correlation with thrill-seeking beliefs. 'Optimistic views of FA' had a medium positive correlation with reckless beliefs. Rebellious and antisocial beliefs are not significantly correlated with either subscale.

6.4.3.5. Discriminative validity AFAB-P

- **Gender**

An independent samples t-test was performed to explore differences in scores between males and females in subscale 1. The difference between males (M=28.89, SD=5.88) and females (M=27.74, SD=6.07) t(140) = -1.15, p=.253) was not significant. The mean difference was 1.16 (95% CI = -.834 to 3.15).

A further t-test explored gender and subscale 2. The difference between males (M=14.45, SD=3.78) and females (M=14.72, SD=4.25, t(140)=-.396, p=.693) was also not significant. The mean difference was -.269 (95% CI = -1.16 to 1.07).

- **Age**

Correlational analysis was run on age and the two subscales (Table 29). Subscale 2, Optimistic beliefs about FA, was significant negatively correlated with age in years at the time of the study. This suggests that in older participants, optimistic beliefs are stronger.

Table 29: Age and AFAB-P subscale correlations

	Emotional and social difficulties	**Optimistic beliefs about FA**
Age in years	.023	**.189***

***. Correlation is significant at the 0.05 level (2-tailed).**

6.5. Discussion

The AFAB comprises of two versions; one for adolescents aged 11-16 years with a current diagnosed FA, and one for adolescent peers aged 11-16 years without a current diagnosed FA (AFAB-P). Each version has two subscales. The AFAB may be useful to determine adolescent beliefs about FA and whether these beliefs need addressing. The FA version may be used in clinics to highlight if psychological support or training is needed, for example if there is a belief that the AAI is too scary for them to use. The version for peers without FA may be useful for friends or siblings, or for school peers (for example in a class where an adolescent has FA), to identify beliefs that may need addressing which may help peers have a better understanding of FA.

The scales contained different items, with the AFAB-P reduced by 30 items and the AFAB reduced by 15. This may be due to the adolescents without FA in this sample having less exposure to people with FA than in the qualitative sample, and as a result having weaker beliefs regarding different aspects of FA. The sample of adolescents with FA may have found more items important and therefore expressed stronger beliefs in relation to these, therefore leading for them to be included. As the two scales were different, this suggests that having two different scales is beneficial for the different populations to be relevant and representative of the adolescents' beliefs.

6.5.1. Reliability

The overall scales and the subscales for each version had good internal reliability. Pallant (2011) recommends a minimum of 0.7, which all scales and subscales exceeded. The full AFAB had an alpha score of .848, and the AFAB-P has an alpha score of .771. The subscales of the AFAB had alpha scores of .892 to .897, and the AFAB-P subscales had alpha scores of .783 to .866.

The subscales that comprise the AFAB and AFAB-P are listed in Table 30 below. Sub-scales are very similar across scales; one sub-scale includes items related to beliefs that FA is low in severity and burden while the other includes items related to beliefs that FA has a high impact and is difficult to manage.

Table 30: Scales and subscales

Scale	Subscale 1	Subscale 2
AFAB	FA1) Low severity and burden	FA2) High impact of FA
AFAB-P	NFA1) Emotional and social difficulties associated with FA	NFA2) Optimistic beliefs about FA

6.5.2. Construct validity of AFAB

The AFAB demonstrated good construct validity, with small, medium and large correlations between the sub-scales and the validation questionnaires. Generally, correlations were small, which may suggest that the AFAB is not strongly related to the constructs assessed, or that power may be low and a higher sample is required.

- BIPQ

In correlations between the AFAB subscales and the BIPQ, ‘Low severity and burden of FA’ had a moderate negative correlation with timeline suggesting the longer an adolescent perceives that their FA will continue, the weaker their beliefs that their FA is low severity and burden. In previous research by Jones et al. (2015), timeline was significantly correlated with adherence in a sample aged 13 to 19 years old. This may support findings in this research as in Jones et al.’s (2015) study, increased perceptions of severity led to increased adherence behaviours.

Lower coherence (an understanding of the condition) was related to an increase in beliefs that FA is not severe or burdensome. Less understanding of the risks associated with FA, such as anaphylaxis, has been linked to beliefs that FA is not severe in the qualitative studies (Chapter 4 and Chapter 5), and has been associated with increased perceived acceptability of risk-taking behaviour such as consumption of food with warning labels or not carrying an AAI. This is supported by Jones et al. (2014), who has suggested that this behaviour is also related to perceived severity and that adherence improves with increased perceived severity of FA.

Treatment control was also associated with stronger beliefs that FA had low severity and burden in the AFAB sample. Confidence in ability to use AAIs and always carrying their AAI with them was linked to beliefs FA was manageable in Chapter 4 of this thesis, where concerns about not being able to administer an AAI properly was related to higher anxiety in the qualitative study with adolescents with FA.

Subscale 2 of the AFAB, ‘High impact of FA’, had positive correlations with consequence, illness concern, emotional representations and the full BIPQ score. These correlations suggest that as consequence, illness concern, emotional representations and perceived threat of illness increase, perceived impact of FA also increases. These correlations suggest that these beliefs may make life with FA feel more challenging. Increased perception of consequences of FA, such as an anaphylactic reaction compared to a rash, or that a reaction could happen at any time, had a stronger impact on adolescents’ lives. This was found in the qualitative interviews, where adolescents who believed their symptoms were mild, often treated their FA with an antihistamine and engaged in FA-related risky behaviours, while those at risk of anaphylaxis were stricter with avoidance. A belief that FA has more impact on their lives was also related to more emotional representations. This is supported by previous literature where FA has been related to strong feelings of anxiety (Stjerna, 2015; DunnGalvin et al., 2009; Marklund et al., 2007; MacKenzie et al., 2010; Fenton et al., 2011).

Personal control and identity were not significantly correlated with the AFAB subscales. The identity construct is concerned with how many symptoms are experienced and adolescents with FA may not have had much experience of symptoms, which only occur after ingestion of sufficient quantities of the allergen. It is unclear why feelings of personal control were not related to any FA beliefs and this needs to be explored further. It could be that adolescents generally have greater beliefs in more external sources of control of their FA, than personal control.

In a previous study by Jones et al. (2015), illness identity, timeline cyclical beliefs and emotional representations explained 25% of the variance in a sample of adolescents aged 13-19 years, which supports some of the correlations of this study. However, correlations with coherence, treatment control, consequence, illness concern, and the full BIPQ score were not found in Jones et al.'s (2015) study, and identity which was correlated in the Jones et al. (2015) study, was not correlated with either of the AFAB subscales.

- MHLC-B

For the MHLC-B subscales, the two external health locus of control variables of chance and powerful others were positively correlated with both subscales of the AFAB. This may be because at this age adolescents are more reliant on external sources for managing their FA, such as parents (DunnGalvin et al., 2009), irrespective of what their beliefs are regarding the impact of their FA. Having an internal locus of control was not significantly correlated with either subscale so may not be relevant to adolescent beliefs about FA.

- Kidcope

'Low severity and burden' was significantly positively correlated with Kidcope frequency scores for self-criticism, blaming others, and emotional regulation. This suggests that increased use of these coping strategies was associated with an increase in the belief that FA was less severe and had less burden. This appears counter-intuitive, as coping strategies would be expected to be used when FA was considered more severe. This may mean that the coping strategies are more effective than the correlations suggest or may suggest that coping strategies are used in stress not associated with FA as the Kidcope is used primarily for stress and the participants were instructed to complete it with general stress in mind. This may mean that they do not view FA as stressful but use these coping strategies in other areas of stress in their lives. High impact of FA had small positive correlations with social withdrawal and blaming others, suggesting that increased use of these coping strategies was associated with stronger beliefs that FA resulted in more impact on life. Blaming others was correlated with both subscales which was surprising but had a stronger correlation with beliefs that FA was perceived as low severity and burden.

'Low severity and burden' of FA had small positive correlations with the effectiveness of using self-criticism and blaming others, and small negative correlations with effectiveness of problem solving and emotional regulation. This suggests that finding problem solving and emotional regulation to be less effective coping strategies and finding self-criticism and blaming others as more effective was related to a stronger belief that FA is not very severe. No coping strategies were correlated with High impact of FA. As sample numbers were lower for effectiveness (N=104 to 128), the low correlations may have been a result of low power.

Significance in the correlational analyses suggests the likelihood of Type-1 error, that the null hypothesis will be rejected when it is true. Power analysis on the other hand, tests the likelihood of Type-2 errors being avoided and Cohen (1988) recommends power parameters are small (>0.2), medium (>0.5), or large (>0.8). Type-2 errors involve the null hypothesis not being rejected when it should be. Post-hoc power calculations using G*Power found Kidcope frequency scores and Low severity and burden subscale correlations with distraction, social withdrawal, wishful thinking, problem solving, and cognitive restructuring had very low power between 0.09 and 0.12. Problem solving and cognitive restructuring had low power from 0.27 to 0.40. These analyses may benefit from being run on a larger sample size. Moderate power of 0.51 was found in this subscale correlated with resignation. All other correlations between social withdrawal, blaming others, and both emotional regulation strategies had high power between 0.83 to 0.98, suggesting that there was an 83-98% likelihood of no Type-2 errors.

In the second subscale, ‘High impact of FA’, correlations with the effectiveness of cognitive restructuring, self-criticism, problem solving, emotional regulation, wishful thinking, social support and resignation had very low power between .05 and .17. Distraction had low power of .45 and blaming others had moderate power of .55. Social withdrawal was the only coping strategy with high power of .83, suggesting a low risk of Type 2 errors. This suggests a larger sample would be more beneficial for the AFAB to test the correlations of the Kidcope and AFAB subscales, especially for subscale 2.

- ARQ-P

Seeing thrill-seeking behaviour as risky negatively correlated with both AFAB subscales, FA1 (Low severity and burden) and FA2 (High impact of FA). This suggests that as the belief that thrill-seeking behaviours is risky increases, the perception that FA has low severity and burden decreases, as does the belief that FA has a high impact on life. As these subscales have different perspectives, it was surprising that this ARQ-P domain was correlated with both subscales, however it may be that all adolescents of this age do not view thrill-seeking behaviour as risky, irrespective of their beliefs about their FA. The sub-scales of the AFAB are also not necessarily about risk-taking behaviour, something that could not be foreseen when the scale was developed.

The belief that reckless behaviours are risky was also positively correlated with ‘Low severity and burden’. This suggests that increased beliefs that reckless behaviours are risky, is related to a stronger belief that FA is not severe and has low burden. As beliefs about risk in rebellious and antisocial behaviours were not significantly correlated with any of the subscales, it could be assumed that these subscales are not relevant to these adolescent beliefs about FA.

6.6.2. Construct validity of AFAB-P

The AFAB-P demonstrated good construct validity, with small to medium correlations between the sub-scales and the validation questionnaires. Similar to the AFAB, correlations were generally small, which suggests that the AFAB is not strongly related to the constructs assessed, or that a higher sample is required to increase statistical power.

- BIPQ

Subscale 1, ‘Emotional and social difficulties’ associated with FA, had positive correlations with consequence, illness concern, emotional representations, and the full BIPQ score. These correlations suggest that as consequence, illness concern, emotional representations and perceived threat of illness increase, perceived impact and difficulties associated with FA also increase, which was also found in the qualitative study with adolescents without FA (Chapter 5).

Identity was also positively correlated with subscale 1, suggesting that having a higher belief that living with FA means experiencing more symptoms is associated with stronger belief in the social and emotional difficulties associated with the condition. This is a different form of identity than is discussed in the qualitative chapters (Chapter 4 and Chapter 5) but is supportive of the perceptions of severity discussed in these chapters.

The belief that FA would last for life and increased illness concern was related to lower scores for the subscale ‘Optimistic views of FA’. Increased treatment control was associated with increased optimistic views in the AFAB-P sample. This was also seen in Chapter 5, where feeling that an AAI would be difficult or scary to use was discussed in relation to FA being less manageable. Stronger optimistic views of FA was related to stronger beliefs in personal control and weaker beliefs in illness concern. In Chapter 5, feeling more in control, for example feeling dietary changes are manageable, was discussed in relation to more optimistic beliefs about living with an FA.

Interestingly, the AFAB-P correlated more highly with all correlated BIPQ outcomes compared to the AFAB. This may be due to participants without FA having stronger beliefs than adolescents who have experienced the condition themselves and therefore have beliefs developed from their own experiences. We have seen in the previous studies how beliefs around AAIs are stronger and more negative in those who had not previously administered them and hypothesising beliefs may result in them being perceived more strongly. Some participants without FA may have not previously considered the condition in this way, and so their initial beliefs may be stronger than those who have been exposed to FA for many years.

Coherence was the only factor not significantly correlated with either of the subscales in the AFAB-P. Adolescents with FA in previous studies have felt that people who do not live with FA do not understand the severity of the condition and lack a good understanding of it (Monks et al., 2010; Stensgaard et al., 2017; Fenton et al., 2011), so it may be that coherence was not considered important by adolescents without FA in this sample.

- MHLC-B

‘Optimistic views of FA’ was the only subscale of the AFAB-P to correlate with the MHLC-B and was only significantly correlated with external locus of control factors. This suggests that as external locus of control increases, ‘Optimistic views of FA’ also increases. These more positive beliefs correlated with an external locus of control may be due to believing that relying on parents and healthcare professionals to support and manage the FA may lead to less concern and distress about management.

- Kidcope

‘Emotional and social difficulties’ associated with FA had a small positive correlation with Kidcope frequency scores for distraction, suggesting that more frequent use of distraction as a coping strategy was associated with stronger beliefs that FA resulted in emotional and social difficulties. ‘Optimistic views of FA’ had a small positive correlation with self-criticism, suggesting that more frequent use of this coping strategy was associated with stronger Optimistic views of FA.

No coping strategy efficacy scores in the Kidcope were significantly correlated with the subscales in the AFAB-P. It may be assumed that these were not considered relevant or this may be due to not experiencing the condition phenomenologically.

Post-hoc power calculations using G*Power for correlations between Kidcope frequency scores and subscale 1, ‘Emotional and social difficulties’, found power to be very small for social withdrawal, cognitive restructuring, self-criticism, problem solving, emotional regulation 2 and wishful thinking, ranging from .06 to .16. There was small power from .20 to .44 for correlations of this subscale with blaming others, emotional regulation 1, social support and resignation. Only the correlation for distraction had medium power of .55.

For subscale 2, ‘Optimistic views of FA’, correlations with cognitive restructuring, problem solving, emotional regulation 2, wishful thinking and resignation had very low power between .05 and .15. There was small power from .25 to .48 for correlations with distraction, social withdrawal, blaming others, emotional regulation 1 and social support. There was one correlation with this subscale with medium power, which was self-criticism, which had a 74% chance of not being a Type-2 error. These power analyses suggest that correlations between the AFAB-P subscales and this validation scale would benefit from being run on a larger sample size to reduce the possibility of Type 2 errors.

- ARQ-P

Thrill-seeking had a low negative correlation with Emotional and social difficulties associated with FA, suggesting stronger beliefs that thrill-seeking behaviour is risky may be associated with weaker beliefs that FA results in emotional and social difficulties, which was an unexpected correlation. Reckless beliefs were also correlated with the other subscale, ‘Optimistic beliefs of FA’. This also suggests that a stronger belief about reckless behaviour being risky increases optimistic views of FA in the sample without FA, which also was an unexpected correlation. These unpredicted correlations may be due to adolescents without FA having less risk perception than adolescents with FA, who engage in risk assessment more frequently. Furthermore, as this scale was based on exploratory research, what items would be seen as important and the resulting subscales were not predictable, and it may be that the resulting sub-scales are not related to risk-taking behaviour.

6.5.3. Discriminative validity of AFAB and AFAB-P

There was no difference in mean scores for males and females in both versions of the scale. Age at time of study had low positive correlations with ‘Low severity and burden’ in the FA sample and ‘Optimistic views about FA’ in the sample without FA. This suggests that beliefs about FA severity reduces with age. This is in contrast to previous research which has suggested that older adolescents view FA as more severe and with a greater burden than younger children (e.g. DunnGalvin et al., 2009). However, this previous research included a larger age range. The current sample included only those at UK secondary school age and so it may be that those aged 11 and 12 at the start of secondary school see FA as more of a burden than those aged 15 to 16 who have had time to learn how to manage their FA. Similar beliefs may also be prevalent in adolescents without FA. This needs further investigation.

Age of diagnosis (for those with an FA) was positively correlated with 'Low severity and burden' on the AFAB, suggesting that being diagnosed later in life was related to an increased belief that FA had low severity and burden. This is in contrast to some of the findings from the qualitative study in this thesis (see Chapter 4), where participants who were recently diagnosed in adolescence found adapting to FA (carrying AAIs, checking labels, etc.) challenging. However, they also believed that their dietary changes were minor. The participants with late diagnoses in Chapter 4 had been diagnosed within a year of the time of interview, which may have affected their beliefs about the impact FA has had on their lives.

There were differences in mean scores for Low severity and burden on the AFAB for prescription of an AAI, with those being prescribed an AAI having stronger beliefs in the low severity of FA. This suggests that having an AAI may present a sense of security. This supports the qualitative findings in Chapter 4, where those who had experienced severe reactions were comforted by the presence of their AAI and gained confidence with administration. Participants who had experienced only minor symptoms previously felt they would never have to use their AAI but were reassured that it was there if they ever needed it. However, in those who had not been prescribed an AAI, they also expressed low perceived severity in the qualitative interviews (Chapter 4). None of the adolescents interviewed who did not have an AAI felt they needed one, which may have been a factor that influenced beliefs in the quantitative sample. However, this data about whether participants felt they needed an AAI if they did not have one were not included in the scale.

6.6. Strengths

This study developed two novel measures for two under-researched target populations, adolescents with FA (AFAB) and adolescent peers without FA (AFAB-P). There was a good representation of gender and ages, particularly those aged 16 years, and participants were spread geographically across the UK. Chronbach alpha scores were also all in a good range, suggesting good internal reliability. Questions were forced response, meaning that there was no missing data in this dataset which increased ease of interpretation. However, this means that some data may have been lost by participants who did not complete the full questionnaire.

6.7. Limitations

The majority of correlations were low to moderate, and some analyses may have been underpowered due to the sample size. Participation numbers may have been low as the original prototype scales were very long and took an average of 20-30 minutes to complete. The original scale was long as it included a lot of items, in addition to the four validation scales which were also quite long. The length of the scale may have caused fatigue effects, resulting in adolescents dropping out and not completing the questions. A recommended ratio of 10 (Pallant, 2011) participants for each item would require 430 participants to complete the prototype scales, which was not achieved. This was also the case for the reduced scales where 230 participants would have been optimal, but only 152 completed it. However, Gorsuch (1983) recommends five participants per item, and so this sample may be considered adequate for the reduced scale. For the AFAB-P, 142 participants completed the original scale of 43 items, which may be considered satisfactory for the reduced scale which contains only 14 items, therefore meeting Pallant's (2011) criteria for 10 participants per item.

Where participants heard about the study was not asked so the effectiveness of the recruitment methods could not be assessed. Although Leicester Royal Infirmary posted out 200 study packs, as these packs included hard copies of the questionnaires as well as online weblinks if participants preferred to complete online, it cannot determine who was recruited through the clinic.

Participants who had grown out of a FA, were included in the scale for adolescents without FA, as previous research has suggested those who grow out of FA are likely to do so in infancy (Sicherer & Sampson, 2014) and so may not have recent memory of living with FA. However, rare cases of adolescents who grew out of their FA recently may have been included in the sample of participants, or they may have stronger awareness of FA as a condition compared to participants who had never experienced a FA.

The reduced AFAB and AFAB-P scales were not assessed by previous participants to determine whether it was still representative of their beliefs about FA. This would have given confirmation over whether the AFAB and AFAB-P were still believed to be useful for assessing adolescent beliefs for use in applied settings such as clinics and schools. However, the previous participants had in-depth qualitative interviews about FA, and may therefore have different views than those who only completed the quantitative scale, especially in the case of adolescents who did not have FA and may have limited knowledge about the condition.

The AFAB and AFAB-P scales need further testing and validation, with a confirmatory factor analysis run to confirm the presence of the sub-scales. Most subscales had only small to moderate correlations, suggesting that they may not be strongly relevant to the scales used in cross-sectional analysis and may not measure aspects such as risk or coping. Importantly, a test-retest needs to be conducted to check consistency over time. It may be useful to do this in a school setting to improve completion rates. Further tests such as cross-cultural validity may be beneficial to test the scale in different countries and see if the AFAB may be useful outside of a UK population.

6.8. Implications

Once further validated, these scales may benefit clinicians, schools, and psychologists working with adolescents with FA. The AFAB may identify beliefs that need addressing, such as distress highlighted by feelings such as sadness or fear, or reluctance to administer AAIs. It may also identify condition barriers, such as perceived difficulties in school, or concerns about developing social relationships. This may highlight when adolescents with FA need further psychological and emotional support. For health professionals working in allergy clinics, a quantifiable measure of patient beliefs can highlight areas that need more support, whether this is reluctance in using an AAI, managing eating outside the home or reducing anxiety about anaphylaxis. In schools, the scales may be used to measure misconceptions that need addressing, for example about FA severity. For psychologists, the scales can measure beliefs of concern and areas to discuss in sessions.

The scale for those without FA can be used for siblings, friends or peers to assess their beliefs and consider how to inform and suggest support. The scales could also be used to assess the effectiveness of interventions to address beliefs. Both scales may be useful for gathering condition beliefs from the adolescent with FA and peers in close contact to develop treatment plans and reduce risk.

6.9. Conclusion

This study aimed to develop and assess two versions of the AFAB, an instrument to measure the strength of condition beliefs in FA. The reliability and validity of the preliminary AFAB and AFAB-P were satisfactory, though further analyses such as confirmatory factor analysis and test re-test are necessary to further validate the scales for use in clinical settings.

Considerations from the results of this scale development, previous research and the qualitative findings will be discussed further in the next and final chapter.

Chapter 7: Discussion

7.1. Overview

This thesis aimed to explore and improve understanding of adolescent beliefs about FA. It intended to do this through four empirical studies. A systematic review identified relevant literature and gaps in research, which in turn informed development of two qualitative studies; a thematic analysis of beliefs of adolescents aged 11-16 years with FA, and a thematic analysis of adolescents aged 11-16 years with no clinical history of FA. These qualitative studies then informed development of two scales; one measuring beliefs of those with FA (AFAB) and one measuring beliefs of peers without FA (AFAB-P). This discussion will frame the findings in terms of dominant theories about beliefs in adolescents to explore how the research contributes to theoretical understanding about the nature and influences on these beliefs. The experience of the research process and the role as a researcher is detailed in a reflexive account, as is appropriate in qualitative research (Lazard & McAvoy, 2017). This chapter then finishes with this research's strengths, limitations, and the overall thesis conclusion.

The main findings of this thesis are that it is believed by those both with and without FA that FA severity is not properly understood, and increased awareness is essential. The need for further education has been highlighted in previous research, but peer acknowledgement of lack of knowledge, combined with empathy and willingness to learn, are unique findings. In the qualitative study with the FA sample, novel themes that explicitly discuss under-researched challenges such as recent adolescent diagnosis and the impact of severity beliefs on risk-taking behaviour are highlighted. The main outcome of this thesis is the development of the Adolescent Food Allergy Belief (AFAB) scale and a version of the scale for peers without FA (AFAB-P), which with further validation, may be useful in clinic and education settings, and improve FA management by addressing patient and peer beliefs.

7.2. Comparison of findings of the qualitative studies to previous research

Three qualitative analyses were conducted during this PhD. The first, a systematic literature review, was analysed qualitatively through a narrative synthesis to review past research. Two interview studies followed this systematic review, the interview schedule developed based on the findings from previous research highlighted in the systematic review. A conceptual framework developed from these studies may be found below in Figure 9.

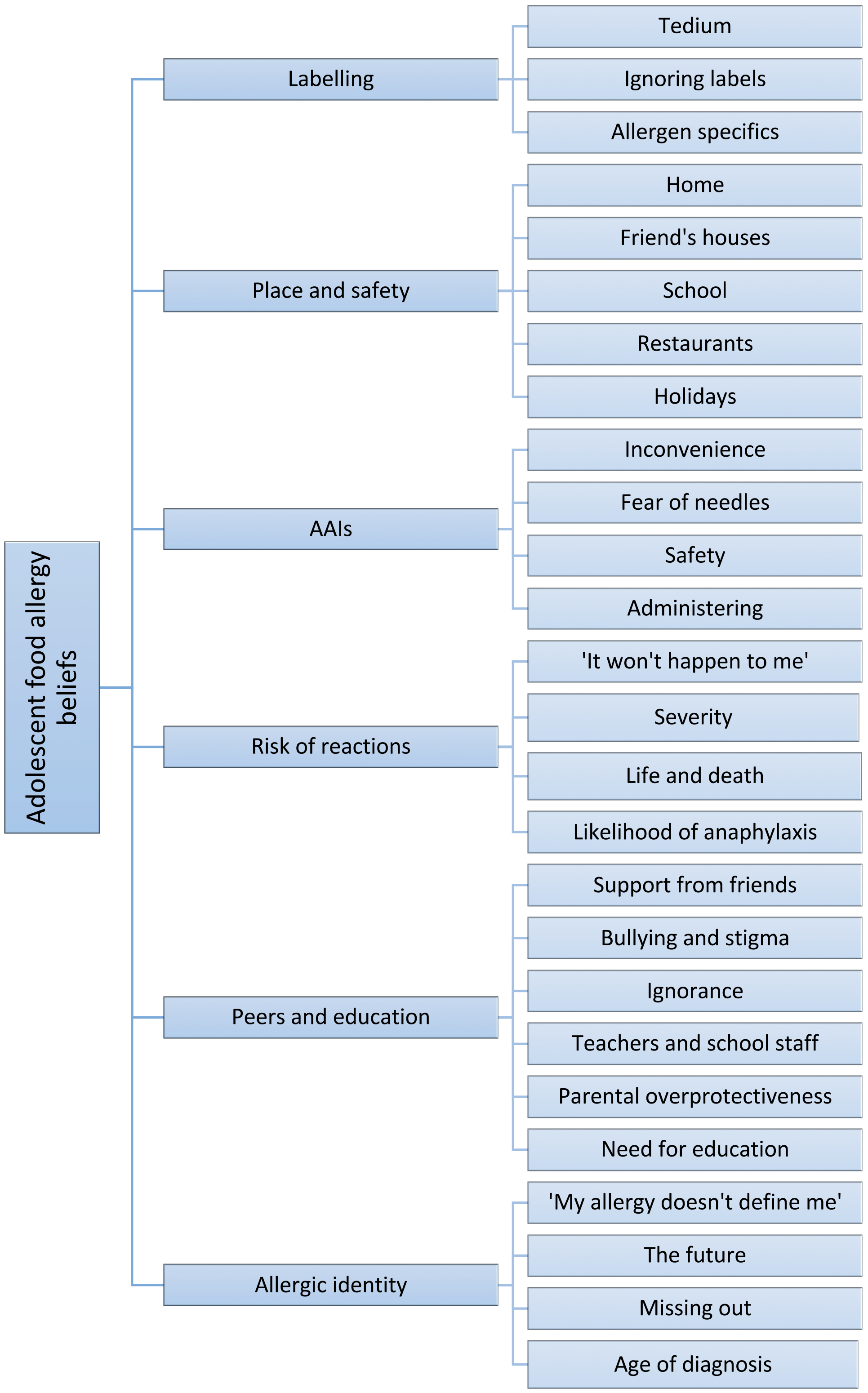


Figure 9: Conceptual framework of adolescent FA based on the systematic review and qualitative studies

The systematic review (Chapter 3) provided a comprehensive view of previous research about the beliefs of adolescents with food allergy aged 11-19 years. The systematic review suggested five themes of interest:

- From home to holidays; navigating different places
- Carriage and use of adrenaline auto-injectors
- Managing the risk of anaphylaxis
- Behaviour and understanding of others
- Food-allergic identity and condition beliefs

In the thematic analysis of interviews of adolescents with FA (Chapter 4), similar elements were seen in the data, however the main themes were different. This thematic analysis identified four themes of focus;

- “I think everyone would take it more seriously.” - Nut allergies as more serious than other FA
- “I don’t like talking about the needle, it just scares me.” – Adrenaline auto-injectors and needle anxiety
- “They’re annoying don’t get me wrong but they’re not super life threatening.” - How severity of FA symptoms affects beliefs
- “I would like to have been born with it and grown up with it because then I would have understood it more and I wouldn’t be so worried.” Challenges of recent diagnosis

Compared to the systematic review and qualitative study of adolescents without FA, two themes have similar elements, while the first and last are different and not previously considered. This may be due to limited previous research in the area of adolescent beliefs about FA but may also be due to the interesting demographics of the sample, including participants recently diagnosed in adolescence, as well as adolescents with milder reported symptoms of FA.

The thematic analysis of adolescents with no clinical history of FA (Chapter 5) identified four themes of interest;

- “I’d feel very worried and scared that I could have an allergic reaction anytime”: Peer perceptions of living with a FA
- “Probably stick to places I know”: The burden of managing FA in safe and risky places

- “Think about how they would feel”: Personal responsibility and supporting people with FA
- “I think that other people should be aware about how bad they can be”: Educating others to increase understanding

There were some thematic similarities in these findings compared to the systematic review, however this data is from the perspective of the peer rather than the person with the condition, for example ‘food-allergic identity and condition beliefs’ were arguably explored through hypothetical scenarios but could not be analysed from the same phenomenological perspective as these adolescents did not have FA themselves.

The systematic review and the thematic analysis of adolescents without FA both identified a theme related to place. While school was briefly mentioned by the adolescents with FA, the majority felt management was good, though some found school trips challenging. Previous research stated adolescents felt home was the safest place to manage FA (Fenton et al., 2013; Stjerna, 2015; Marklund et al., 2007), and the further from home, hospitals and parental safety, the more dangerous a place was believed to be (Stjerna, 2015; Macadam et al., 2012; Akeson et al., 2007). Holidays abroad were considered the most difficult for this reason (Sommer et al., 2014). School was also felt to be difficult to navigate in previous research, due to issues such as stigma, exclusion or bullying (Fenton et al., 2011; Dean et al., 2016; Stensgaard et al., 2017; Fenton et al., 2013) especially in the transition from primary to secondary school (Fenton et al., 2011).

Participants without FA shared these beliefs about home being safest and distance from home being more difficult for those with FA, while participants with FA did not believe this was much of an issue. In regard to holidays abroad, the sample without FA believed that most challenges could be overcome by using an online translator, which was not suggested in previous research but may be a tool more commonly used in recent years. The sample without FA also believed secondary school may be more challenging than primary school due to smaller classes and more observation in primary school. However, concerns about exclusion or bullying was not considered to be an issue by the sample without FA, as they felt that FA did not mark someone as ‘different’ outside of their diet. This is also supported by the FA sample who reported very little experience of stigma or bullying from peers. The theme of ‘Behaviour and understanding of others’ in the systematic review is also supported by the theme ‘“I’d feel very worried and scared that I could have an allergic reaction anytime”: Peer perceptions of living with a FA’.

In the systematic review, the theme of ‘food-allergic identity and condition beliefs’ has similar elements to a theme drawn from the data from adolescents with FA in chapter 5: ‘“They’re annoying don’t get me wrong but they’re not super life threatening.” - How severity of FA symptoms affects beliefs’. In previous research, some adolescents believe FA to be severe which results in anxiety, maladaptive coping strategies (Fenton et al., 2011) and struggles of living with FA such as being out of control of their own bodies (Stjerna, 2015). Other adolescents are more dismissive of the risks of FA and more likely to engage in risky behaviours such as not carrying an AAI or not abiding by allergen label warnings. Both of these themes found in this thesis provide support that perceptions of severity are important in shaping beliefs, which fits well with the severity and susceptibility constructs of the HBM (see further explanation below).

In the thematic analysis of adolescents with FA, the majority of participants appeared to be less anxious about their FA management, a finding that is different to previous research and the systematic review. Optimistic beliefs that an individual’s FA could be worse, were shown in Chapter 4. This could be because some of the sample of adolescents with FA in this thesis had mild symptoms with no history of anaphylaxis and had not been prescribed an AAI. Severity of FA has not been as clear in previous research which either does not specify severity or focuses on adolescents at risk of anaphylaxis who generally have an AAI. The inclusion of both adolescents with perceived severe FA compared to perceived mild symptoms (no history of anaphylaxis or with no prescription of an AAI) offered an interesting point of comparison in this thesis.

Both thematic analyses of qualitative interviews from the FA sample and the participants without FA consider AAIs, reactions, and peer education, supporting previous research that these topics are important in beliefs of FA. Carrying and using AAIs are a strongly expressed concern of adolescents with FA, with previous research exploring adherence to AAI carriage (Macadam et al., 2012; MacKenzie et al., 2010; Gallagher et al., 2011; Monks et al., 2010; Jones et al., 2014) as a barrier to treating anaphylaxis. Adolescents without FA were concerned about the needle (Monks et al., 2010; Macadam et al., 2012) and the thought of administration, stating they were reluctant to use it and if they must use it, they would rather inject somewhere privately. Adolescents with FA were also concerned about the needle and administration, younger adolescents showing a preference for an adult to administer the injection (Gallagher et al., 2011; Monks et al., 2010) and more fear around the needle. In those who had used the AAI previously, these anxious beliefs were greatly reduced, and these participants felt confident in managing AAI administration in the future, their beliefs more based in realism than in fear (Chapter 4). A systematic review into AAI administration techniques (El Turki, Smith, Llewellyn & Jones, 2017) found that training greatly improved rates of correct administration, with the most common error being not holding the device in place for a long enough duration. Good administration was seen more in those who had a history of anaphylaxis, were over 18 years of age, prescribed an AAI more than 30 months, membership of a support group and AAI administration training by an allergist.

Most adolescents also believed the AAI was inconvenient to carry, supporting previous research that found participants believed AAIs to be bulky (Sampson et al., 2006; MacKenzie et al., 2010; Gallagher et al., 2011). Deciding whether to carry the AAI was mostly dependent on the situation, such as if food was likely to be present (Macadam et al., 2012; MacKenzie et al., 2010; Gallagher et al., 2011; Monks et al., 2010), though those who had previously experienced anaphylaxis in the qualitative interviews were more vigilant in carrying their AAI, while others were less concerned. In the FA sample without an AAI prescription, they felt that if they were prescribed an AAI, then they would take their FA more seriously and be more careful.

Beliefs about managing the risk of anaphylaxis were discussed by adolescents both with and without FA. Adolescents without FA were concerned about reactions, having previously underestimated the potential severity of FA. They expressed the desire for further education to understand more about FA symptoms, types of reaction and how to use an AAI to address concerns. They believed that concern around judgement of others could increase the fear of having a reaction. However, they expressed that they wanted to know how to help in case a reaction occurred. This belief was especially apparent in the female participants with a close friend with FA.

In the sample with FA, reactions and risk were again strongly determined by previous reactions and symptom severity. Those who had not previously experienced anaphylaxis or had their strongest reaction at a very young age, felt that anaphylaxis was very unlikely and that they would never have to use their AAI, supporting research by Akeson et al. (2007) who’s participants viewed reactions as not an issue. In those who had experienced anaphylaxis and had administered an AAI, they were confident they would be able to manage the situation. When considering whether to consume a food with an allergen warning label, this was dependent on whether the food was considered enjoyable and worth the risk (Marklund et al., 2007; Stjerna, 2016).

7.3. Beliefs of adolescents with and without FA: Further comparison of the thematic analyses

Differences were to be expected between adolescents with and without FA as one had lived experience of a condition, while the other did not. Despite this, there were similarities across groups. For both groups, where they had not experienced use of an AAI or a reaction, they had fearful beliefs that these experiences would be painful, difficult to manage and lead to peer judgement. AAI needles were considered scary and the act of injection to be unpleasant and painful. Reactions, especially the risk of anaphylaxis was also considered scary and dangerous. However, adolescents who did not consider themselves at risk did not have these beliefs. Participants who had experienced use of an AAI and anaphylaxis were much more confident and less anxious about using an AAI again, showing that education and past experience are important when considering beliefs and this may be useful in interventions aimed at reducing anxiety and increasing self-efficacy regarding AAI use.

Frustration towards labelling was expressed by both allergic and non-allergic participants as the labels were considered to be inaccurate and, at times, unnecessary. Labels were believed to be restrictive of food choice, especially in instances of ‘may contain nuts’ labelling where the type of nut was not specified. Trying foods that have a ‘may contain’ label was seen by most participants as an acceptable risky behaviour. This was so not to be excluded from experiences such as enjoying the same foods as their friends or trying foods that were popular. All adolescents felt that the labels were presented more for the benefit of the company, rather than to protect and inform the consumer.

Although ‘may contain’ labelling was frustrating for adolescents, often it is impossible to remove all traces of an allergen from a manufacturing process, as this would entail large costs that would need to be passed on to the consumer. A ‘may contain’ label is used if there is any risk of a trace of an allergen, but this is not currently regulated, so companies do different things. It is a complex area that is often not understood by the consumer, though the family of Natasha, a teenage girl who passed away from anaphylaxis in 2016, have recently successfully campaigned to pass a law on food labelling to include full ingredients on pre-packaged food, to be introduced across the UK in 2021 (BBC News, 2019; GOV.UK, 2019). Furthermore, the TRACE study (Food Standards Agency, 2019) has been exploring the thresholds of reactivity to peanut normally and in the case of exercise and sleep deprivation. The majority of adult participants reached reactivity threshold at 214mg of peanut (a single peanut is approximately 330mg). Exercise and sleep deprivation then halved this, suggesting that reactivity thresholds are not static, but may be influenced by other biological factors. Further awareness of this study and the potential for testing thresholds for reaction may give adolescents more confidence with managing their FA if adolescent testing and testing of allergens other than peanut becomes available.

In a variety of hypothesised situations and scenarios such as school or social activities, many adolescents without FA believed that there would be no difference between someone with or without a FA. Some felt that it was dependent on the individual differences of the person, rather than whether they have a FA, for example if a person was very anxious, they may have different FA beliefs compared to someone who was more confident about managing their FA. This was seen in the interviews of those with FA, where the adolescents coped in different ways and viewed peer support very differently, with females preferring more traditional support, some males preferring a light-hearted and teasing approach of ‘banter’ and others preferring to not discuss their FA at all with their friends.

Nuts were considered the most serious of allergens in both groups, as they were considered the most common and understanding of severe reactions was associated with nut allergies. This was surprising as the high-profile media coverage of Natasha Ednan-Laperouse, who went into fatal anaphylactic shock due to sesame, and Karanbir Cheema who had an anaphylactic reaction to cheese, raised awareness of FA generally but neither died from a nut allergy. The adolescents talked about knowing of nut bans, in schools but not of bans of other allergens. Despite this, nut allergies were believed to be easier to manage as they were common and therefore more known about, and nuts were not a popular component of the participants diets. Despite nut allergies being considered the most severe, milk and egg allergies were considered the most difficult to navigate in terms of dietary changes as they are a common ingredient in baking and cooking and are more difficult to replace than nuts. Alternative milks were known about, but adolescents who did not use them were sceptical about the taste. However, ‘allergen-free’ alternatives were seen positively by participants both with and without FA.

In addition to these similarities, the main difference between beliefs of adolescents with and adolescents without FA was the perception of social relationships in relation to managing FA. From previous research, it is known that many adolescents with FA choose not to talk about their condition with peers outside of close friendships. From data in this thesis, it is also apparent that in close friendships talk of FA may be avoided to avoid unnecessary attention, or coping mechanisms such as teasing, and humour are used instead. However, the group without FA in this thesis expressed a desire to know about FA if their friend had one so that they could help and understood that they needed better education about FA. There was however a reluctance to ask questions about FA as they did not want to probe or cause discomfort.

Further differences were found between the adolescents with and without FA in their beliefs about how to manage FA and the impact it can have, which may stem from a lack of knowledge and understanding of FA. In participants without FA, knowledge was relational to direct exposure to a person with FA, for example if they had a sibling or close friend with a FA, they were knowledgeable about that specific type of allergy. Some of the participants without FA held beliefs that it was not a serious condition and therefore were surprised that anaphylaxis could be potentially fatal, suggesting a lack of understanding of severity. Participants without FA also struggled to understand differences in severity, trying to determine the difference between an intolerance, FA where anaphylaxis was unlikely and FA where there was a risk of anaphylaxis. Despite this, participants without FA were enthusiastic to know more about FA.

The peer study also had a stronger focus on emotional and peer support, being empathetic of the anxiety that may come with having FA. Female participants in particular believed that their friends with FA should be supported, not excluded or stigmatised, and wanted to help with management such as reading labels. This is in line with findings from a study looking into peer beliefs about diabetes in 12-14 year olds found that a supportive peer network may be valuable for adolescents with diabetes for management of the condition and that further education in schools is important (Brooks et al., 2015). Those with FA focussed more on interventions being educational as ignorance and misinformation were believed to be the biggest barriers in FA management. This was suggested through events such as assemblies or Personal, Social, Health and Economic (PSHE) Education classes. Educational interventions have also been recommended in diabetes research as an effective way to address health beliefs, with Shaak et al. (2018) recommending diagnosis awareness and progression of risk to be points to focus on in health promotion, which was also supported by Birkett et al. (2004) and Safeer, Cooke and Keenan (2006).

- General demographics

As the 11-16 years age range is an age of change and transition (DunnGalvin et al., 2009) in adolescent beliefs, independence and relationships, demographic factors were considered in relation to FA beliefs in these qualitative studies. Gender differences were limited; however, females expressed a more supportive and empathetic tendency in their relationships, especially in the study of adolescents with no clinical history of FA. A study by Stensgaard et al. (2017) suggests health-related quality of life in FA is worse in females, and so females in particular may benefit the most from social support from friends (Helgeson et al., 2007). Furthermore, despite previous studies suggesting that males found AAI carriage more inconvenient (Gallagher et al., 2011; Macadam, et al., 2012; Monks et al., 2010), both males and females in the qualitative studies felt AAI carriage would be bothersome.

Age was also a factor of interest in the qualitative studies. DunnGalvin et al. (2009) have previously discussed the transitional period of adolescence. The findings in this thesis suggest that younger adolescents are still more reliant on their parents and are happy to be so. Age of diagnosis was considered to effect beliefs as it was believed that growing up with FA from a young age would make it easier to adapt to.

The older sample aged 13-17 years of Dean et al.'s (2015) Ontario-based study viewed FA as a 'big deal', but this was not apparent in the adolescents with FA in this thesis. However, Dean et al.'s (2015) study was conducted in Canada, while recruitment for the studies in this thesis was focused in the UK. Prevalence data across countries is difficult to determine due to different diagnostic criteria (Fiocchi & Fierro, 2017) though previous research reports 7% prevalence of FA in Canada (Ben-Shoshan et al. 2010) and 5-8% in the UK (Food Standards Agency, 2017). It is important to note that the UK figures are more recent than the reported figures available for Canada, so it is difficult to determine whether location also had an impact on these beliefs. Dean et al.'s (2015) research was conducted with consideration of Sabrina's Law, a policy following the death of a girl with FA in Ontario, Canada the same place the study was conducted. This may have led to increased awareness about FA and anaphylaxis, which in turn may increase understanding that FA is a condition to take seriously.

DunnGalvin et al. (2009) have suggested conflict can occur around 12 years of age as adolescents wish to become independent. This was also apparent in the adolescents in this thesis. Younger participants at 11-12 years of age, particularly females, were happy to be supported by their parents when managing their FA. Older participants expressed the desire for more independence through checking labels and carrying their AAI themselves. Participants without FA also felt it may be more difficult to manage FA when they were younger and felt relying on parents was a good idea.

While cultural differences were less apparent in the qualitative studies of this thesis where all participants resided in the UK, cultural differences were apparent across studies in the systematic review. Previous research into FA in the Netherlands suggested that parental knowledge about FA was lower than in US samples with attitudes and beliefs described as 'more optimistic' (Goosens et al., 2013). Low knowledge was also found in a study with pharmacists, where none were able to demonstrate how to use an AAI correctly (Saleh-Langenberg et al., 2016). There were more beliefs around anaphylaxis and FA as 'a way of life' in previous studies with participants recruited from the UK (Akeson et al., 2007; MacKenzie et al., 2010), which was reflected in the interviews of adolescents with FA in this thesis. Cultural differences in previous studies may be applied to various factors such as parenting styles, education, healthcare systems and policies, although future research would be required to explore these factors. Differences in beliefs may also be attributed to a shift across time, as the more anxious beliefs are displayed in the more recent studies, however there is no clear change in FA which could be attributed to this and this is not replicated in the studies in this thesis conducted in 2018. The anxious beliefs in other recent studies in FA may have been influenced by the high-profile media coverage of Natasha's anaphylactic death in 2016, or Sabrina's in Canada in 2013 which may have increased awareness. Alternatively, anxiety has become more identifiable and diagnoses of anxiety have increased in the UK with a 1.5% increase between 2013 and 2014, with 19.7% of people over 16 years of age showing symptoms of anxiety or depression (Mental Health Foundation, 2016). For children and young people in the UK, 8.1% were reported to have an emotional disorder such as anxiety and depression in 2017, and 9% in 11-16 year olds (Vizard et al., 2018). Disorders relating to anxiety such as generalised anxiety disorder and panic disorder were the most prevalent in children and young people (Vizard et al., 2018). Prevalence across time was only reported in the 5-15 year age group, where in 2004 prevalence was reported as 3.9% but has increased to 5.8% in 2017) (Vizard et al., 2018). This increase in anxiety generally may have had an influence on the anxious beliefs identified in more recent research.

Cultural differences were not directly explored in this thesis due to the lack of ethnic diversity in the sample, however, one participant did discuss differences in allergy treatment in the UK and India where the AAI device used when visiting family in India was believed to be bigger. The participant's mother also discussed difficulty managing the condition on frequent holidays to India, suggesting further research may want to explore cultural differences in allergy beliefs, understanding and management. The systematic review presented in this thesis included data from different countries, however a study directly comparing beliefs cross-culturally is not currently available but would be an interesting area for future research.

- FA characteristics

All participants stated they would have preferred to be diagnosed at a young age so they could adapt to their FA as part of their life. In participants recently diagnosed, they were more concerned about their new FA and how to effectively manage it, which was also demonstrated by adolescents without FA who imagined how their life would change if they were diagnosed with FA. However, they felt dietary changes were minimal as all who received a late diagnosis were allergic to nuts and previously had not eaten nuts regularly. This was also discussed by most adolescents without FA who felt avoiding nuts would be manageable, apart from one participant who lamented the thought of being unable to eat hazelnut spread. If adolescents both with a nut FA or with no FA received a diagnosis to a different allergen, for example milk or egg, which are commonly used as ingredients, this was believed to have a greater impact. While nuts were considered the most severe of allergens in both samples, milk and eggs were also thought to be problematic in dietary restrictions, which was a factor considered in nutritional or eating behaviour research (Meyer, 2018; Maslin et al., 2015; Maslin et al., 2016) but not seen in previous research considering the psychological impact of FA. Multiple nuts were considered to be the most severe allergen, though all participants with FA felt that their allergen ‘could be worse’.

In participants with FA, symptom severity was ultimately determined by history of anaphylaxis and previous reactions. Regardless of if participants had an AAI, if they had mild symptoms they could manage with antihistamine or by sleeping until symptoms subsided, they felt their FA was not an issue. For those not prescribed an AAI, they believed if they were given an AAI that they would behave more cautiously as they would believe their FA was more severe. The comparison of adolescents prescribed an AAI to those who had not been prescribed an AAI had not been seen in reviewing the previous research, nor had its influence on beliefs or behaviour, instead focusing on AAI carriage or administration (Warren et al., 2016; Jones et al., 2014). Use of an AAI was met with reluctance, as if participants had not used an AAI in the past, they felt they would not in the future. Furthermore, if they had not used an AAI, they were hesitant to use it and worried they would not be able to. For those who had an AAI and had used it, they were more positive and felt that the AAI was far more manageable to use and were confident to use it in the future. Challenges with medication is seen in a variety of condition. One participant in the FA study suggested their inhaler was easier to use than their AAI but research into how adolescents with asthma feel about their inhaler links to how adolescents with FA feel about their AAI as both worry about technique, carriage, involvement of parents, as well as social stigma and public ignorance (De Simoni et al., 2017). However, as the AAI involves use of a needle, this may cause increased anxiety comparatively. In diabetes research beliefs about the efficacy of their treatment was found to predict self-management and self-care better than barriers or perceived severity (Lau, Bernard & Hartman, 1989; Hampson, Glasgow & Foster, 1995; Glasgow, Hampson, Strycker & Rugierro, 1997; Ashraff, Siddiqui & Carline, 2013).

7.4. Integrating the findings from different methodologies

Following the results from the qualitative thematic analyses, two quantitative psychometric scales were developed and validated; one version explored adolescent beliefs when living with FA (AFAB), and the other explored beliefs in peers with no clinical history of FA (AFAB-P). This mixed methods approach is useful as it allowed for a responsive approach to the research (Dures et al., 2010) and the method was chosen flexibly to best fit with the research aim (Yardley & Bishop, 2015; Dures et al., 2011; Flick et al., 2012). This allowed coverage of both breadth and depth of understanding in the chosen topic of beliefs of FA in adolescents (Johnson et al., 2007). Bishop (2014) reflects that a common form of mixed methods is to use qualitative research to inform development of a psychometric scale, which may in turn test reliability and validity, as was conducted in this thesis. This pragmatic approach allowed for an abductive connection between exploratory theory and the data, with an intersubjective research process, leading to transferable results.

Both the AFAB and AFAB-P had high internal reliability with low risk of item redundancy, highlighting the importance of the items in these scales. The AFAB has an alpha score of .848, and the AFAB-P has an alpha score of .771. The subscales of the AFAB had alpha scores of .892 to .897, and the AFAB-P subscales had alpha scores of .783 to .866. Both scales also demonstrated good construct validity with the validation scales, with small to medium correlations.

However, some points considered important in the qualitative studies were not included as items in the final scale. This may be due to the opportunity in interviews to ask questions and request clarification, or an element of social desirability when completing the quantitative study remotely. The qualitative study in adolescents with FA suggested nut allergens were considered the most serious, and there were challenges with recent diagnosis, but items relating to either of these themes did not load highly enough to be included in the subscales. Needle phobia in AAI was included only in the AFAB, not in the AFAB-P, however the data from the interviews of children without FA in this thesis demonstrate that using an AAI was a concern. It may be that the majority of the sample without FA that completed the AFAB-P scale did not know someone personally with FA which could have affected their answers. An item about perceived severity, that FA seriousness is exaggerated, was included in a subscale in both the AFAB and AFAB-P, supporting the importance of FA severity beliefs. Items regarding identity and seeing FA as part of your life were also included in the AFAB in the items about whether FA had a big impact on life and on social life.

Peer beliefs of FA are the foundation of the AFAB-P, but personal responsibility and education, which were both themes of importance in the qualitative interviews, did not have items that loaded onto the subscales. This may be due to the participants not personally knowing someone with FA, which may have limited their knowledge. Beliefs identified in the scales may be used in future research to inform behaviour change interventions as beliefs may mediate behaviours (Wallston, 1992), influencing individuals to act depending on how they think and feel.

7.5. Consideration of exploratory data in relation to theoretical models

Theories and models have not been applied extensively in adolescent FA beliefs research, with only Jones et al. (2014; Jones et al., 2015) considering the use of the HBM and CS-SRM in relation to this demographic. These models were applied to this data to see if they are relevant and provide an explanation of the data.

7.5.1. Health Belief Model

Elements of the HBM have been highlighted as relevant in this thesis data. Figure 10 demonstrates how FA may be applied to the HBM in accordance with these findings.

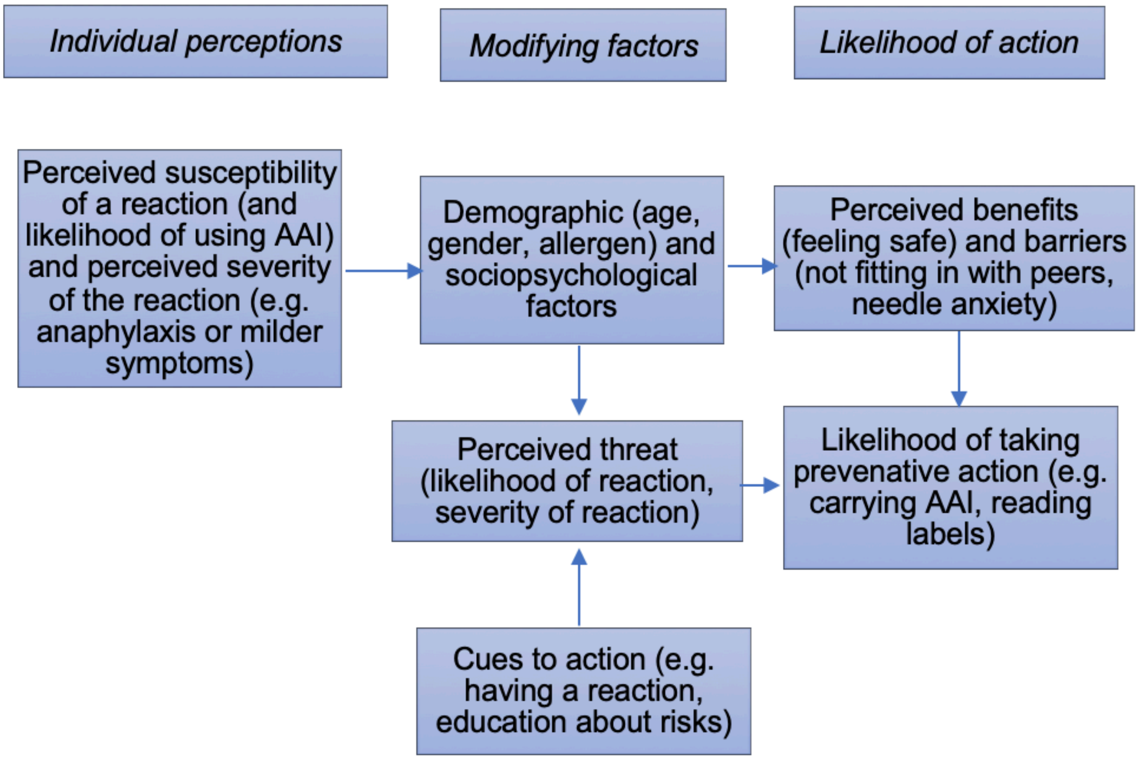


Figure 10: HBM applied to adolescent FA

Barriers in particular are highlighted in previous research and in the qualitative studies in this thesis and focus on social interaction with peers, including stigma from lack of understanding in peers and distress about missing out on experiences. Further barriers such as anxiety around needles in the AAI are also a point of importance. Demographic factors also were shown to have an impact, with younger participants more reliant on parents and believing that FA was not as stressful, females believing their friends were more supportive and trustworthy while males believed it was better to avoid attention of their FA, and different allergens being considered more severe, were all important factors in understanding FA beliefs. Having a reaction or learning more about FA may encourage adherence to health protective behaviours such as reading food labels and carrying an AAI dependent on perceived threat from a reaction. Likelihood of action may focus on adherence to health protective behaviours such as consistent carriage of an AAI and checking labels but does not consider the rapid nature of severe reactions and that ingestion of allergens is often unintentional. The HBM also considers how beliefs may lead to behaviours, showing how FA beliefs such as AAIs being scary may lead to a reduced likelihood of taking action in the event of a reaction. The HBM may therefore be useful as a tool in behaviour change interventions to inform what beliefs influence health promoting behaviour and to work with changing these beliefs to healthier perspectives.

The limitation of the HBM is that is it potentially too simplified, and that beliefs leading to action are not direct and linear but are malleable and open to change from experiences and changes in knowledge. In addition, the HBM considers what beliefs are related to health promoting behaviour but does not consider why these beliefs are in place past the concept of perceived benefits and barriers and does not consider benefits or barriers the individual does not perceive to be benefits or barriers. For example, they may believe they can administer an AAI effectively, but in the event of a reaction are unable to because they do not understand how to. The focus is on the likelihood of action but does not give much weight to the social factors that may influence this or action from external sources. In the adolescent sample, both of these factors are important. Peer perceptions may influence beliefs and action, and although may fit into the 'barriers' of the HBM, it does not consider the positive effects of supportive friends. Similarly, external action, such as with parents carrying AAIs or checking labels, as is common particularly in younger adolescents, is not considered. Furthermore, the HBM does not take into account that FA reactions are often sudden and unplanned, rather than a determined action.

Overall, the HBM mapped well to the findings of these exploratory studies and suggests areas of interest for further research. The use of the HBM in predicting and explaining behaviour has been previously documented (Carpenter, 2010; Harrison, Mullen, & Green, 1992) and perceived benefits and barriers are reported to be the strongest predictors of behaviour (Carpenter, 2010). General beliefs about FA in samples with and without FA may fit well in the components of the HBM, which may be useful in future research and analysis. However, use of the HBM in FA beliefs should be used with understanding of HBM limitations.

7.5.2. Common Sense Self-Regulation Model

In addition to the HBM, the CS-SRM also offers insight into the adolescent beliefs of FA found in this thesis. When applying the CS-SRM of FA in adolescents (Figure 11), cognitive illness representations factors such as consequences and control may affect beliefs regarding their FA as they try to balance independence and responsibility.

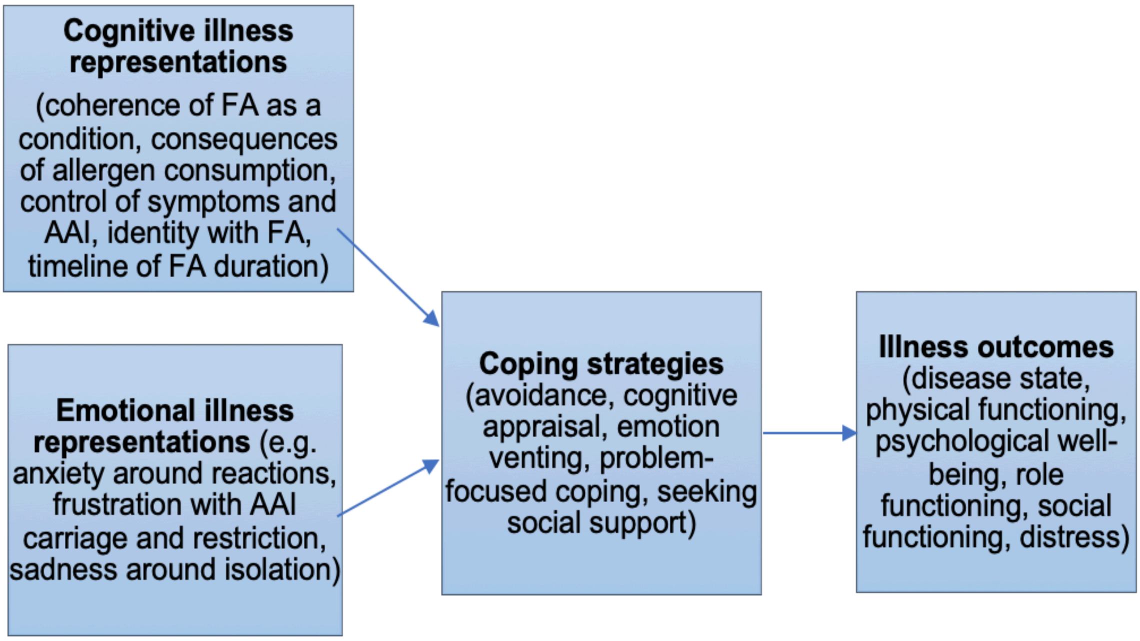


Figure 11: CS-SRM applied to adolescent FA

As a time of transition, emotional perceptions of the condition might be heightened with the shift in independence and responsibility from parents and beliefs may have an impact on whether the emotions are particularly positive or negative. Cyclical timeline beliefs may shift with encountering different beliefs from peers and with the transitions across adolescence. Coherent understanding is something that may develop as the adolescents take more control of their condition, making their own choices and learning about their FA in more detail to improve management. The resulting coping strategies and illness and emotional outcomes may be influenced by these illness representations, which is interesting for this PhD work on beliefs. Cause of FA was asked about in the BIPQ validation scale but was not compulsory to answer, however both groups of participants considered the primary potential causes to be genetics, diet in infancy and bad luck. Situational stimuli was linked to these representations, meaning a person's information from memory, expert sources and experienced somatic and symptomatic information, may affect beliefs.

For this thesis both hypothetical and outsider beliefs were presented by the sample without FA. Illness stimuli was greatly affected by how much knowledge and understanding the adolescents had. In all adolescents there were gaps in knowledge, and they expressed that they did not have much information from external sources such as school. Cognitive illness representations suggested that they were not initially aware of consequences but were concerned about anaphylaxis once they learned about it. Once they had information about anaphylaxis, they felt that FA was far less controllable both personally and in form of the main treatment of antihistamines and AAIs. Adolescents were also unaware of potential causes and unsure about medication available. Identity and illness concern were difficult for the adolescent participants to consider, but they felt that though they would be concerned by having FA, but their identity would not change substantially as FA management was believed to be like a diet (e.g. vegan) and that social life would not change. Coherence varied among the adolescents, though all participants agreed they would benefit from further education, such as about anaphylaxis. Emotional representations were believed to be primarily fear, panic, worry, frustration and caution. Reactions and AAIs were perceived particularly negatively, however this may be due to having no exposure and limited understanding of these.

When considering how they would cope, the majority of adolescents considered that they would be vigilant with checking labels and carrying their AAI. They primarily focused on problem-focused coping to manage their FA and reduce chance of reaction in addition to social support, primarily from parents. They considered that this coping would be effective and that they would be able to live a normal life from this. Physical functioning was not considered to be affected but psychological functioning was believed to be an issue due to emotional distress and anxiety surrounding the condition and its management. Social functioning was only believed to be affected in situations where food was present such as in restaurants but not in things such as sports or the cinema. Emotionally and socially, good social support and education was considered key to improve this.

In the sample with a diagnosed FA, perceived consequence was dependent on previous symptom and reaction experience. Consequences of risky behaviour were thus believed to be more severe dependent on perceived severity of FA. Participants felt that growing out of their FA was very unlikely, and beliefs changed with age and emerging independence and autonomy to become more anxious. Personal and treatment control again varied dependent on perceived severity and age of diagnosis, more recent diagnoses led to feeling less in control and adolescents found it harder to adapt. Perceived personal and treatment control may be much higher in the sample that did not consider themselves at risk of anaphylaxis as they chose to try a small bit of a risky food and then take an antihistamine to combat the symptoms. Treatment may be difficult to answer in the FA sample as there is no cure for FA (Sheikh & Alves, 2000). Having food prepared outside the home could have an impact on control and safety. Identity was stronger in this sample as they had phenomenological experience of the condition, while the participants without FA did not. Identity also seemed to be linked to severity, where those with stronger reactions felt their FA was more a part of who they were, while those who had milder symptoms preferred to largely ignore their FA. Again, illness concern was linked to how dangerous they felt their FA was. While those with mild symptoms felt their FA was annoying, those at risk of anaphylaxis but who had not had a severe reaction felt more concern than those who had experienced anaphylaxis. Coherence also varied based on severity and age of diagnosis. Those with severe FA who had lived with the condition since a young age felt they had a good understanding of FA, while those with milder symptoms or a newer diagnosis felt there was much they did not know about more severe FA.

Emotionally, all adolescents with FA found their condition annoying, but anxious beliefs were varied. Some adolescents were confident and relaxed, while others felt more cautious and nervous in regard to their FA. Individual differences in emotional representations were more apparent in this sample than in the sample without FA, potentially due to lived experience. Coping with their FA was largely suggested through acceptance and being dismissive of their condition. Some participants admitted they could adhere to their AAI carriage and check labels more dutifully, but this was not felt to be essential. Generally, avoidance of the allergen or discussion of the condition, or social support from parents, were considered effective coping strategies. Illness outcomes were not really considered, though participants felt if their psychological wellbeing was affected, that they had people to turn to for support.

In the quantitative study where preliminary scales were developed, the BIPQ was used as a validation scale. The BIPQ is informed by illness representations developed by Leventhal et al. (1984), and correlations between the subscales and the BIPQ can be found in the scale chapter (Chapter 6). Cause was not considered in the subscales, as it was not a point of interest found in previous research of FA beliefs or the qualitative studies. However, illness beliefs have been used effectively in a study into diabetic foot ulcers, where illness beliefs were reported to account for moderately high variance in foot care behaviour, with identity and coherence beliefs significant predictors at six weeks (Vedhara et al., 2014) so may still be useful when applied to FA.

While the CS-SRM provides interesting insight to FA beliefs and expands on cognitive and emotional illness representations missed by the HBM, such as coherence and management of FA, coping strategies and illness outcomes may be less relevant to FA beliefs.

Furthermore, the CS-SRM misses the general information gathered in the HBM such as demographic factors, susceptibility and severity of reactions, and benefits and barriers. Similar to the HBM, the CS-SRM also considers what cognitions and emotional representations there are but not why and what factors effect these. In combination with the HBM, the CS-SRM may provide insight to what beliefs adolescents with FA experience and assist in informing further research. Similarly to the HBM, the CS-SRM may be useful to inform behaviour change interventions with identification of emotional and cognitive illness representations being used to identify why selected coping strategies are or are not used and thus what may influence the outcomes. For example, if there are strong emotional representations of anxiety around FA (e.g. that if a reaction occurs, death is unavoidable), and this leads to avoidance of going outside of the home to cope, this may inform the researcher why psychological well-being is poor and then a researcher can use this to produce an adequate intervention (e.g. CBT) based on these beliefs. The theory of planned behaviour (Ajzen, 1991) has seen success in research following how attitudes apply to behaviour, and with further research, arguably beliefs may also be linked more strongly to behaviour.

7.5.3. Ecological Systems Theory

The focus on peer relationships was apparent in the qualitative studies, where adolescents spoke about their relationship with their friends and what beliefs they thought these friends had. School life also understandably featured in interviews with adolescents, as a place where most adolescents spend a large portion of their time. This supports Brofenbrenner's theory, which suggests that close friends, peers and the community are a close and important part of the adolescent world, with ideology and the change of beliefs over time also a part of the theory (Figure 12). In relation to Brofenbrenner's Ecological System's Theory (1994), both scales of the AFAB considered friendships and relationships items significant for inclusion. Furthermore, two questions ask about school, one focusing on school trips. Timeline beliefs featured in the BIPQ also had one of the strongest correlations with the AFAB subscales. The Ecological Systems Theory does not provide detail into beliefs affected by these systems but was nonetheless useful for exploring beliefs and relationships in adolescent FA. Thus, exploring adolescent peer beliefs was important for this thesis, to have a deeper understanding of the adolescents with FA's world, presenting a more detailed coherence of beliefs in adolescents.

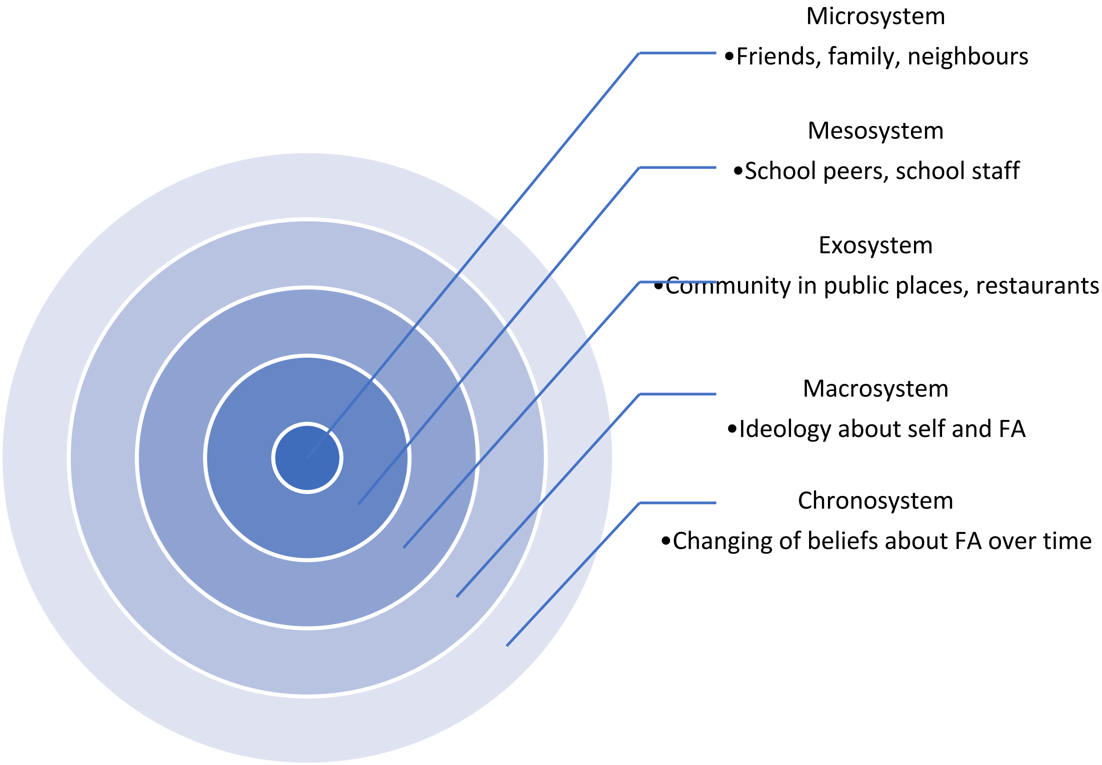


Figure 12: Application of Ecological Systems Theory to adolescent FA

Previous research into peers of adolescents with FA was limited and focused primarily on secondary beliefs of peers from the adolescents with FA. Only one previous study was found which interviewed adolescent peers alongside adolescents with FA as a point of comparison (Sommer et al. 2014). However, no previous studies had explored what peers directly thought about FA, to gain understanding of their beliefs and understanding about the condition. This direct understanding of peer beliefs may more accurately inform peer interventions in schools, and as a result reduce risky behaviours and bullying that may endanger adolescents with FA. Furthermore, as a close component of an adolescent's world, better peer understanding may reduce stigma around FA and improve QoL and reduce anxiety in adolescents with FA.

7.6. Reflexive account

Reflexivity is important to unpack the perceptions researchers bring to their research and question assumptions that influence the research (Lazard & McAvoy, 2017). In this reflexive account I consider my history with FA, the limitations of not having the condition myself and the challenges of conducting research with adolescents.

My first encounter with food allergies was in primary school, where in my class there was a boy named Barney* (pseudonym) who had a nut allergy. There were posters in our classroom warning about the allergy, however otherwise his allergy was not discussed by teachers. Notably, a significant amount of time has passed since then, and food allergy is more prevalent and there is more awareness around the condition now than there was 15-20 years ago.

As someone who does not have a food allergy myself, in some areas of these studies I struggled to truly empathise with the experiences shared with me. To an extent I understood the frustration of not being able to eat what you wished, having developed a lactose intolerance in my early twenties. For the study with adolescents without FA, I felt more prepared to ask questions based on my own experiences and my previous gaps in knowledge or aspects I was surprised by.

Encouraging adolescents to chat and open up to a stranger is not an easy feat. While I had experience in conducting qualitative research and had interacted with adolescents in sensitive topics during my part-time job in a pharmacy, I had not previously sat down with a teenager and persuaded them to open up to me. As I progressed through the interviews, I did develop a skill for it, even proudly having interviews for over an hour with initially reluctant teenage boys – which mothers assure me is not an easy task. I found initial warm up conversations incredibly useful in this, including discussing popular concepts in adolescents' lives from YouTube and videogames to build camaraderie and show that I was listening. I also asked my participants about themselves; what they enjoyed in and out of school and used this information to make my future questions more relevant e.g. 'Where do you put your epi-pen when you play tennis?' or 'You mentioned friend X really helped you on your school trip to France…' and this really helped the interviews.

Positive experience is something I strive for as an interviewer and I feel that I have improved in providing a positive experience throughout the qualitative section of my PhD. I aim for all participants to feel like they have been listened to and to end on a positive, reflecting on the interview process. Overall, as my participants are adolescents, I feel this is especially important to give a good reputation to research and to create a feeling of accomplishment in the participants, and to express my gratitude.

If I was to complete this research again, older, more experienced, and hopefully wiser, I would focus on completing ethics and building strong connections earlier. I have grown a supportive network on social media and at conferences, but this took three years of hard work to achieve. Ethics and slow recruitment in my first study led to delays that may have been avoided but also gave me valuable lessons in conducting research. Overall, this PhD has been a challenge but has given me a priceless opportunity to grow as an academic and as a person.

7.7. Strengths of the PhD

The pragmatic mixed methods approach allowed for breadth and depth of this exploratory research, providing detailed accounts of experience and a quantifiable measure of FA beliefs. This provides a more rounded view of adolescent beliefs of FA from a larger sample across different methods. This PhD has contributed to research by identifying new aspects of importance in FA that had not previously been considered, and also covers a much larger breadth of adolescent beliefs about FA.

The systematic review provides comprehensive findings of all available prior research of adolescent beliefs about FA, which has not previously been collected. This allows a research base and list of publications to inform beliefs research in consideration of FA and allowed development of qualitative and quantitative items in this exploratory study. The systematic review also considered a range of methods and participants from various countries, providing significant breadth to inform this research.

The qualitative study of the FA sample provided broader insight to beliefs, where previous research has focused on beliefs of a specific factor of FA (e.g. AAI adherence). This data provides a larger understanding of living with FA and identified challenges of recent diagnosis and differing beliefs of FA dependent on severity, which were interesting topics. The data also suggested a different form of peer interaction and coping through the form of ‘banter’ where previous research suggested empathetic support, hiding FA or bullying, but not this playful form of teasing as a form of management.

This research also uniquely identifies direct beliefs of peers about FA. Previous research has considered peer views in comparison to adolescents with FA in the areas of general food choice (Sommer et al., 2014) but has not specifically considered what peers without FA think of living with the condition.

The development of two scales; the AFAB and AFAB-P also provide a tool to measure beliefs in both adolescents with FA and their peers without a current FA. In both scales, different items were highlighted as important for inclusion in the reduced scales. This confirms that having two scales, one for adolescents with FA and one for adolescents without a currently diagnosed FA, is beneficial as the scales focus on different items, representing different beliefs. With further refinement through test re-test analysis and further validation, this tool may assist clinicians in identifying problematic beliefs in adolescents with FA and highlight patients in need of psychological support. The AFAB-P may assist in identifying beliefs of siblings and close friends that also may need addressing for further support in the adolescent with FA's close social network. The AFAB-P may also be useful in schools, where students sharing classes with students with FA may have their beliefs assessed and if necessary, an educational intervention may be arranged in the school to address beliefs that FA is not serious. This could also be applied in social community settings such as youth groups, in a similar format as in schools. These scales may therefore in future, reduce distress of those with FA to lead to more positive experience of FA and increase beliefs of safety and manageability. This may also address peer beliefs to prevent bullying or misunderstanding of FA and reduce the risk of reactions in schools.

A final key strength of this research was the development of the researcher as an interviewer. Interview data was rich, especially in the sample with FA, and participants claimed to thoroughly enjoy the research experience, which was relayed through participants themselves or parents. Positive experience was highlighted by Kvale and Brinkman (2009) as an important aspect in qualitative interviewing and this positive research experience led to participants being eager to assist when developing the scale and being optimistic about future research.

7.8. Limitations of the PhD

While recruitment numbers were satisfactory, there were some areas that may have been improved. Participants were not requested to divulge where they heard about the study, which could inform recruitment strategies in further studies. Certain demographic factors in the non-allergic sample, such as ethnicity, were also not collected, which may have provided context to participant answers. The qualitative sample also had a majority of female participants, which may not be fully representative of male beliefs.

In the qualitative interview studies, the interview schedules were developed from the findings of the systematic review. To strengthen the interview schedule, piloting the questions with adolescents or involving adolescents in developing the questions may have made the interviews more relevant and captured data that may have been missed. This was greatly beneficial in the quantitative study, where adolescent input was used to develop the questions for the scales.

In the quantitative study, a follow up study was not conducted to further assess re-test reliability and confirmatory factor analysis could be run to check the sub-scales found. A test-retest was not performed in this study as participants were anonymous and therefore could not be contacted again by the researcher. An amendment to IRAS to recruit from schools for the scale studies was not approved until the last day of term, and summer schools were not responsive, which resulted in a potential participant pool being unavailable. The original AFAB scale length was queried by clinicians at LRI, and may be why scale completion was initially low, however previous participants felt all items were important for inclusion.

7.9. Recommendations for practice and management

The results of this research provide recommendations in different areas related to FA. In allergy clinics, psychological aspects of FA in adolescence would benefit from more consideration. Although training is provided on how to use an AAI, psychological barriers such as fear of pain from the needle, worries about not being able to use the device correctly, or worries about judgement must be addressed to improve adherence to AAI use. Beliefs about FA severity should also be challenged, so FA symptoms and associated risks are understood. In those diagnosed in adolescence, participants felt that their FA was confusing, and they were more anxious, wishing they had been diagnosed earlier for easier management. Further psychological support for those who are diagnosed late may be beneficial, for example Cognitive Behavioural Therapy (CBT), addressing beliefs of concern, which may then lead to positive behaviour change as they learn to manage their condition. CBT has previously been found to significantly improve depression, anxiety, stress, worry and general mental health significantly improved (Knibb, 2015). This technique may also be effective in adolescents with FA, especially in the case of needle phobia, concerns of eating new foods, or fear of being away from parents. Polloni et al. (2014) have also highlighted the need for psychological support in those with FA and their families, and the majority of psychological treatments were for adolescents who struggled most psychologically with their FA. The counselling component of the intervention addressed awareness of strengths and challenges of FA, where participant beliefs would have been addressed.

Many adolescents in these studies were positive about the school experience, however felt more could be done regarding food choice and on school trips. Discussion with catering staff at school so that allergy policy is clear was considered important by participants and their families. Furthermore, safety and inclusion on school trips was important to participants and they were frustrated when food choice was limited. Strong communication between schools, and adolescents with FA and their families may change beliefs that FA is manageable and reduce perceived barriers of burden. In schools for adolescents of a younger age, observation of peer interaction may also reduce risks from bullying.

For support networks, the importance of good peer relationships should not be underestimated. Where adolescents were teased or bullied when they were younger, they were reluctant to open up to their friends when older. Female friends were often more supportive and empathetic, though this could become overprotective. In other participants, both males and females reflected on the increased use of ‘banter’ to manage their FA with their peers. Though this helps them to keep their friends aware of their FA and lighten the conversation, this could lead to more risky behaviour (for example with Freddie, who had an apple thrown at him when he was allergic to multiple fruits). Participants were largely positive about their families, having a good support network. However, there was strain and conflict in some where adolescents were looking to become more independent (DunnGalvin, 2009) and parents still felt protective. In participants with less severe allergies, risk-taking behaviour, such as eating foods that ‘may contain’ the allergen, sometimes occurred as it was believed any symptoms could be managed with an antihistamine. In rare and mild allergies, such as in Freddie’s case, his family did not believe he was allergic which led to tension when he was younger. In the sample without FA, the participant who had a younger brother with FA was much more relaxed about FA than many of the other participants, showing more confidence and understanding. Therefore, further community education of symptoms of FA may assist parents in identifying mild FA symptoms in their children, such as an itchy mouth. In clinical settings, inclusion of the family in FA support is essential as outside of clinics, the parents are actively involved in managing FA. Psychological support for parents to manage conflict in the adolescent's transition to independence, may reduce this conflict and anxiety experienced by parents and adolescents with FA.

Food labelling was believed not to be accurate by those with and without FA. There was frustration in those with nut allergies, where they believed 'may contain nuts' labels should specify which nut to increase food choice and transparency. Further work similar to the TRACE study (Food Standards Agency, 2019) may help with this, as patients find out what their thresholds are for reaction. This may allow individuals with allergies to make informed choices about risk, for example they may choose to try foods with warning labels stating that the food was made in the same facility as their allergen if they perceive their threshold as good, or they may be more adherent to guidance if they find they are likely to have a reaction from a smaller amount of the allergen. However, it is important to note that the TRACE study currently only uses peanut protein in their research. Although cross-contamination in food facilities may be difficult to avoid, educating the FA community about the labelling process and addressing label decisions, may improve the relationship and confidence in food labelling. A more open dialogue may help with these beliefs, where information about risks of consuming 'may contain' products may help with reduction of risk-taking behaviour.

7.10. Implications for future research

This research highlights the importance of beliefs in understanding adolescents with FA, as well as areas for improvement and intervention in peers with no clinical history of FA. Future research may consider further exploration of how beliefs differ across factors such as allergen, age of diagnosis, symptom severity and culture. Interventions in schools and clinics to consider beliefs of adolescents with FA and their peers may provide more effective support dependent on the adolescents needs, for example if they believe that their AAI is scary and difficult to use, more training and support can be implemented in this area.

Recommendations for further research include further in-depth exploration of the themes found in the qualitative studies. In the thematic analysis of adolescent with FA, there were strong views of nuts being more serious than other allergens rather than focusing on the risk of anaphylaxis. An intervention highlighting the risk of other allergens, may change these beliefs. Recent diagnosis and differences in severity also affected beliefs of FA and may benefit from further exploration. A longitudinal study exploring diagnosis in adolescence to explore whether this affects reactions, distress or management, may highlight a patient group in need of further support. An additional study following those who believe their symptoms are mild and therefore take risks may be beneficial, to see if this risk-taking behaviour has an effect on reactions. Interventions to educate schools and peers about FA severity, reactions and addressing fears about AAIs may improve FA management beliefs and reduce risky behaviours in schools. A further intervention addressing the beliefs about FA labelling accuracy, may also be beneficial in reducing risk-taking behaviour and improving communication and attitudes between companies and those with FA. Finally, further research into developing the AFAB and AFAB-P scales may lead to them being suitable and beneficial in practice, improving understanding of beliefs of adolescents with and without FA.

Interventions may consider a focus of directly changing the beliefs about FA that may be problematic, such as misconceptions about severity or reluctance to carry and use AAIs. This would be useful for increasing cues to action and readiness to act and may remove barriers that may inhibit support through an educational program or training in clinics. The goal of interventions like these is to focus on the cognition, which may as an effect reduce barriers to behaviour. Other interventions may wish to focus more on behaviour change and instead consider beliefs as a tool for measurement, as beliefs have been considered mediators of behaviour (Wallston, 1992). Measurement of beliefs may give an indication on how effective an intervention is, for example in developing a peer-support program, testing beliefs to assess whether aspects such as seriousness are understood.

7.11. Conclusion

This PhD thesis aimed to explore the research question of ‘what are the beliefs of adolescents aged 11-16 with and without food allergy in the United Kingdom?’ The major findings of this thesis include the beliefs influencing concerns of AAI use, that nuts are perceived as the most severe allergen regardless of the individual’s own allergens or lack thereof, the challenges of recent diagnosis in adolescence and how symptom severity affects beliefs and behaviour. This research adds to previous literature with the first known qualitative study of adolescent peer views of FA, and a dedicated study exploring secondary school age beliefs in a sample of the age range considered most at risk of anaphylactic and fatal reactions, including a sample of recently diagnosed participants. The psychometric scales are also the first to consider beliefs of those with or without FA with a dedicated scale for each, which may be used in clinical or non-clinical settings to inform treatment, interventions or school improvements.

Over the course of this PhD, there has been media attention brought to the severity of FA and the need for education, support, and better labelling laws to protect adolescents with FA. By knowing what beliefs lead to these behaviours and the intentions for these behaviours, this thesis advises that adolescents require further support to reduce psychological strain, discovered areas where there are misunderstandings and provided data to help inform interventions that may reduce risk-taking behaviour, especially in adolescents at risk of food-induced anaphylaxis. This thesis has explored peer beliefs, and suggests peers have the potential for empathy, the desire for further knowledge and a strong belief of equality in food choice. This research also led to the development of two scales, which upon refinement, may be used in practice, schools, or social community settings to identify and address beliefs about FA in adolescents. This research further highlights the areas needed to inform healthcare professionals such as doctors and allergists, caregivers such as parents and school staff, and the wider community, for how best to support adolescents with FA to live safer and more confident lives with more equality in food choice, less stigma and more peer support.

List of references

Abi, J. (2018). *Teen saves her best friend's life after she suffers severe allergic reaction*. Retrieved December 20, 2019 from https://honey.nine.com.au/latest/teen-saves-friends-life-food-allergy/fa64131d-acac-4ac8-8c97-92f613f93525

Abdurrahman, Z. B., Kastner, M., Wurman, C., Harada, L., Bantock, L., Cruickshank, H., & Waserman, S. (2013). Experiencing a first food allergic reaction: A survey of parentand caregiver perspectives. *Allergy Asthma & Clinical Immunology, 9*(1), 18. https://doi.org/10.1186/1710-1492-9-18

Ajzen, I. (1991). The theory of planned behaviour. *Organizational Behavior and Human Decision Processes, 50*, 179-211. https://doi.org/10.1016/0749-5978(91)90020-T

Ajzen, I. (2002). Perceived behavioral control, self-efficacy, locus of control, and the theory of planned behavior. *Journal of Applied Social Psychology, 32*(4), 665-683. https://doi.org/10.1111/j.1559-1816.2002.tb00236.x

Akeson, N., Worth, A. & Sheikh, A. (2007). The psychosocial impact of anaphylaxis on young people and their parents. *Clinical and Experimental Allergy, 37*, 1213-1220. doi:10.1111/j.1365-2222.2007.02758.x

Alanne, S., Laitinen, K., & Paavilainen, E. (2014). Living ordinary family life with an allergic child—The Mother's perspective. *Journal of Pediatric Nursing: Nursing Care of Children and Families, 29*(6), 679–687. https://doi.org/10.1016/j.pedn.2014.06.012

Albargawi, M., Snethen, J., Gannass, A. A. L. & Kelber, S. (2016). Perception of persons with type 2 diabetes mellitus in Saudi Arabia. *International Journal of Nursing Science, 3*(1):39-44. https://doi.org/10.1016/j.ijnss.2016.02.007

Albargawi, M., Snethen, J., Gannass, A. A. L. & Kelber, S. (2017). Relationship between person's health beliefs and diabetes self-care management regimen. *Journal of Vascular Nursing, 35*(4), 187-192. http://dx.doi.org/10.1016/j.jvn.2017.07.002

Albaum, G. (1997). The Likert Scale Revisited. *Market Research Society Journal*, *39*(2), 1–21. doi:10.1177/147078539703900202

Aldurаywish, S. A., Lodge, C. J., Vicendese, D., Lowe, A. J., Erbas, B., Matheson, M.C., … Dharmage, S. C. (2015). Sensitization to milk, egg and peanut from birth to 18 years: A longitudinal study of a cohort at risk of allergic disease. *Pediatric Allergy and Immunology, 27*(1). https://doi.org/10.1111/pai.12480

Allen, K. J., Hill, D. J. & Heine, R. G. (2006). Food allergy in childhood. *The Medical Journal of Australia, 185*, 394–400. https://doi.org/10.5694/j.1326-5377.2006.tb00618.x

Allen, J. P., Porter, M. R., McFarland, F. C., Marsh, P. & McElhaney, K. B. (2005). The two faces of adolescents' success With peers: Adolescent popularity, social adaptation, and deviant behavior. *Child Development, 76*(3): 747–760. https://doi.org/10.1111/j.1467-8624.2005.00875.x

Alexiadou, N., Dovemark, M., Erixon-Arreman, I., Holm, A.-S., Lundahl, L., & Lundström, U. (2016). Managing inclusion in competitive school systems: The cases of Sweden and England. *Research in Comparative and International Education, 11*(1), 13–33. doi:10.1177/1745499916631065

Anaphylaxis Campaign. (2019). *The Anaphylaxis Campaign's views on the proposed changes to School Foods Standards, to be made statutory from January 2015.* Retrieved September 01, 2019, from: https://www.anaphylaxis.org.uk/2015/07/20/the-anaphylaxis-campaigns-views-on-the-proposed-changes-to-school-foods-standards-to-be-made-statutory-from-january-2015/

Ary, D. V., Duncan, T. E., Duncan, S. C. & Hops, H. (1999). Adolescent problem behavior: the influence of parents and peers. *Behaviour Research and Therapy, 37,* 217-230. https://doi.org/10.1016/S0005-7967(98)00133-8

Ashraff, S., Siddiqui, M. A., & Carline, T. E. (2013). The Psychosocial Impact of Diabetes in Adolescents: A Review. *Oman Medical Journal*, 28(3), 159–162. doi:10.5001/omj.2013.46

Atkinson, P. and Silverman, D. (1997). Kundera's immortality: The invention of self, *Qualitative Inquiry, 3*, 304-325. https://doi.org/10.1177/107780049700300304

Báez-Mendoza, R., & Schultz, W. (2013). The role of the striatum in social behavior. *Frontiers in Neuroscience*, *7*, 233. doi:10.3389/fnins.2013.00233

Bandura, A. (1991). Social cognitive theory of self-regulation. *Organizational Behavior and Human Decision Processes, 50*, 248-287. https://doi.org/10.1016/0749-5978(91)90022-l

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review, 84*, 191-215. https://doi.org/10.1037//0033-295x.84.2.191

Barclay, T. R., Hinkin, C. H., Castellon, S. A., Mason, K. I., Reinhard, M. J., Marion, S. D., … Durvasula, R. S. (2007). Age-associated predictors of medication adherence in HIV-positive adults: health beliefs, self-efficacy, and neurocognitive status. *Health Psychology: Official Journal of the Division of Health Psychology, American Psychological Association*, *26*(1), 40–49. doi:10.1037/0278-6133.26.1.40

Barnett, J., Vasileiou, K. Gowland, M. H., Raats, M. M. & Lucas, J. S. (2013). Beyond labelling: What strategies do nut allergic individuals employ to make food choices? A qualitative study. *PLoS ONE, 8*(1): e55293. doi:10.1371/journal.pone.0055293

Baruch, G. (ed.) (2001). *Community based psychotherapy with young people: Evidence and innovation in practice*, Hove: Brunner-Routledge.

BBC News. (2018). Girl with allergy dies after Heathrow Pret baguette. Retrieved July 20, 2019, from https://www.bbc.co.uk/news/uk-england-london-45617845

BBC News. (2019). Food allergies: Tougher labelling law to prevent deaths. Retrieved August 23, 2019, from https://www.bbc.co.uk/news/health-46994179

BBC News. (2019). Pret allergy death: Parents 'delighted' by 'Natasha's law' plan. Retrieved August 23, 2019, from https://www.bbc.co.uk/news/uk-politics-48752388?fbclid=IwAR3kxIbZ400GtIqJ9m8SqGTEygBgUfE4By8FoUIzTW9QaVnCousSwpQBV1U

Beck, A. T. (1976). *Cognitive Therapy and the Emotional Disorders*. New York, NY: International Universities Press.

Begen, F. M., Barnett, J., Barber, M., Payne, R., Gowland, M. H., & Lucas, J. S. (2018). Parents' and caregivers' experiences and behaviours when eating out with children with a food hypersensitivity. *BMC Public Health,18*(1), 38. https://doi.org/10.1186/s12889-017-4594-z.

Behrmann J. (2010). Ethical principles as a guide in implementing policies for the management of food allergies in schools. *Journal of School Nursing, 26*, 183–193. https://doi.org/10.1177/1059840510364844

Belle, D. (1987) Gender differences in the social moderators of stress. In: R. Barnett, L. Beiner, G. K. Baruch (Eds.). *Gender and Stress* (pp. 257-277) New York, NY: Free Press.

Ben-Shoshan, M., Harrington, D. W., Soller, L., Fragapane, J., Joseph, L., St Pierre, Y., … Clarke, A. E. (2010). A population-based study on peanut, tree nut, fish, shellfish, and sesame allergy prevalence in Canada. *Journal of Allergy and Clinical Immunology, 125*(6), 1327–1335. doi:10.1016/j.jaci.2010.03.015

Birdi, G., Cooke, R. & Knibb, R. (2016). Quality of life, stress, and mental health in parents of children with parentally diagnosed food allergy compared to medically diagnosed and healthy controls. *Journal of Allergy*, *2016*, 1-7. http://dx.doi.org/10.1155/2016/1497375

Birkett, D., Johnson, D., Thompson, J. R. & Oberg, D. (2004). Reaching low-income families: Focus group results provide direction for a behavioral approach to WIC services. *Journal of the American Dietic Association, 104*(8), 1277-1280. https://doi.org/10.1016/j.jada.2004.05.211

Bishop, F. L. (2014). Using mixed methods research designs in health psychology: An illustrated discussion from a pragmatist perspective. *British Journal of Health Psychology, 20*, 5–20. doi:10.1111/bjhp.12122

Bock, S. A., Munoz-Furlong, A. & Sampson, H.A. (2007). Further fatalities caused by anaphylactic reactions to food, 2001-2006. *Journal of Allergy and Clinical Immunology, 119*: 1016-1018. https://doi.org/10.1016/j.jaci.2006.12.622

Bollinger, M. E., Dahlquist, L. M., Mudd, K.,,Sonntag, C., Dillinger L & McKenna K. (2006). The impact of food allergy on the daily activities of children and their families. *Annals of Allergy Asthma and Immunology, 96,* 415–421. https://doi.org/10.1016/s1081-1206(10)60908-8

Boyce, J., Assa'ad, A., Burkes, A. W., Jones, S. M., Sampson, H. A., Wood, R. A. … Schwaninger, J. M. (2010). Guidelines for the diagnosis and management of food allergy in the United States: Report of the NIAID-sponsored expert panel. *Journal of Allergy and Clinical Immunology*, *126*(6),S1-S58. doi:10.1016/j.jaci.2010.10.007

Braun, V. & Clarke, V. (n.d.). *Thematic Analysis | a reflexive approach.* Retrieved https://www.psych.auckland.ac.nz/en/about/our-research/research-groups/thematic-analysis.html

Braun, V. & Clarke, V. (2019). *Answers to frequently asked questions about thematic analysis.* Retrieved from https://cdn.auckland.ac.nz/assets/psych/about/our-research/documents/Answers%20to%20frequently%20asked%20questions%20about%20thematic%20analysis%20April%202019.pdf

Braun, V. & Clarke, V. (2008). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. http://dx.doi.org/10.1191/1478088706qp063oa

Broadbent, E., Petrie, K. J., Main, J. and Weinman, J. (2006). The Brief Illness Perception Questionnaire. *Journal of Psychosomatic Research*, 60, 631-637. https://doi.org/10.1016/j.jpsychores.2005.10.020

Bronfenbrenner, U. (1994). Ecological models of human development. In *International Encyclopaedia of Education, Vol. 3, 2nd. Ed.* Oxford: Elsevier. Reprinted in: Gauvain, M. & Cole, M. (Eds.), *Readings on the development of children, 2nd Ed.* (1993, pp. 37-43). NY: Freeman.

Brooks, J., Kime, N., King, N., Wearden, A., Gillibrand, W. & Campbell F. (2015) Exploring how young people think about and respond to diabetes in their peers. *Diabetes Care for Children & Young People 4*: 14–18

Broome, S. B., Lutz, B. J., & Cook, C. (2015). Becoming the parent of a child with life-threatening food allergies. *Journal of Pediatric Nursing: Nursing Care of Children and Families, 30*(4), 532–542. https://doi.org/10.1016/j.pedn.2014.10.01

Bunge, M. (1993). Realism and antirealism in social science. *Theory and Decision, 35*, 207-235. https://doi.org/10.1007/BF01075199

Cacioppo, J. T. & Petty, R. E. (1984). *"The Elaboration Likelihood Model of Persuasion",* in NA – Advances in Consumer Research, 11, eds. Thomas C. Kinnear, Provo, UT: Association for consumer research, 673-675. http://acrwebsite.org/volumes/6329/volumes/v11/NA-11

Carpenter, C. J. (2010). A meta-analysis of the effectiveness of health belief model variables in predicting behavior. *Health Communication, 25*(8), 661-669. doi:10.1080/10410236.2010. 521906

Carpenter, S. (2018). Ten Steps in Scale Development and Reporting: A Guide for Researchers. *Communication Methods and Measures*, 12(1), 25–44. https://doi.org/10.1080/19312458.2017.1396583

Chafen, J. J. S., Newberry, S. J., Riedl, M. A., Bravata, D. M., Maglione, M., Suttorp, M. J., … Shekelle, P. G. (2010). Diagnosing and Managing Common Food Allergies. *Journal of the American Medical Association, 303*(18), 1848. doi:10.1001/jama.2010.582

Chambers, R. A., Taylor, J. R., & Potenza, M. N. (2003). Developmental neurocircuitry of motivation in adolescence: A critical period of addiction vulnerability. American Journal of Psychiatry, 160, 1041–1052. https://doi.org/10.1176/appi.ajp.160.6.1041

Charmaz, K. (2006). *Constructing grounded theory: A practice guide through qualitative analysis*. Thousand Oaks, CA: Sage.

Chein, J., Albert, D., O'Brien, L.,Uckert, K. & Steinberg, L. (2011). Peers increase adolescent risk-taking by enhancing activity in the brain's reward circuitry. *Developmental Science, 14*(2): F1–F10. doi:10.1111/j.1467-7687.2010.01035.x.

Choi, J. H. & Rajagopal, L. (2012). Food allergy knowledge, attitudes, practices, and training of foodservice workers at a university foodservice operation in the Midwestern United States. *Food Control, 31*, 474-481. http://dx.doi.org/10.1016/j.foodcont.2012.10.023

Cohn, L. D., Macfarlane, S., Yanez, C., & Imai, W. K. (1995). Risk-perception: Differences between adolescents and adults. Health Psychology, 14(3), 217–222. doi:10.1037/0278-6133.14.3.217

Connors, M. H. & Halligan, P.W. (2015). A cognitive account of belief: a tentative road map. *Frontiers in Psychology, 5(*1588), 1-14. doi:10.3389/fpsyg.2014.01588

Conroy, M. E. (2013). Food allergy: Review of epidemiology, risk factors, and future treatments. *American Journal of Lifestyle Medicine, 9*(4), 280-287. doi:10.1177/1559827613510865

Conway, S., & Hockey, J. (1998). Resisting the “mask” of old age?: The social meaning of lay health beliefs in later life. *Ageing and Society, 18*(4), 469–494. doi:10.1017/s0144686x98006916

Croasmun, J. T. & Ostrom, L. (2011). Using Likert-type scales in the social sciences. *Journal of Adult Education, 40*,19-22. Retrieved from https://files.eric.ed.gov/fulltext/EJ961998.pdf

Cummings. A., Knibb, R.C., King, R. & Lucas, J. (2010). The psychosocial impact of food allergy on children and adolescents: A review. *Allergy, 65*, 933-945. doi:10.1111/j.1398-9995.2010.02342.x.

Davies, G. (2018, September 19). Boy, 13, with dairy allergy died after schoolmate threw cheese down his T-shirt, inquest hears. *The Telegraph.* Retrieved from https://www.telegraph.co.uk/news/2018/09/19/boy-13-dairy-allergy-died-schoolmate-threw-cheese-t-shirt-inquest/

De Simoni, A., Horne, R., Fleming, L., Bush, A., & Griffiths, C. (2017). What do adolescents with asthma really think about adherence to inhalers? Insights from a qualitative analysis of a UK online forum. BMJ Open, 7(6), e015245. doi:10.1136/bmjopen-2016-015245

Dean, J., Fenton, N. E., Shannon, S., Elliott, S. J., & Clarke, A. (2016). Disclosing food allergy status in schools: Health-related stigma among school children in Ontario. *Health and Social Care in the Community,24* (5), 43–52. https://doi.org/10.1111/hsc.1224

Dielman, T. E., Leech, S., Becker, M. H., Rosenstock, I. M., Horvath, W. J., & Radius, S. M. (1982). Parental and Child Health Beliefs and Behavior. Health Education Quarterly, 9(2-3), 60–77. doi:10.1177/109019818200900207

Donovan, J. E. & Jessor, R. (1985). Structure of problem behaviour in adolescence and young adulthood. *Journal of Consulting and Clinical Psychology, 53*, 890-904. http://dx.doi.org/10.1037/0022-006X.53.6.890

DunnGalvin, A., Gaffney, A., & Hourihane, J. O'B. (2009). Developmental pathways in food allergy: A new theoretical framework. *Allergy, 64*(4), 560-568. doi:10.1111/j.1398-9995.2008.01862.x

DunnGalvin A, Polloni, L., Le Bovidge, J., Muraro, A., Greenhawt, M., Taylor, S., ... Hammond, J. (2018). Preliminary Development of the Food Allergy Coping and Emotions Questionnaires for Children, Adolescents, and Young People: Qualitative Analysis of Data on IgE-Mediated Food Allergy from Five Countries. *Journal of Allergy and Clinical Immunology in Practice.* 6(2), 506-13. https://doi.org/10.1016/j.jaip.2017.11.044

Dupuis, R., Meuisel, Z., Grande, D., Strupp, E., Kounaves, S., Graves, A. … Cannusico, C. C. (2016). Food allergy management among restaurant workers in a large U.S. city. *Food Control, 63*, 147-157. http://dx.doi.org/10.1016/j.foodcont.2015.11.026

Dures, E., Rumsey, N., Morris, M., & Gleeson, K. (2011). Mixed methods in health psychology: Theoretical and practical considerations of the third paradigm. *Journal of Health Psychology,16*, 332–341. doi:10.1177/1359105310377537

Eagly, A. H., and Chaiken, S. (1993). *The Psychology of Attitudes*. Orlando, FL: Harcourt Brace Jovanovich.

Eigenmann, P. A., Caubet, J.-C., & Zamora, S. A. (2006). Continuing food-avoidance diets after negative food challenges. *Pediatric Allergy and Immunology, 17*(8), 601–605. doi:10.1111/j.1399-3038.2006.00455.x

El Turki, A., Smith, H., Llewellyn, C. & Jones, C. J. (2017) A systematic review of patients', parents' and healthcare professionals' adrenaline auto-injector administration techniques. *Emergency Medicine Journal, 34*:403-416. https://doi.org/10.1136/emermed-2016-205742

Ercan, H., Ozen, A., Karatepe, H., Berber, M., & Cengizlier, R. (2012). Primary school teachers' knowledge about and attitudes toward anaphylaxis. *Pediatric Allergy and Immunology, 23*(5), 428–432. doi:10.1111/j.1399-3038.2012.01307.x

European Academy of Allergy and Clinical Immunology (EAACI). (2015). *Food Allergy & Anaphylaxis Public Declaration.* Retrieved from http://www.eaaci.org/attachments/FoodAllergy&AnaphylaxisPublicDeclarationCombined.pdf

Fenton, N. E., Elliott, S. J., Cicutto, L., Clarke, A. E., Harada, L. & McPhee, E. (2011). Illustrating risk: Anaphylaxis through the eyes of the food-allergic child. *Risk Analysis, 13*(1), 171-183. doi:10.1111/j.1539-6924.2010.01488.x

Fenton, N. E., Elliott, S. J. & Clarke, A. (2013). Tag, you're different: the interrupted spaces of children at risk of anaphylaxis. *Children's Geographies*, 11:3, 281-297. doi:10.1080/14733285.2013.812273

Fishbein, M., & Ajzen, I. (1975). *Belief, attitude, intention, and behavior: An introduction to theory and research.* Reading, MA: Addison-Wesley.

Fiocchi, A. & Fierro, V. (2017). *Food Allergy.* Retrieved, August 18 2019, from https://www.worldallergy.org/education-and-programs/education/allergic-disease-resource-center/professionals/food-allergy

Flick, U., Garms-Homolová, W. J., Herrmann, W.J., Kuck, J. & Röhnsch, G. (2012), "I can't prescribe something just because someone asks for it.”: Using mixed methods in the framework of triangulation. *Journal of Mixed Methods Research, 6*, 97–110. doi:10.1177/1558689812437183

Flokstra-de Blok, B. M. J. (2014). *Food Allergy Quality of Life Questionnaires (FAQLQ)*. In: Michalos A.C. (eds) Encyclopedia of Quality of Life and Well-Being Research. Springer, Dordrecht

Food Standards Agency. (2019). *The effect of extrinsic factors on food allergy*. Retrieved from https://www.food.gov.uk/research/food-allergy-and-intolerance-research/the-effect-of-extrinsic-factors-on-food-allergy

Food Standards Agency. (2018). *Food Allergy and Intolerance*. Retrieved from https://www.food.gov.uk/safety-hygiene/food-allergy-and-intolerance

Food Standards Agency. (n.d.). *Rules and Legislation*. Retrieved from https://allergytraining.food.gov.uk/english/rules-and-legislation/#know-the-law

Food Standards Agency (n.d.). *Food allergy facts*. Retrieved from http://allergytraining.food.gov.uk/english/food-allergy-facts.aspx

Food Standards Agency. (2017). *Food Standards Agency: Board Meeting 15 March 2017: Food allergy and intolerance programme*. Retrieved from: https://www.food.gov.uk/sites/default/files/media/document/fsa170306.pdf

Friedman, A. H. & Morris, T. L. (2006). Allergies and anxiety in children and adolescents: A review of the literature. *Journal of Clinical Psychology in Medical Settings, 13(3),* 323-336*.* doi:10.1007/s10880-006-9026-7

Fusch, P. I., & Ness, L. R. (2015). Are we there yet? Data saturation in qualitative research. *The Qualitative Report, 20*(9), 1408-1416. Retrieved from http://nsuworks.nova.edu/tqr/vol20/iss9/3

Gallagher, M., Worth, A., Cunningham-Burley, S. & Sheikh, A. (2011). Epinephrine auto-injector use in adolescents at risk of anaphylaxis: A qualitative study in Scotland, UK. *Clinical & Experimental Allergy, 41*, 869-877. doi: 10.1111/j.1365-2222.2011.03743.x

Gallagher, M., Worth, A., Cunningham-Burley, S. & Sheikh, A. (2012). Strategies for living with the risk of anaphylaxis in adolescence: qualitative study of young people and their parents. *Primary Care Respiratory Journal, 21*(4), 392-397. doi: 10.4104/pcrj.2012.00072

Gay, L. R., Mills, G. E., & Airasian, P. (2009). *Educational research: Competencies for analysis and applications.* Columbus, OH: Merrill.

Gillespie, C. A., Woodgate, R. L., Chalmers, K. I., & Watson, W. T. (2007). "Living with risk": Mothering a child with food-induced anaphylaxis. *Journal of Pediatric Nursing,22*(1), 30–42. https://doi.org/10.1016/j.pedn.2006.05.00

Goodhue, D. (1988). I/S attitudes: toward theoretical and definitional clarity. *ACM SIGMIS Database, 19*(3-4), 6–15. doi:10.1145/65766.65768

Gore, S. & Eckenrode, J. (1994). Context and processes in research on risk and resilience. In Haggery, R. J., Sherrod, L. R., Gamezy, N. & Rutter, M. (Eds.) *Stress, risk and resilience in children and adolescents: processes, mechanisms and interventions.* (pp. 19-57) New York: Cambridge University Press.

Goosens, N. J., Flokstra-de Blok, B. M. J., van der Meulen, G. N., Botjes, E., Burgerhorf, H. G., Cupta, R. S., … Dubois, A. E. (2013). Food allergy knowledge of parents – is ignorance bliss? *Pediatric Allergy and Immunology, 24*(6), https://doi.org/10.1111/pai.12099

GOV.UK. (2019). *Gove to Introduce 'Natasha's Law.'* Retrieved August 29 2019 from https://www.gov.uk/government/news/gove-to-introduce-natashas-law

Green, B. L., Krupnick, J. L., Stockton, P., Goodman, L., Corcoran, C., & Petty, R. (2005). Effects of adolescent trauma exposure on risky behavior in college women. *Psychiatry: Interpersonal & Biological Processes, 68*(4), 363–378. doi:10.1521/psyc.2005.68.4.363

Greene, K., Krcmar, M., Walters, L. H., Rubin, D. L., Hane, J. & Hane, L. (2000). Targeting adolescent risk-taking behaviours: The contributions of egocentrism and sensation seeking*. *Journal of Adolescence, 23*, 439-461. doi:10.1006/jado.2000.0330.

Greenhawt, M. J., Singer, A. M. & Baptist, A. P. (2009). Food allergy and food allergy attitudes among college students. *Journal of Allergy and Clinical Immunology*, *124*, 323-327. doi:10.1016/j.jaci.2009.05.028

Grundy, J., Matthews, S., Bateman, B., Dean, T. & Arshad, S. H. (2002). Rising prevalence of allergy to peanut in children: Data from 2 sequential cohorts 1. *The Journal of Allergy and Clinical Immunology, 110*(5), 784–789. http://dx.doi.org/10.1067/mai.2002.128802

Guest, G., Bunce, A. & Johnson, L. (2006). How many interviews are enough?: An Experiment with Data Saturation and Variability. *Field Methods, 18*; 59. doi:10.1177/1525822X05279903

Gullone, E., Moore, S., Moss, S., & Boyd, C. (2000). The Adolescent Risk-Taking Questionnaire. *Journal of Adolescent Research, 15*(2), 231–250. doi:10.1177/0743558400152003

Gupta, R., Sheikh, A., Strachan, D. P. & Anderson, H. R. (2007). Time trends in allergic disorders in the UK. *Thorax, 62*, 91-96. doi:10.1136/thx.2004.038844

Gupta, R. S., Kim, J. S., Barnathan, J. A., Amsden, L. B., Tummala, L. S., & Holl, J. L. (2008). Food allergy knowledge, attitudes and beliefs: Focus groups of parents, physicians and the general public. *BMC Pediatrics, 8*(1), 36. https://doi.org/10.1186/1471-2431-8-36.

Gupta, R. S., Springston, E. E., Smith, B., Kim, J. S., Pongracic, J. A., Wang, X., & Holl, J. (2010). Food allergy knowledge, attitudes, and beliefs of parents with food-allergic children in the United States. *Pediatric Allergy and Immunology, 21*(6), 927–934. doi:10.1111/j.1399-3038.2010.01005.x

Gupta, R. S., Springston, E. E., Kim, J. S., Smith, B., Pongracic, J.A., Wang, X. & Holl, J.

(2010). Food Allergy Knowledge, Attitudes, and Beliefs of Primary Care Physicians. *Pediatrics, 125*(1) doi:10.1542/peds.2009-1116

Hagger, M. S., Koch, S., Chatzisarantis, N. L. D., & Orbell, S. (2017). The common sense model of self-regulation: Meta-analysis and test of a process model. *Psychological Bulletin, 143*(11), 1117-1154. http://dx.doi.org/10.1037/bul0000118

Hagger, M. S. & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology and Health, 18*(2), 141-184. https://doi.org/10.1080/088704403100081321

Halligan, P.W. & Aylward, M. (Eds.) (2006). *The Power of belief: Psychosocial influence on illness, disability and medicine.* Oxford: Oxford University Press.

Halligan, P. W. (2007). Belief and illness. *The Psychologist, 20(6)*, 358–361. Retrieved from http://thepsychologist.bps.org.uk/volume-20/edition-6/belief-and-illness

Hampson, S. E., Glasgow, R. E., & Foster, L. S. (1995). Personal Models of Diabetes Among Older Adults: Relationship to Self-Management and Other Variables. *The Diabetes Educator, 21*(4), 300–307. doi:10.1177/014572179502100407

Harrington, D. W., Elliott, S. J., Clarke, A. E., Ben-Shoshan, M. & Godfrey, S. (2012). Exploring the determinants of the perceived risk of food allergies in Canada. *Human and Ecological Risk Assessment, 18*, 1338–1358, doi:10.1080/10807039.2012.722857

Harrison, J. A., Mullen, P. D., & Green, L. W. (1992). A meta-analysis of studies of the health belief model with adults. *Health Education Research, 7*(1), 107-116. doi:10.1093/her/7.1.107

Hartley, J. (2014). Some thoughts on Likert-type scales. *International Journal of Clinical and Health Psychology, 14*(1), 83–86. doi:10.1016/s1697-2600(14)70040-7

Hefle, S. L., Furlong, T. J., Niemann, L., Lemon-Mule, H., Sicherer, S. & Taylor, S. L. (2007).

Consumer attitudes and risks associated with packaged foods having advisory labeling regarding the presence of peanuts. *Journal of Allergy and Clinical Immunology*, *120*, 171-176. doi:10.1016/j.jaci.2007.04.013

Heisler, M., Bouknight, R. R., Hayward, R. A., Smith, D. M., & Kerr, E. A. (2002). The relative importance of physician communication, participatory decision making, and patient understanding in diabetes self-management. *Journal of General Internal Medicine, 17*(4), 243–252. doi:10.1046/j.1525-1497.2002.10905.x

Helgeson, V. S., Reynolds, K. A., Escobar, O., Siminerio, L. & Becker, D. (2007). The role of friendship in the lives of male and female adolescents: Does diabetes make a difference? *Journal of Adolescent Health, 40,* 36 – 43. doi:10.1016/j.jadohealth.2006.07.007

Herbert, L. J., Mehta, P., & Sharma, H. (2017). Mealtime behavior among parents and their young children with food allergy. *Annals of Allergy, Asthma & Immunology, 118*(3), 345–350. doi:10.1016/j.anai.2016.12.002

Hepburn, A., & Bolden, G. (2017). *Transcribing for Social Research*. London, UK: SAGE Publications.

Hikosaka, O., Takikawa, Y. & Kawagoe, R. (2000). Role of the Basal Ganglia in the Control of Purposive Saccadic Eye Movements, *Physiological Reviews, 80*(3), 953-978. https://doi.org/10.1152/physrev.2000.80.3.953

Hofmann, S. G., Asnaani, A., Vonk, I. J. J., Sawyer, A. T., & Fang, A. (2012). The efficacy of cognitive behavioral therapy: a review of meta-analyses. *Cognitive Therapy and Research*, *36*, 427–440. doi:10.1007/s10608-012-9476-1

Hong, Q. N., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., … Pluye, P. (2018). The Mixed Methods Appraisal Tool (MMAT) version 2018 for information professionals and researchers. *Education for Information,* 34(4), 285–291. doi:10.3233/efi-180221

Hourihane, J.O., Dean, T.P. & Warner, J.O. (1996). Peanut allergy in relation to heredity, maternal diet, and other atopic diseases: Results of a questionnaire survey, skin prick testing, and food challenges. *The British Medical Journal,* 518-521. http://dx.doi.org/10.1136/bmj.313.7056.518

Hugh-Jones, S. & Gibson, S. (2012). *Collecting your data.* In Sullivan, C., Gibson, S., & Riley, S. *Doing your qualitative psychology project* (pp. 101-126). London: SAGE Publications Ltd. doi:10.4135/9781473914209

Ivankova, N., Creswell, J., & Stick, S. (2006). Using mixed methods in sequential explanatory design: From theory to practice. Field Methods, 18(3), 3-20. https://doi.org/10.1177/1525822x05282260

Janz, N. K. & Becker, M. H. (1984). The health belief model: A decade later. *Health Education Quarterly, 11*(1), 1-47. https://doi.org/10.1177/109019818401100101

Jefferson, G. (2004). Glossary of transcript symbols with an introduction. In G. H. Lerner (Ed.), *Conversation analysis: Studies from the first generation.* pp. 13-31. Philadelphia: John Benjamins.

Johnson, R., Onwuegbuzie, A., & Turner, L. (2007). Toward a definition of mixed methods research. Journal of Mixed Methods Research, 1(2), 112–133. https://doi.org/10.1177/1558689806298224

Johnson, S. F. & Woodgate, R. L. (2017). Qualitative research in teen experiences living with food-induced anaphylaxis: A meta-aggregation. *Journal of Advanced Nursing.* doi:10.1111/jan.13325

Jones, C.J., Llewellyn, C.D., Frew, A.J., Du Toit, G., Mukhopadhyay, S. & Smith, H. (2015). Factors associated with good adherence to self-care behaviours amongst adolescents with food allergy. *Pediatric Allergy and Immunology, 26,* 111–118. doi:10.1111/pai.12333

Jones, C.J., Smith, H. E., Frew, A.J., Du Toit, G., Mukhopadhyay, S. & Llewellyn, C.D. (2014). Explaining adherence to self-care behaviours amongst adolescents with food allergy: A comparison of the health belief model and the common sense self-regulation model. *British Journal of Health Psychology, 19*, 65-82. doi:10.1111/bjhp.12033

Jones, C. J., Sommereux, L. A., & Smith, H. E. (2018). Exploring what motivates and sustains support group engagement amongst young people with allergies: A qualitative study. *Clinical & Experimental Allergy, 48*(9), 1195–1205. doi:10.1111/cea.13193

Joshi, A. Kale, S., Chandel, S. & Pal, D. K. (2015). Likert scale: Explored and explained. *British Journal of Applied Science & Technology 7*(4): 396-403. https://doi.org/10.9734/bjast/2015/14975

Ju, S., Park, J. H., Kwak, T. K. & Kim, K. (2015). Attitudes and preferences of consumers toward food allergy labeling practices by diagnosis of food allergies. *Nutrition Research and Practice* 9(5), 517-522. doi:10.4162/nrp.2015.9.5.517

Kapoor, S., Roberts, G., Bynoe, Y., Gaughan, M., Habibi, P., & Lack, G. (2004). Influence of a multi-disciplinary paediatric allergy clinic on parental knowledge and rate of subsequent allergic reactions. *Allergy, 59*, 185–191. https://doi.org/10.1046/j.1398-9995.2003.00365.x

King, R., Knibb, R.C. & Hourihane, J. O'B. (2009) Impact of peanut allergy on quality of life, stress and anxiety in the family. *Allergy, 64*, 461-468. doi:10.1111/j.1398-9995.2008.01843.x

Klinnert, M. D., McQuaid, E. L., Fedele, D. A., Faino, A., MStrand, M., Robinson, J. … Fransen, H. (2015). Children's Food Allergies: Development of the Food Allergy Management and Adaptation Scale. *Journal of Pediatric Psychology, 40*(6), 572–580 doi:10.1093/jpepsy/jsv009

Knibb, R. (2015). Effectiveness of Cognitive Behaviour Therapy for Mothers of Children with Food Allergy: A Case Series. *Healthcare, 3*(4), 1194–1211. doi:10.3390/healthcare3041194

Knibb, R. C., Huissoon, A. P., Baretto, R., Ekbote, A., Onyango-Odera, S., Screti, C., Newman, K. L. and Krishna, M. T. (2019), ‘It's not an illness, it's just bad luck’: The impact of anaphylaxis on quality of life in adults. Clin Exp Allergy. doi:10.1111/cea.13410

Kronemyer, D., and Bystritsky, A. (2014). A nonlinear dynamical approach to belief revision in cognitive behavioral therapy. *Frontiers in Computational Neuroscience, 8*,55. doi:10.3389/fncom.2014.00055

Kvale, S., & Brinkmann, S. (2009). InterViews: Learning the craft of qualitative research interviewing (2nd ed.). Thousand Oaks, CA: Sage.

Lack, G. (2008). Epidemiologic risks for food allergy. *Journal of Allergy & Clinical Immunology 121*(6): 1331-6. https://doi.org/10.1016/j.jaci.2008.04.032

Lagercrantz, B., Persson, Å., & Kull, I. (2017). “Healthcare seems to vary a lot”: A focus group study among parents of children with severe allergy. *Journal of Asthma, 54*(7), 1–7. https://doi.org/10.1080/02770903.2016.1258079.

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology, 3*(2), 102-120. http://dx.doi.org/10.1191/1478088706qp062oa

Lazard, L. & McAvoy, J. (2017): Doing reflexivity in psychological research: What’s the point? What’s the practice? *Qualitative Research in Psychology* doi:10.1080/14780887.2017.1400144

Lau, R. R., Bernard, T. M., & Hartman, K. A. (1989). Further explorations of common-sense representations of common illnesses. *Health Psychology, 8*(2), 195–219. doi:10.1037/0278-6133.8.2.195

Leach, L., Smith, H., Brown, C., Davies, M., & Jones, C. (2018). Young People’s Views on the Design of Adrenaline Auto-Injectors: A Qualitative Study. *Journal of Allergy & Therapy, 09*(01). doi:10.4172/2155-6121.1000271

Leventhal, H., Nerenz, D.R. and Steele, D.J. (1984). Illness representations and coping with health threats. In: Baum, A., Taylor, S.E. and Singer, J.E. (Eds.), *Handbook of Psychology and Health: Social psychological aspects of health*, Vol. 4. pp. 219–252. Earlbaum, Hillsdale, NJ.

Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gøtzsche, P. C., Ioannidis, J. P. A. … Moher, D. (2009) The PRISMA Statement for Reporting Systematic Reviews and Meta-Analyses of Studies That Evaluate Health Care Interventions: Explanation and Elaboration. *PLoS Med* 6(7): e1000100. https://doi.org/10.1371/journal.pmed.1000100

Loerbroks, A., Tolksdorf, S. J., Wagenmann, M., & Smith, H. (2019). Food allergy knowledge, attitudes and their determinants among restaurant staff: A cross-sectional study. *PLoS ONE 14*(4): e0214625. https://doi.org/10.1371/journal.pone.0214625

Lucas, P., Patterson, E., Sacks, G., Billich, N., & Evans, C. (2017). Preschool and school meal policies: An overview of what we know about regulation, implementation, and impact on diet in the UK, Sweden, and Australia. *Nutrients, 9*(7), 736. doi:10.3390/nu9070736

Macadam, C., Barnett, J., Roberts, G., Stiefel, G., King, R., Erlewyn-Lajeunesse, M., Holloway, J. A. & Lucas, J. S. (2012). What factors affect the carriage of epinephrine auto-injectors by teenagers. *Clinical and Translational Allergy, 2*(3). https://doi.org/10.1186/2045-7022-2-3

MacKenzie, J., Roberts, G., Van Laar, D. & Dean, T. (2010). Teenagers' experiences of living with food hypersensitivity: A qualitative study. *Pediatric Allergy and Immunology, 21: 595–602. doi:10.1111/j.1399-3038.2009.00938.x*

Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology, 91*(1), 1–20. doi:10.1348/000712600161646

Marklund, B., Ahlstedt, S. & Nordstrom, G. (2004). Health-related quality of life among adolescents with allergy-like conditions – with emphasis on food hypersensitivity . *Health and Quality of Life Outcomes*, *2*, 65. doi:10.1186/1477-7525-2-65

Marklund B, Ahlstedt S, Nordstrom G. (2006) Health-related quality of life in food hypersensitive schoolchildren and their families: parents' perceptions. *Health and Quality of Life Outcomes,* 4, 48. https://doi.org/10.1186/1477-7525-4-48

Marklund, B., Wilde-Larsson, B., Ahlstedt, S. & Nordström, G. (2007). Adolescents' experiences of being food-hypersensitive: A qualitative study *BMC Nursing, 6*(8). https://doi.org/10.1186/1472-6955-6-8

Maslin, K., Dean, T., Arshad, S. H. & Venter, C. (2015). Fussy eating and feeding difficulties in infants and toddlers consuming a cows' milk exclusion diet. *Pediatric Allergy & Immunology, 26*: 503–508. doi:10.1111/pai.12427

Maslin, K., Grundy, J., Glasbey, G., Dean, T., Arshad, S.H., Grimshaw, K., … Venter, C. (2016). Cows' milk exclusion diet during infancy: Is there a long-term effect on children's eating behaviour and food preferences? *Pediatric Allergy & Immunology, 27,* 141–146. doi:10.1111/pai.12513

McIntyre, C. L., Sheetz, A.H., Carroll, C. R, & Young, M. C. (2005). Administration of epinephrine for life-threatening allergic reactions in school settings. *Pediatrics, 116*, 1134–1140. https://doi.org/10.1542/peds.2004-1475

McMurtry, C. M., Noel, M., Taddio, A., Antony, M. M., Asmundson, G. J. G., Riddell, R. P., … Shah, V. (2015). Interventions for Individuals With High Levels of Needle Fear. *The Clinical Journal of Pain, 31*, S109–S123. doi:10.1097/ajp.0000000000000273

McMurtry, C. M., Taddio, A., Noel, M., Antony, M. M., Chambers, C. T., Asmundson, G. J. G., … Scott, J. (2016). Exposure-based Interventions for the management of individuals with high levels of needle fear across the lifespan: a clinical practice guideline and call for further research. *Cognitive Behaviour Therapy, 45(*3), 217–235. doi:10.1080/16506073.2016.1157204

Melia, C. & Newman, K. (2019) Finding power in words: Redeeming the reputation of transcription, *QMiP Bulletin, 27* (Spring). 41-45. Retrieved from https://shop.bps.org.uk/publications/qmip-bulletin-issue-27-spring-2019.html

Mental Health Foundaton. (2016). *Fundamental Facts about mental health 2016.* Retrieved from https://www.mentalhealth.org.uk/publications/fundamental-facts-about-mental-health-2016

Meyer, R. (2018). Nutritional disorders resulting from food allergy in children. *Pediatric Allergy & Immunology, 29*, 689–704. https://doi.org/10.1111/pai.12960

Moher, D. Liberati, A., Tetzlaff, J., Altman, D. G. & The PRISMA Group. (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Medicine, 6*(7), e1000097, doi:10.1371/journal.pmed1000097

Møller, A. M. & Myles, P. S. (2016). What makes a good systematic review and meta-analysis? *British Journal of Anaesthesia, 117*(4): 428–30. doi:10.1093/bja/aew264

Moen, Ø. L., Opheim, E. & Trollvik, A. (2019). Parents experiences Raising a Child with Food Allergy; AQualitative Review. Journal of Pediatric Nursing, 46, e52–e63. https://doi.org/10.1016/j.pedn.2019.02.036

Moneret-Vautrin, D. A., Kanny, G., Morisset, M., Flabbee, J., Guenard, L., Beaudouin, E. & Parisot, L. (2001). Food anaphylaxis in schools: evaluation of the management plan and the efficiency of the emergency kit. *Allergy, 56*, 1071–1076. https://doi.org/10.1034/j.1398-9995.2001.00047.x

Monks, H., Gowland, M. H., MacKenzie, H., Erlewyn-Lajeunesse, M., King, R., Lucas, J. S. & Roberts, G. (2010). How do teenagers manage their food allergies? *Clinical & Experimental Allergy, 40*, 1533–1540. doi: 10.1111/j.1365-2222.2010.03586.x

Morgan, D. (2006). Connected contributions as a motivation combining qualitative and quantitative methods. In L. Curry, R. Shield, & T. Wetle (Eds.), *Applying qualitative and mixed methods in aging and public health research*. Washington, DC: American Public Health Association.

Morgan, D. (2007). Paradigms Lost and Pragmatism Regained: Methodological Implications of Combining Qualitative and Quantitative Methods. *Journal of Mixed Methods Research, 1* (1), 48-76 doi:10.1177/2345678906292462

Morou, Z., Tatsioni, A., Dimoliatis, I. D. K. & Papadopoulos, N. G. (2014). Health related quality of life in children with food allergy and their parents: A systematic review of the literature. *Journal of Investigational Allergology and Clinical Immunology, 24*(6): 382-395. Retrieved from http://www.jiaci.org/issues/vol24issue6/2.pdf

Munoz-Furlong, A. (2003). Daily coping strategies for patients and their families. *Pediatrics*, *111*, 1654–1661. Retrieved from https://pediatrics.aappublications.org/content/pediatrics/111/Supplement_3/1654.full.pdf

Muraro A, Agache I, Clark A, Sheikh A, Roberts G, Akdis CA, … Wickman M. (2014). EAACI Food Allergy and Anaphylaxis Guidelines: Managing patients with food allergy in the community. *Allergy, 69*: 1046–1057. doi:10.1111/all.12441

National Institute for Health and Clinical Excellence. (2011). Food allergy in children and young people: Diagnosis and assessment of food allergy in children and young people in primary care and community settings. *Nice Clinical Guideline 116,* Accessed https://www.nice.org.uk/guidance/cg116/evidence/full-guideline-136470061

Newman, K. L. & Williamson, I. (2018). Why aren't you stopping now?!' Exploring accounts of white women breastfeeding beyond six months in the East of England. *Appetite, 129*, 228-235. https://doi.org/10.1016/j.appet.2018.06.018

NHS. (2019). *Overview: Food allergy*. Retrieved from https://www.nhs.uk/conditions/food-allergy/

NHS. (2016). *Overview: Anaphylaxis*. Retrieved from https://www.nhs.uk/conditions/anaphylaxis/

NHS. (2016). *Treatment: Anaphylaxis*. Retrieved from https://www.nhs.uk/conditions/anaphylaxis/treatment/

Noimark, L., Gardner, J. & Warner, J. O. (2009). Parents' attitudes when purchasing products for children with nut allergy: A UK perspective. *Pediatric Allergy and Immunology, 20*, 500-504. doi: 10.1111/j.1399-3038.2008.00796.x

Novembre, E., Cianferoni, A., Bernardini, R., Mugnaini, L., Caffarelli, C., Cavagni, G. … Vierucci, A. (1998) Anaphylaxis in children: clinical and allergologic features. *Pediatrics,101*:E8.

Nowicki, S., & Strickland, B. R. (1973). A locus of control scale for children. *Journal of Consulting and Clinical Psychology, 40*(1), 148–154. doi:10.1037/h0033978

Orenius, T., LicPsych, Säilä, H., Mikola, K., & Ristolainen, L. (2018). Fear of Injections and Needle Phobia Among Children and Adolescents: An Overview of Psychological, Behavioral, and Contextual Factors. *SAGE Open Nursing, 4*, 237796081875944. doi:10.1177/2377960818759442

Ostblom, E., Egmar, A. C., Gardulf, A., Lilja, G. & Wickman. M. (2008). The impact of food hypersensitivity reported in 9-year-old children by their parents on health-related quality of life. *Allergy, 63,* 211–218. https://doi.org/10.1111/j.1398-9995.2007.01559.x

Pallant, J. (2011). *SPSS survival manual: A step by step guide to data analysis using the SPSS program. 4th Edition*, Allen & Unwin, Berkshire

Perestelo-Pérez, L. (2013). Standards on how to develop and report systematic reviews in Psychology and Health. *International Journal of Clinical and Health Psychology, 13*, 49−57. https://doi.org/10.1016/s1697-2600(13)70007-3

Petty, R. E., Cacioppo, J. T. & Goldman, R. (1981). Personal involvement as a determinant of argument-based persuasion. *Journal of Personality and Social Psychology, 41*(5), 847-855. https://doi.org/10.1037//0022-3514.41.5.847

Plantin, L., Månsson, S.-A., & Kearney, J. (2003). Talking and doing fatherhood: On fatherhood and masculinity in Sweden and England. *Fathering: A Journal of Theory, Research, and Practice About Men as Fathers, 1*(1), 3–26. doi:10.3149/fth.0101.3

Pluye, P., Robert, E., Cargo, M., Bartlett, G., O'Cathain, A., Griffiths, F., Boardman, F., Gagnon, M.P. & Rousseau, M.C. (2011). Proposal: A mixed methods appraisal tool for systematic mixed studies reviews. *Department of Family Medicine, McGill University, Montreal, Canada*. Retrieved from http://mixedmethodsappraisaltoolpublic.pbworks.com.

Polloni, L., Lazzarotto, F., Bonaguro, R., Toniolo, A., Celegato, N., & Muraro, A. (2015). Psychological care of food-allergic children and their families: an exploratory analysis. *Pediatric Allergy and Immunology, 26*(1), 87–90. doi:10.1111/pai.12325

Pope, C., van Royen, P. & Baker, R. (2002). Qualitative methods in research on healthcare quality. *Quality and Safety in Healthcare, 11*(2), 148-152. http://dx.doi.org/10.1136/qhc.11.2.148

Powers, J., Bergern, M. D. & Finnegan, L. (2007). Comparison of school food allergy emergency plans to the Food Allergy and Anaphylaxis Network's standard plan. *The Journal of School Nursing, 23*(5), 252-258. doi:10.1177/10598405070230050301

Pseudovs, K., Burr, J. M., Harley, C. & Elliott, D. B. (2007). The Development, assessment, and selection of questionnaires. *Optometry and Vision Science, 84*(8), 663–674. doi:10.1097/opx.0b013e318141fe75

Pumphrey, R. S. H. (2000). Lessons for management of anaphylaxis from a study of fatal reactions. *Clinical and Experimental Allergy, 30,* 1144-1150. https://doi.org/10.1046/j.1365-2222.2000.00864.x

Pumphrey, R. S. H., & Gowland, M. H. (2007). Further fatal allergic reactions to food in the United Kingdom, 1999-2006. *Journal of Allergy and Clinical Immunology, 119*(4), 1018–1019. doi:10.1016/j.jaci.2007.01.021

Raaijmakers, Q. A. W., Verbogt, T. F. M. A., & Vollebergh, W. A. M. (1998). Moral reasoning and political beliefs of dutch adolescents and young adults. *Journal of Social Issues, 54*(3), 531–546. doi:10.1111/0022-4537.811998081

Rankin, K. E., & Sheikh, A. (2006). Serious shortcomings in the management of children with anaphylaxis in Scottish schools. *PLoS Medicine, 3*(8), e326. doi:10.1371/journal.pmed.0030326

Rathert, C., Wyrwich, M. D., & Boren, S. A. (2012). Patient-centered care and outcomes. *Medical Care Research and Review, 70*(4), 351–379. doi:10.1177/1077558712465774

Renner, B., Knoll, N., & Schwarzer, R. (2000). Age and body make a difference in optimistic health beliefs and nutrition behaviors. *International Journal of Behavioral Medicine, 7*(2), 143–159. doi:10.1207/s15327558ijbm0702_4

Rogers, R. W. (1975). A Protection Motivation Theory of Fear Appeals and Attitude Change. *The Journal of Psychology, 91*(1), 93–114. doi:10.1080/00223980.1975.9915803

Romer, D. (2010). Adolescent risk-taking, impulsivity, and brain development: Implications for prevention. *Developmental Psychobiology, 52*: 263–276. https://doi.org/10.1002/dev.20442

Romer, D., & Hennessy, M. (2007). A biosocial-affect model of adolescent sensation seeking: The role of affect evaluation and peer-group influence in adolescent drug use. Prevention Science, 8, 89–101. https://doi.org/10.1007/s11121-007-0064-7

Rosenstock, I. M. (1974). Historical origins of the health belief model. *Health Education Monographs, 2*(4), 328–335. https://doi.org/10.1177/109019817400200403

Rotter JB. (1954). *Social learning and clinical psychology*. Englewood Cliffs, NJ, US: Prentice-Hall, Inc.

Rotter, J. B. (1966). Generalized expectancies for internal versus external control of reinforcement. Psychological Monographs (General & Applied), 80, 1-28. https://doi.org/10.1037/h0092976

Rouf, K., White, L., & Evans, K. (2012). A qualitative investigation into the maternal experience of having a young child with severe food allergy. *Clinical Child Psychology and Psychiatry, 17*(1), 49–64. https://doi.org/10.1177/1359104511415636

Sacks, D. (2003). Age limits and adolescents. *Paediatrics & Child Health,* 8(9), 577–577. doi:10.1093/pch/8.9.577

Safeer, R. S., Cooke, C. E., & Keenan, J. (2006). The impact of health literacy on cardiovascular disease. *Vascular Health and Risk Management, 2*(4), 457–464. doi:10.2147/vhrm.2006.2.4.457

Saleh-Langneberg, J., Flokstra-de Blok, B. M. J., Goossens, N. J., Kemna, J. C., van der Velde, J. L. & Dubois, A. E. J. (2016). The compliance and burden of treatment with the epinephrine auto-injector in food-allergic adolescents. *Pediatric Allergy and Immunology, 27*, 28–34. doi:10.1111/pai.12458

Saleh-Langenberg, J., de Vries, S., Bak, E., Kollen, B. J., Flokstra-de Blok, B. M. J. & Dubois, A. E. J. (2016). Incomplete and incorrect epinephrine auto-injector training to food-allergic patients by pharmacists in the Netherlands. *Pediatric Allergy and Immunology, 28*(3). https://doi.org/10.1111/pai.12688

Sales, J. M., Irwin, C. E. (2013). A Biopsychosocial Perspective of Adolescent Health and Disease. In: O'Donohue W., Benuto L., Woodward Tolle L. (eds) *Handbook of Adolescent Health Psychology*. Springer, New York, NY

Sampson, M.A., Munoz-Furlong, A., Campbell, R. L., Adkinson Jr., N. F., Brock, S. A., Branum A. … Decker, W. W. (2006). Second Symposium on the Definition and Management of Anaphylaxis: Summary Report—Second National Institute of Allergy and Infectious Disease/Food Allergy and Anaphylaxis Network Symposium. *Annals of Emergency Medicine, 47*(4), 373-380. doi:10.1016/j.annemergmed.2006.01.018

Sampson, M.A., Munoz-Furlong, A. & Sicherer, S. H. (2006). Risk-taking and coping strategies of adolescents and young adults with food allergy. *The Journal of Allergy and Clinical Immunology, 117*: 1440-1445. doi:10.1016/j.jaci.2006.03.009

Sasaki, M., Peters, R. L., Koplin, J. J., Field, M. J., McWilliam, V., Sawyer, S. M., … Allen, K. J. (2018). Risk factors for food allergy in early adolescence: The SchoolNuts study. *Journal of Allergy and Clinical Immunology: In Practice, 6*(2), 496-505 https://doi.org/10.1016/j.jaip.2017.12.011

Schwitzgebel, E. (2010). *"Belief,"* in The Stanford Encyclopedia of Philosophy, ed. E. N. Zalta (Stanford: Stanford University).

Shaak, K., Johnson, M. B., Marsh, J. K., Hansen, S. E., Banerjee, E. S., Stello, B., & Careyva, B. A. (2018). Exploring health beliefs among hispanic adults with prediabetes. *Journal of Community Health, 43*(5), 962–968. doi:10.1007/s10900-018-0512-2

Shafie, A. A. & Azman, A. W. (2015). Assessment of knowledge, attitude and practice of food allergies among food handlers in the state of Penang, Malaysia. *Public Health, 129*, 1278-1284. doi: http://dx.doi.org/10.1016/j.puhe.2015.03.016

Shah, S., Peat, J. K., Mazurski, E. J., Wang, H., Sindhusake, D., Bruce, C., … & Gibson, P. G. (2001). Effect of peer led programme for asthma education in adolescents: cluster randomised controlled trial. *British Medical Journal, 322*. https://doi.org/10.1136/bmj.322.7286.583

Shaw, R. (2010). Conducting literature reviews. In M. A. Forrester (Ed.), *Doing Qualitative Research in Psychology: A Practical Guide.* London: Sage.

Sheikh A & Alves B. (2000). Hospital admissions for acute anaphylaxis: Time trend study. *The British Medical Journal: Clinical Research,* 320:1441. doi:10.1136/bmj.320.7247.1441

Sicherer, S.H., Furlong, T.J., Maes, H.H., Desnick, R.J., Sampson, H.A. & Gelb, B.D. (2000). Genetics of peanut allergy: A twin study. *The Journal of Allergy and Clinical Immunology, 106*, 53-56. http://dx.doi.org/10.1067/mai.2000.108105

Sicherer, S. H., & Sampson, H. A. (2014). Food allergy: Epidemiology, pathogenesis, diagnosis, and treatment. *Journal of Allergy and Clinical Immunology, 133*(2), 291–307.e5. doi:10.1016/j.jaci.2013.11.020

Skypala, I. J., Venter, C., Meyer, R., deJong, N. W., Fox, A. T., … Vlieg-Boerstra, B. J.

(2015). The development of a standardised diet history tool to support the diagnosis of food allergy. *Clinical and Translational Allergy, 5*(1). doi:10.1186/s13601-015-0050-2

Sommer, I., Mackenzie, H., Venter, C. & Dean, T. (2014). An exploratory investigation of food choice behavior of teenagers with and without food allergies. *Annals of Allergy, Asthma & Immunology, 112*(5), 446-452. doi:10.1016/j.anai.2014.02.009

Sommers-Flanagan, J., Sommers-Flanagan, R., & Baldridge, M. J., & Murray, K. W. (2012). Counseling and psychotherapy theories in context and practice: Skills, strategies, and techniques (2nd ed.). Hoboken, NJ, US: John Wiley & Sons Inc.

Soon, J. M. (2018). ‘No nuts please’: Food allergen management in takeaways’. *Food Control, 91*, 349-356. https://doi.org/10.1016/j.foodcont.2018.04.024

Spirito, A., Stark, L. J., & Williams, C. (1988). Development of a brief coping checklist for use with pediatric populations. *Journal of Pediatric Psychology, 13*, 555-574. https://doi.org/10.1093/jpepsy/13.4.555

Stensgaard, A., Bindslev-Jensen, C. and Nielsen, D. (2017), Peanut allergy as a family project: Social relations and transitions in adolescence. *Journal of Clinical Nursing, 26*, 3371–3381. doi:10.1111/jocn.13696

Stensgaard, A., Bindslev-Jensen, C., Nielsen, D., Munch, M. & DunnGalvin, A. (2017). Quality of life in childhood, adolescence and adult food allergy: Patient and parent perspectives. *Clinical & Experimental Allergy, 47*, 530–539. doi:10.1111/cea.12849

Stjerna, M. L. (2015). Food, risk and place: Agency and negotiations of young people with food allergy. *Sociology of Health & Illness, 37*(2), 284-297. doi:10.1111/1467-9566.12215

Stjerna, M. -L., Vetander, M., Wickman, M., & Olin Lauritzen, S. (2014). The management of situated risk: A parental perspective on child food allergy. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine, 18*(2),130–145. https://doi.org/10.1177/1363459313481234

Sullivan, C. & Forrester, M. A. (2019). *Doing qualitative research in psychology: A practical guide* (2^{nd} ed.). London: SAGE.

Tabachnick, B. G., & Fidell, L. S. (2007). *Using Multivariate Statistics* (5th ed.). New York: Allyn and Bacon

Taylor, G. W. & Ussher, J. M. (2001). Making sense of S&M: A discourse analytic account. *Sexualities, 4*(3), 293-314. https://doi.org/10.1177/136346001004003002

The British Psychological Society. (2017). *Practice Guidelines: Third Edition*. Retrieved from https://www.bps.org.uk/sites/bps.org.uk/files/Policy/Policy%20-%20Files/BPS%20Practice%20Guidelines%20(Third%20Edition).pdf

The British Psychological Society. (2014). *Code of Human Research Ethics*. Retrieved from https://www.bps.org.uk/sites/bps.org.uk/files/Policy/Policy%20-%20Files/BPS%20Code%20of%20Human%20Research%20Ethics.pdf

Thomas, J. J. & Daubman, K. A. (2001). The relationship between friendship quality and self-esteem in adolescent girls and boys. *Sex Roles, 45,* 53– 65. https://doi.org/10.1023/a:1013060317766

Tullett, A. M., Prentice, M. S., Teper, R., Nash, K. A., Inzlicht, M., and Mcgregor, I. (2013). “Neural and motivational mechanics of meaning and threat,” in *The Psychology of Meaning*, eds K. D. Markman, T. Proulx, and M. J. Lindberg (Washington, DC: American Psychological Association), 401–419.

Twichell, S., Wang, K., Robinson, H., Accebal, M. & Sharma, H. (2015). Food allergy knowledge and attitudes among school nurses in an urban public school district. *Children, 2,* 330-341. doi:10.3390/children2030330

U.S. Department of Health and Human Services FDA Center for Drug Evaluation and Research, U.S. Department of Health and Human Services FDA Center for Biologics Evaluation and Research and U.S. Department of Health and Human Services FDA Center for Devices and Radiological Health (2006). Guidance for industry: patient-reported outcome measures: use in medical product development to support labeling claims: draft guidance. *Health and Quality of Life Outcomes, 4*, 79. doi:10.1186/1477-7525-4-79

Valentine, T. & Knibb, R.C. (2011). Exploring quality of life in families of children with and without a severe food allergy. *Appetite, 57,* 467-474. http://dx.doi.org/10.1016/j.appet.2011.06.007

Van der Velde, J. L., Flokstra-de Blok, B. M. J., Hamp, A., Knibb, R. C., Duiverman, E. J., & Dubois, A. E. J. (2011). Adolescent-parent disagreement on health-related quality of life of food-allergic adolescents: who makes the difference? *Allergy, 66*(12), 1580–1589. doi:10.1111/j.1398-9995.2011.02726.x

Vedhara, K., Dawe, K., Wetherell, M. A., Miles, J. N. V., Cullum, N., Dayan, C., … Campbell, R. (2014). Illness beliefs predict self-care behaviours in patients with diabetic foot ulcers: A prospective study. *Diabetes Research and Clinical Practice, 106*(1), 67–72. doi:10.1016/j.diabres.2014.07.018

Vizard, T., Pearce, N., Davis, J., Sadler, K., Ford, T., Goodman, A. … McManus, S. (2018). *Mental Health of Children and Young People in England, 2017: Emotional disorders.* Retrieved from https://files.digital.nhs.uk/14/0E2282/MHCYP%202017%20Emotional%20Disorders.pdf

Waddington, H., White, H., Snilstveit, B., Hombrados, J. G., Vojtkova, M., Davies, P., … Tugwell, P. (2012). How to do a good systematic review of effects in international development: a tool kit. *Journal of Development Effectiveness, 4*(3), 359–387. doi:10.1080/19439342.2012.711765

Wallston, K. A. (1992). Hocus-pocus, the focus isn't strictly on locus: Rotter's social learning theory modified for health. *Cognitive Therapy and Research,16*(2): 183-199. https://doi.org/10.1007/bf01173488

Wallston, K. A., Strudler-Wallston, B., & DeVellis, R. (1978). Development of the Multidimensional Health Locus of Control (MHLC) Scales. *Health Education Monographs, 6*(1), 160–170. https://doi.org/10.1177/109019817800600107

Walsh, D., & Evans, K. (2014). Critical realism: An important theoretical perspective for midwifery research. *Midwifery, 30*(1), e1–e6. doi:10.1016/j.midw.2013.09.002

Warren, C. M., Dyer, A. A., Otto, A. K., Smith, B. M., Kauke, K., Dinakar, C. & Gupta, R. S. (2016). Food Allergy-Related Risk-Taking and Management Behaviors Among Adolescents and Young Adults. *Journal of Allergy and Clinical Immunology: In Practice, 5*(2), 381-390. http://dx.doi.org/10.1016/j.jaip.2016.12.012

Wold, S., Esbensen, K., & Geladi, P. (1987). Principal component analysis. *Chemometrics and Intelligent Laboratory Systems, 2*(1-3), 37–52. doi:10.1016/0169-7439(87)80084-9

Wu, M., Tam, H. P., & Jen, T.-H. (2016). Classical Test Theory. *Educational Measurement for Applied Researchers*, 73–90. doi:10.1007/978-981-10-3302-5_5

Valentine, A. Z., & Knibb, R. C. (2011). Exploring quality of life in families of children living with and without a severe food allergy. Appetite, 57(2), 467–474. doi:10.1016/j.appet.2011.06.007

Yardley, L. & Bishop, F. L. (2015). Using mixed methods in health research: Benefits and challenges. *British Journal of Health Psychology, 20*(1). https://doi.org/10.1111/bjhp.12126

Yonamine, G. H., Contim, D., Castro, A. P. B. M., Jacob, C. M. A., & Pastorino, A. C. (2013). Perceptions of caregivers of patients with cow's milk allergy regarding the treatment. *Journal of Human Growth and Development, 23*(1), 58–64. https://doi.org/10.7322/jhgd.50392

Young, M. C., Muñoz-Furlong, A., & Sicherer, S. H. (2009). Management of food allergies in schools: A perspective for allergists. *Journal of Allergy and Clinical Immunology, 124*(2), 175–182.e4. doi:10.1016/j.jaci.2009.04.004

Zolnierek, K. B., & DiMatteo, M. R. (2009). Physician communication and patient adherence to treatment. *Medical Care, 47*(8), 826–834. doi:10.1097/mlr.0b013e31819a5acc

Zuckerman, M. (1979). Sensation Seeking and Risk-taking. *Emotions in Personality and*

Psychopathology, 161–197. doi:10.1007/978-1-4613-2892-6_7

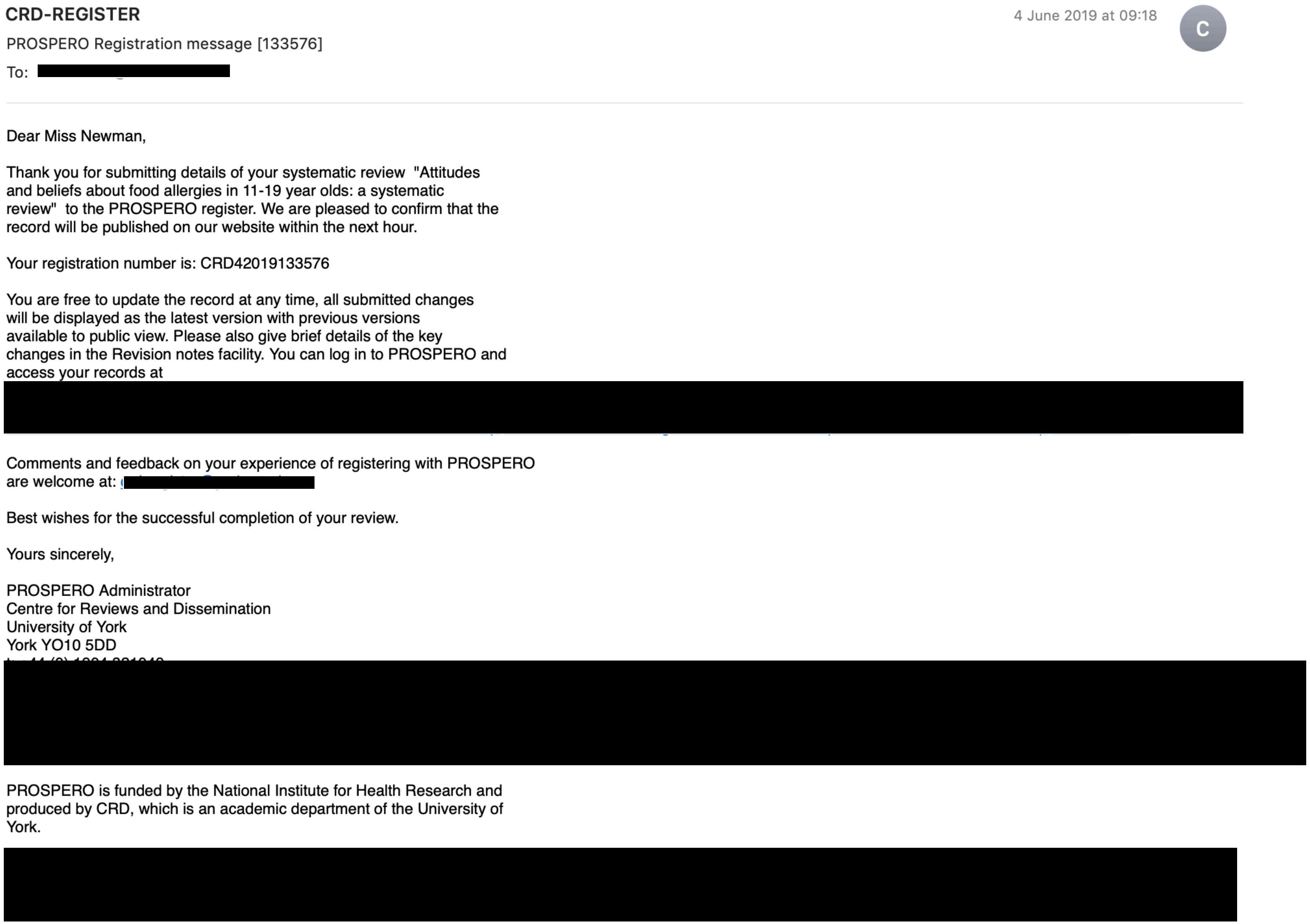
Appendices

Study 1: Systematic literature review

Appendix 1.1: Excluded studies and reason removed

Title	Author	Year	Reason Removed
Beyond Labelling: What Strategies Do Nut Allergic Individuals Employ to Make Food Choices? A Qualitative Study	Barnett, J., Vasileiou, K. Gowland, M. H., Raats, M. M. & Lucas, J. S.	2013	Age range too broad.
Food allergy knowledge, perception of food allergy labeling, and level of dietary practice: A comparison between children with and without food allergy experience	Choi, Y., Ju, S. & Chang, H.	2015	Not enough relevant data for adolescent attitudes.
Health-related quality of life of food allergic patients: comparison with the general population and other diseases	Flokstra-de Blok, B. M. J.	2010	Interpreted as too focused on quality of life rather than attitudes.
The psychosocial impact of an activity holiday for young children with severe food allergy: a longitudinal study	Knibb, R. C. & Hourihane, J. O'B.	2013	Interpreted as too focused on quality of life and any attitudes were related specifically to the specific study rather than their food allergies.
The psychological impact of oral immunotherapy for children with food allergy: Perceived benefits and treatment burden.	LeBovidge, J. S., Haskel, S., Olney, E. K., Hoyte, L., Rachid, R., Nadeau, K. C., Umetsu, D. C. & Schneider, L. C.	2014	Interpreted as attitudes that were related specifically to the study rather than their food allergies generally.
Risk taking and coping strategies of adolescents and young adults with food allergy	Sampson, M. A., Munoz-Furlong, A. & Sicherer, S. H.	2006	Age range (13-21) too broad compared to inclusion criteria. Unable to separate data by age.
Adolescent–parent disagreement on health-related quality of life of food-allergic adolescents: who makes the difference?	Van der Velde, J. L., Flokstra-de Blok, B. M. J., Hamp, A., Knibb, R. C., Duiverman, E. J. & Dubois, A. E. J.	2011	Paper looked into comparing differences between parental and adolescent beliefs about QoL rather than adolescent beliefs specifically.

Appendix 1.2. PROSPERO registration



CRD-REGISTER

4 June 2019 at 09:18

PROSPERO Registration message [133576]

To: [redacted]

Dear Miss Newman,

Thank you for submitting details of your systematic review "Attitudes and beliefs about food allergies in 11-19 year olds: a systematic review" to the PROSPERO register. We are pleased to confirm that the record will be published on our website within the next hour.

Your registration number is: CRD42019133576

You are free to update the record at any time, all submitted changes will be displayed as the latest version with previous versions available to public view. Please also give brief details of the key changes in the Revision notes facility. You can log in to PROSPERO and access your records at

[redacted]

Comments and feedback on your experience of registering with PROSPERO are welcome at: [redacted]

Best wishes for the successful completion of your review.

Yours sincerely,

PROSPERO Administrator
Centre for Reviews and Dissemination
University of York
York YO10 5DD

[redacted]

PROSPERO is funded by the National Institute for Health Research and produced by CRD, which is an academic department of the University of York.

[redacted]

Study 2: Adolescents with FA beliefs: Qualitative study and scale development

Appendix 2.1: NHS IRAS ethical approval: Project ID 226560

NHS
Health Research Authority

Email: hra.approval@nhs.net

Dr Rebecca Knibb
School of Life and Health Sciences
Aston University
Birmingham
B4 7ET

26 January 2018

Dear Dr Knibb

Letter of HRA Approval

Study title:	**Attitudes, beliefs and understanding of food allergy in children and adolescents**
IRAS project ID:	**226560**
Protocol number:	**205-2017-KN**
REC reference:	**18/EM/0012**
Sponsor	**Aston University**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix 2.2: Letter from clinic

University Hospitals of Leicester NHS
NHS Trust

maaRa MIDLANDS ASTHMA & ALLERGY RESEARCH ASSOCIATION

Aston University
Birmingham

Clinic Address

[Date]
[Parental/Guardian address]

Re: Attitudes and beliefs about food allergy.

Dear Parent/guardian

We are helping Aston University in Birmingham with a study to look at how children and adolescents view food allergy. This research is being conducted as part of a PhD project and is being funded by the Midlands Asthma and Allergy Research Association. We are writing to you as your child is aged 11 to 16 years and has had a diagnosis of food allergy. We would be very grateful if you would consider taking part.

Food allergy seems to be on the increase, and yet there is not much research that looks at how children and adolescents view their food allergy. So we can develop ways in which we can help children and teenagers manage their food allergy, it is important to understand their attitudes towards their allergy and how they manage it. We can then develop questionnaires that reliably measure this and find ways to help them manage better.

The research team would like to talk to your child about how they manage their food allergy. Interviews can take place at your home, at the University, in another quiet and safe location or can be done over the telephone or by Skype. The study follows the British Psychological Society requirements regarding ethics and also conforms to the regulations outlined in The Data Protection Act (1998). The study has received ethical approval from Derby NHS Research Ethics Committee.

Further information about this study can be found in the enclosed information sheets. We have also included an information sheet for your child to read. If you have any questions about the research please contact **Kristina Newman (PhD student) on** [redacted] or Dr Rebecca Knibb on [redacted]

If your child is happy to take part in the study, **please email or phone Kristina**. We will then send out consent/assent forms for you and your child to complete and arrange a time to complete the interview.

In return for your help your child will receive £10 in book tokens or Love to Shop vouchers.

Thank you for taking the time to consider this request.

Yours sincerely

Consultant
Email:

Appendix 2.3: Social media advert

Facebook/Twitter

“Looking for 11-16 year olds in the UK with food allergies to have a chat about their food allergies. Do you know anyone who would like to help? There’s a £10 book or love to shop voucher available as a thank you!

Please send me a message or email me at [redacted]

Appendix 2.4: Information sheet for adolescents

School of Life and Health Sciences
Aston University
Aston Triangle
Birmingham
B4 7ET
[redacted]

Attitudes, beliefs and understanding of children and adolescents with food allergy

INFORMATION SHEET FOR TEENAGERS - INTERVIEWS

My name is Kristina Newman. I am a PhD student at Aston University, and I am looking at the attitudes, beliefs and understanding of adolescents towards food allergies. You are being invited to take part in this research. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read this information carefully and discuss it with others if you wish to. If anything is not clear and you need more information before you decide whether or not you should take part in the study, please get in touch with a member of the study team (details at end of information sheet).

Thank you for reading this.

The purpose of the study:

Food allergy seems to be on the increase, and yet there is not much research that looks at the views adolescents have about their food allergy. We would like to find out what you think about your food allergy which will help us develop questionnaires that can measure these views. We hope that this will help doctors and nurses develop ways in which you can be supported to understand and manage your food allergy.

Why have I been chosen and what would I need to do?

You have been asked to take part in the study because you go to the allergy clinic in Leicester for your food allergies and you are between 11 and 16 years old. We would like you to take part in an interview and will ask you about your views about your allergies. This will last around 30 to 45 minutes. You can do this in person or over Skype, Facetime or the telephone.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you decide to take part, you are free to withdraw (stop taking part in the study) at any time without giving a reason. If you do take part in the study and within two weeks you change your mind, you can just contact us and we will destroy all the information you gave us. Withdrawing from the study will **not** affect the care you receive now or in the future.

What are the benefits of taking part?

By looking at your views about your food allergies we hope to be able to develop a questionnaire that will be able to measure these. We hope that this will help doctors and nurses develop ways in which you can be helped to manage and understand your food allergy and the questionnaires will be able to measure whether this works.

Also, to say thank you for taking part in this study, you will receive a £10 bookshop or Love to Shop voucher.

What are the disadvantages or risks of taking part?

You may feel upset answering questions about your food allergy. You will be able to stop answering questions at any time you wish and either take a break or decide you do not want to take part anymore. If there are any questions you don’t want to answer we can skip the question and move on to the next one.

What do I need to do if I decide to take part?

Please let the person who looks after you or your doctor at the allergy clinic know that you would like to take part and they will get in touch with us. We can then arrange a time to talk to you.

INFORMATION ABOUT THE CONDUCT OF THE STUDY

Will the information I give in this study be kept confidential?

Yes, all information collected from you will be kept strictly confidential. That means that no one outside of the research team will see any of the information you give us. Each person taking part in the study will be given a code or study number that we will use when looking at the information from the study. Information will be kept in a locked filing cabinet and on a password protected computer at Aston University for 6 years and then it will be destroyed.

What will happen to the results of the study?

The interviews will only be looked at by Kristina, the researcher who interviewed you, and members of the study team. Your name will be removed and everything said will be completely anonymous. We will write a report of the study which will be published and the results will be written up as part of a PhD. We can send you a summary of the results if you would like them.

What if there is a problem?

If you are worried about anything to do with this study, please speak to the research team and we will do our best to answer your questions. You can ring Dr Rebecca Knibb or email her (phone number and email address are at the bottom of this information sheet). If she cannot help you and you still have any worries about the way in which the study has been conducted, then you should contact the Director or Governance of the University Research Ethics Committee, [redacted]

Who has reviewed the study?

This study has been looked by the Derby NHS Research Ethics Committee. These are a group of people who check research to make sure that it protects the safety, rights, wellbeing and dignity of anyone who takes part.

Can I get more information?

If you are interested in taking part in this study but would like some more information before you decide, please talk to Dr Rebecca Knibb or email us. Or please feel free to talk to the person who looks after you, such as your mum or dad. If you would like to talk to an independent person about taking part in this study or about research in general in Psychology at Aston University please contact the Director of the Aston Research Centre for Children's and Young People's Health, [redacted], [redacted]

If you would like independent advice on any aspect of this study, you can also contact the PALS (Patient Advice and Liaison Service) at the Leicester Hospitals NHS Trust on [redacted].

Thank you for taking time to read this information sheet.

Yours sincerely

Kristina Newman	Dr Rebecca Knibb
PhD Student	Chief Investigator
[redacted]	[redacted]

Study telephone number: [redacted]

Research Team:
Kristina Newman (PhD Student), Dr Knibb (chief investigator/supervisor), Dr Richard Cooke (co-investigator/supervisor), [redacted], clinical allergy specialist

Appendix 2.5: Information sheet for parents

School of Life and Health Sciences
Aston University
Aston Triangle
Birmingham
B4 7ET
[redacted]

Attitudes, beliefs and understanding of children and adolescents with food allergy

INFORMATION SHEET FOR PARENTS – INTERVIEWS

My name is Kristina Newman. I am a PhD student at Aston University, and I am studying the attitudes, beliefs and understanding of adolescents towards food allergies. I am inviting your child to take part in a study we are running with [redacted] and the allergy clinic in Leicester and with the charity Midlands Asthma and Allergy Research Association (MAARA).

Before you decide if you would like your child to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. If anything is not clear and you would like some more information you can get in touch with me on the above number or email address. Please take your time to decide whether or not you wish to take part.

Thank you for reading this.

The purpose of the study:

Food allergy seems to be on the increase, and yet there is not much research that looks at the views adolescents have about their food allergy. We would like to find out what children and adolescents think about food allergies and develop questionnaires that reliably measure these views. We hope that this will help health care professionals develop ways in which children can be supported to understand and manage their food allergy.

Why has my child been chosen and what would we need to do?

Your child has been asked to take part in the study because they have been to the allergy clinic at Leicester and are aged between 11 and 16 years. If your child would like to take part we would like to interview them about their views about their food allergies. For the interviews you can come to Aston University, or we could come to your house or another quiet location of your choosing. We can also do interviews over the telephone or by Skype/Facetime. We will tape the interviews and will ask your child if they are happy for us to use their words when we write about the study (with their name removed). In total this will take about 45 minutes to an hour.

Does my child have to take part?

No, it is up to your child to decide whether or not to take part. If they decide to take part you will be asked to keep this information sheet and to sign a consent form, which says you are happy for your child to take part. If your child decides to take part and wishes to stop the interview at any point, they may do so and withdraw (stop taking part) from the study without giving a reason.

If after taking part in the interview your child wishes to withdraw from the study, they are free to withdraw at any time without giving a reason. Just contact us and we will destroy all the information you gave us.

Whether you decide to take part or not will not affect the standard of care that you or your child receives at the clinic.

What are the benefits of taking part?

By looking at children and adolescents views about food allergies, we hope to be able to develop a questionnaire that will be able to reliably measure these. We hope that the information we gather will help health care professionals develop ways in which children can be supported to manage and understand their food allergy and the questionnaires will be able to measure whether this works.

Will I be reimbursed for my time?

If you travel to Aston University to take part in interviews we can refund your travel and car park expenses.

What are the disadvantages of taking part?

There are no disadvantages or risks to taking part. Your child may feel upset answering questions about their food allergy. If your child decides during the interview that they want to stop or take a break, they can do this at any time. They also do not have to answer any questions they don't want to.

What will I need to do if I decide to allow my child to take part?

If your child would like to take part, please get in touch with Kristina Newman by email on [redacted] by phone on [redacted]. We will then get in touch with you to arrange an interview.

INFORMATION ABOUT THE CONDUCT OF THE STUDY

Will the information I give in this study be kept confidential?

Yes, all information collected from your child for the study will be kept strictly confidential. That means that no one outside of the research team will see any of the information you give us. Each person taking part in the study will be given a code or study number that we will use when looking at what your child has said in the interview. Information will be kept in a locked filing cabinet and on a password protected computer at Aston University for 6 years and then it will be destroyed. The procedures for handling, processing, storage and destruction of the questionnaire data collected during the study are compliant with the Data Protection Act 1998.

If your child tells us something which we feel is putting them at risk we may need to talk to you about this or to your doctor, but we will talk to you about that before we talk to anyone else.

What will happen to the results of the study?

The information you and your child give us will be looked at by Kristina Newman and the research team. The information you provide will help us to develop a questionnaire that will measure how your child views their food allergy. Data we collect will also be written up as part of a PhD. We can send you a copy of the report if you would like them. Your child's name will not be in anything we publish.

What if there is a problem?

If you have any concerns or complaints about anything to do with this study, please speak to the research team and we will do our best to answer your questions. You can ring Dr Rebecca Knibb on [redacted] email her on [redacted]
If she cannot help you and you still have any worries about the way in which the study has been conducted, then you should contact the Director of Governance of the University Research Ethics Committee, [redacted]

Who has reviewed the study?

This study has been looked by the Derby NHS Research Ethics Committee. These are a group of people who check research to make sure that it protects the safety, rights, wellbeing and dignity of anyone who takes part.

Can I get more information?

If you are interested in taking part in this study but would like some more information before you decide, please talk to Dr Rebecca Knibb or email us. Or please feel free to talk to your child's consultant at your clinic. If you would like to talk to an independent person about taking part in this study or about research in general in Psychology at Aston University please contact the Director of the Aston Research Centre for

Children's and Young [redacted]

If you would like independent advice on any aspect of this study, you can also contact the PALS (Patient Advice and Liaison Service) at the Leicester Hospitals NHS Trust on [redacted].

Thank you for taking time to read this information sheet.

Kristina Newman	Dr Rebecca Knibb
PhD Student	Chief Investigator
[redacted]	[redacted]

Study telephone number: [redacted]

Research Team:
Kristina Newman (PhD Student), Dr Knibb (chief investigator/supervisor), Dr Richard Cooke (co-investigator/supervisor), [redacted], clinical allergy specialist

Appendix 2.6: Consent form for adolescents aged 16 years old

University Hospitals of Leicester NHS Trust

CONSENT FORM FOR YOUNG PERSON 16 YEARS OF AGE OR OVER - INTERVIEWS

Project Title: Attitudes, beliefs and understanding of food allergy in children and adolescents

Name of Researcher: Kristina Newman

Name of Project Supervisor: Rebecca Knibb

Participant ID:

	Please initial each box to indicate if you agree with the statement:
I have read the study information (version_______) and know who to contact should I have any questions about taking part in the study.	☐
I understand that taking part in the study is voluntary, and that I am free to withdraw (stop taking part) at any time. I do not have to give any reasons for this. I have been provided with details of who I should contact if I wish to withdraw.	☐
I am aware that any anonymised research data already analysed cannot be destroyed, withdrawn or recalled.	☐
I am happy for my interview to be recorded and understand it will be kept confidential and saved using a participant number.	☐
I am happy for what I say in the interview to be used for this research and understand that my name will not be used in any publications from this research.	☐
I understand that relevant sections of my medical notes and data collected during the study, may be looked at by member of the research team or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	☐
I agree to take part in this study.	☐
I am happy to be contacted again about this study.	☐
I would like to receive a summary of the results of this project.	☐

______________________ ______________________ ____________
Name of Participant Signature Date

______________________ ______________________ ____________
Researcher Signature Date

If you would like to be contacted again about this study or get a summary of the results, please put your contact email address or telephone number here. We will store this separately from the study data.

Email/Telephone______________________________

1 copy for participant, 1 copy for researcher, 1 copy for patient records

Appendix 2.7: Assent form for adolescents aged 11-16 years old

ASSENT FORM FOR CHILDREN AND YOUNG PERSONS UNDER 16 YEARS - INTERVIEWS

Project Title: Attitudes, beliefs and understanding of food allergy in children and adolescents

Name of Researcher: Kristina Newman

Name of Project Supervisor: Rebecca Knibb

Participant ID:

Child (or if unable, parent on their behalf) /young person, **please initial all the ones you agree with:**

	Initials
I have read the study information (version________) and somebody has explained this project to me.	
I know who to contact should I have any questions about taking part in the study	
I have asked questions and they have been answered in a way that I understand.	
I understand that it is ok to stop taking part at any time and I do not have to give any reasons for this.	
I am happy for my interview to be recorded and understand and that no one will know that I have taken part from anything that is written about this project.	
I understand that everything I say will be kept safe and confidential.	

I agree to take part in this study.	
I am happy to be contacted again about this study.	
I would like to receive a copy of the results from this project.	YES/NO

PLEASE TURN OVER

If you don't want to take part, do not sign your name.

If you do want to take part in this study, please sign your name and write today's date.

Your name…………………………… Date……………………………………………….

Your Mum, Dad or the person who looks after you, needs to sign here to show that they are happy for you to take part in the research

------------------------------	--------------------------------------	-----------
Parent/guardian name	Parent/guardian signature	Date

The researcher who explained this project to you needs to sign here too:

--------------------------------	--------------------------------------	-----------
Researcher name	Parent/guardian signature	Date

If you and your child would like to be contacted again about this study or get a summary of the results, please put your contact email address or telephone number here. We will store this separately from the study data.

Email/Telephone_____________________________

1 copy for participant, 1 copy for researcher, 1 copy for patient records

Appendix 2.8: Consent form for parents

University Hospitals of Leicester NHS
NHS Trust

MAARA
MIDLANDS ASTHMA & ALLERGY RESEARCH ASSOCIATION

Aston University
Birmingham

CONSENT FORM FOR PARENTS OF CHILDREN UNDER 16 YEARS - INTERVIEW

Project Title: Attitudes, beliefs and understanding of food allergy in children and adolescents

Name of Researcher: Kristina Newman

Name of Project Supervisor: Rebecca Knibb

Participant ID:

Please initial each box to indicate you agree with each statement:

I and my child have read the study information (version ______) and know who to contact should we have any questions about participation in the study. ☐

I understand that my child's participation in the study is voluntary, and that they are free to withdraw at any time. We do not have to give any reasons or explanations for doing so. We have been provided with details of who to contact if we wish to withdraw. ☐

I am aware that any anonymised research data already analysed cannot be destroyed, withdrawn or recalled. ☐

I am happy for the interview to be recorded and understand that all data my child provides will be saved using a participant number and kept confidential and stored securely on a password protected computer. Any hard copies of data will be stored in a locked filing cabinet. ☐

I understand that relevant sections of my medical notes and data collected during the study, may be looked at by member of the research team or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

I am happy for my child to be contacted again if my child agrees to this. ☐

I agree for my child to participate in this research study. ☐

Name of child	Name of person giving consent for child	
Relationship to child	Signature	Date

Name of researcher	Signature of researcher	Date

If you and your child would like to be contacted again about this study or get a summary of the results, please put your contact email address or telephone number here. We will store this separately from the study data.

Email/Telephone______________________________

1 copy for participant, 1 copy for researcher, 1 copy for patient records

Appendix 2.9: Demographics form

Attitudes, beliefs and understanding of food allergy in children and adolescents

Demographics and food allergy questionnaire for children and adolescents to complete.

Researcher names: Kristina Newman; Dr Rebecca Knibb, [redacted]

Participant ID number_____

Please answer the following questions. If there is anything you don't want to answer or don't know the answer too, please skip the question and go to the next one. If you need help with any questions you could ask your mum or dad or the person who looks after you.

- Gender: Male [ ] Female [ ]
- Age: ……………………..
- How many food allergies do you have? ....
- Do you have any of the following:

▪ Asthma	YES	[ ]	NO	[ ]
▪ Eczema	YES	[ ]	NO	[ ]
▪ Hay fever	YES	[ ]	NO	[ ]

- What are you allergic to? *(tick as many as apply)*

▪ Peanut	[ ]	• Fish	[ ]
▪ Other nuts	[ ]	• Shellfish	[ ]
▪ Type of nuts ……………………..		• Latex	[ ]
▪ Cow's milk	[ ]	• Tree pollen	[ ]
▪ Egg	[ ]	• Grass pollen	[ ]
▪ Soya	[ ]	• Other	[ ]
If other please specify:			

- Have you had any allergies to foods which you can now eat?

▪ Egg	YES	[ ]	NO	[ ]
▪ Milk	YES	[ ]	NO	[ ]
▪ Other	YES	[ ]	NO	[ ]

If other please say what allergies they have outgrown:

- What medicine do you have for your food allergy? (*tick as many as apply)*

▪ Antihistamines	[ ]
▪ Adrenaline injection (Emerade, Epi-Pen or JEXT)	[ ]
▪ None	[ ]

- Which of the following symptoms do you get? *(tick as many as apply)*

▪ Wheals/lumps on skin	[ ]	▪ Reflux/heartburn	[ ]
▪ Rash	[ ]	▪ Blocked up nose	[ ]
▪ Atopic dermatitis/eczema	[ ]	▪ Irritable or itchy nose	[ ]
▪ Itchy skin	[ ]	▪ Runny nose	[ ]
▪ Dry skin	[ ]	▪ Throat tightening/difficulty swallowing	[ ]
▪ Scabby skin	[ ]	▪ Breathing difficulties	[ ]
▪ Face swelling	[ ]	▪ Tight chest	[ ]
▪ Tingling/sore mouth	[ ]	▪ Asthma	[ ]
▪ Swelling of lips or tongue	[ ]	▪ Wheeze/coughing	[ ]
▪ Vomiting	[ ]	▪ Blue around the lips	[ ]
▪ Bloated stomach	[ ]	▪ Collapse/faint	[ ]
▪ Stomach pain	[ ]	▪ Other	[ ]
▪ Diarrhoea	[ ]	▪	

If other please specify:

- Have you ever been to hospital with an allergic reaction to food?

  YES [ ] NO [ ]

- Have you seen a doctor about your food allergy/allergies?

  YES [ ] NO [ ]

- If you have seen a doctor, how did the doctor test for food allergy?

  Skin prick tests [ ] Blood tests [ ] Food challenge [ ]

  Other please state……………………………………………………………

Appendix 2.10: Interview schedule

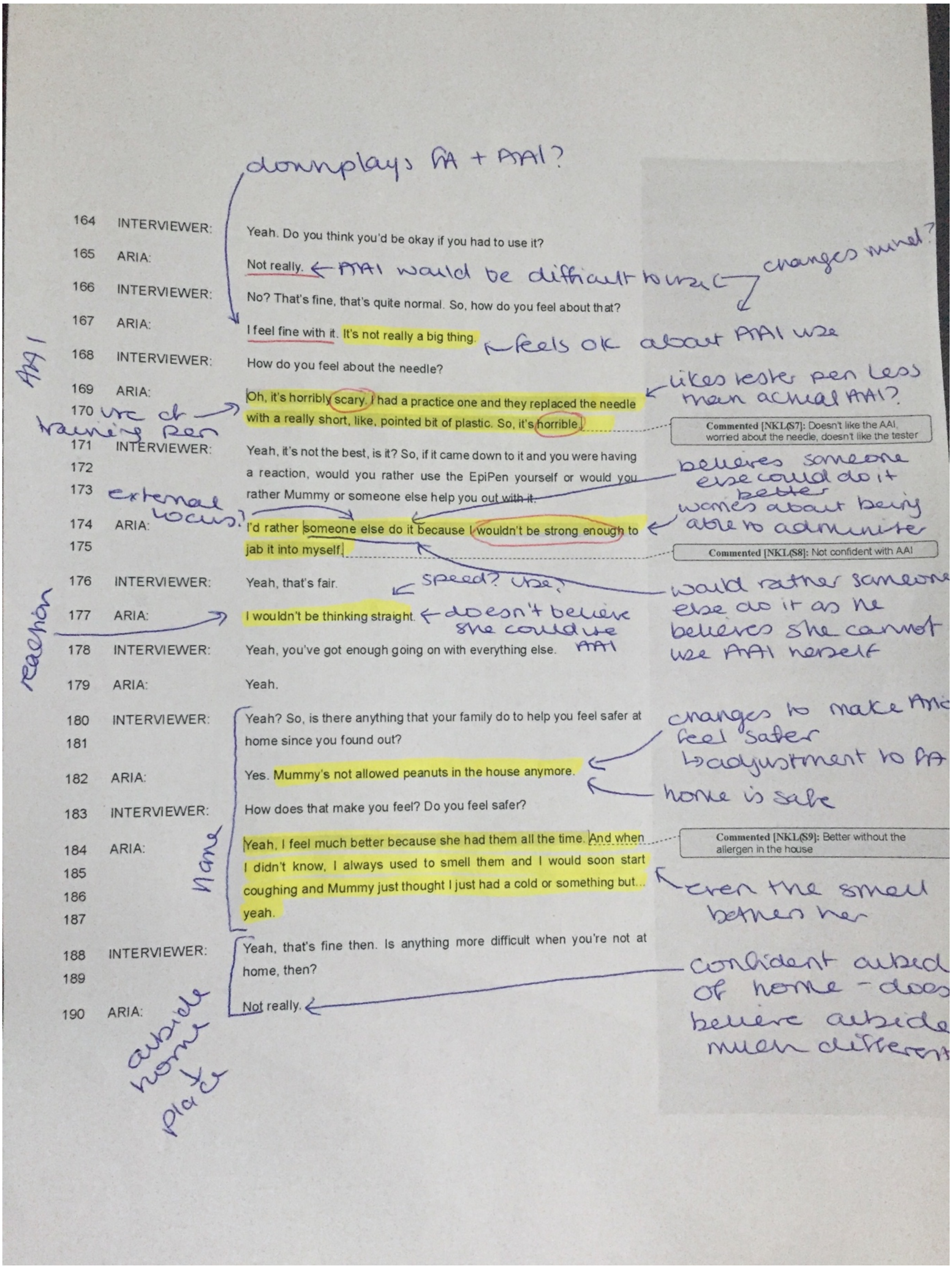
Draft interview schedule – Children/adolescents with food allergy

Topic	Question	Prompts
About your allergy	Can you tell me a bit about yourself?	Family/school etc (Background info)
	Tell me about your food allergy (FA)?	Allergens? Severity? Symptoms? When diagnosed? Is it annoying to you/part of life? Eczema/asthma?
	Have you ever had an allergic reaction?	Mild/severe? When? Who was with you? Where? Why? Did you use AAI? More than once? Scary?
	How do you manage your FA to make sure you don't have a reaction?	Carry medicine? Read labels? Ask parent/teachers? Do you feel you can manage ok? How likely do you think it is that you would have a reaction?
	What do you think/feel about your FA?	Serious? Worrying? Fed up/angry/ok? Does this change when in different situations/places e.g. with friends
	Do you feel in control of your FA?	Why? What helps/makes it worse? Different situations?
	Do you still feel like you can have a normal life?	Why? What makes it easier/harder?
	How much do you worry about your FA?	A lot/ok/less worried? More than parents? Why do you think that?
Medication	Do you have medicine for your FA?	What do you use? Antihistamines/AAI? How often do you use it? Do you know how to use it?
	What do you think about auto injectors?	Bulky/annoying/keeps me safe
	How do you feel about carrying your medicine?	Annoyed/embarrassed/uncomfortable/not bothered? Do you always carry it? Does it depend where (e.g. sports)? Why? Do you worry if you don't have it? Do you trust it? Does someone else carry it for you? Would anything stop you using it?
Family/Home	Do you/your family do anything to help keep you safe from reacting?	What strategies? Who uses these? Why do you use these? Are they helpful?
	How do you manage your FA at home?	Easier/safer at home? Does anyone help? What do they do? Do you prefer help or to manage on your own? Would you like more help? Why?
	When not at home, is anything more difficult?	What is? Why? How do you feel about this?
School	How is your allergy managed at school?	Does the school take precautions to keep you safe? Do you feel treated differently? How do you make it better for you? Do your friends know about your FA? What do you think about school?
	How do you keep safe with your FA at school?	Avoid foods? Sit away from others? Is it easy/hard? Why? Do you feel confident managing your FA? Do you worry about

		having a reaction in school? Do you feel you have to be more careful at school?
	Do you ever feel like you miss out on school trips/events because of your FA?	Why? Does your school do anything to help? How does it make you feel? What could make it better for you?
	How do you think other people in school feel about your FA?	Teachers? Friends? Bullies? Isolated/excluded? Is there anyone that helps/supports you?
	Is there anything that could be done at school to help you manage better?	Education or training/ more awareness of teachers/friends/other pupils? Primary vs Secondary? Nut free?
Social life/friends	How does having an allergy impact on your social life?	Better/worse? How do you manage this? Does this impact how you manage your allergy (e.g. more risks)? How do you feel about it?
	Do you ever miss out on going to friend's houses parties because of your FA?	Why? How did this make you feel? What did you do instead? What could have made it better?
	Do friends ever eat food you are allergic to in front of you?	What do you do? How do you manage this? Does it work? How do you feel? Do you ever ignore your allergy to hang out with friends? Do you feel jealous if you can't eat the same foods? Do your friends know about your allergy? Why?
	How do you feel about going out to eat?	Worried/embarrassed/scared/annoyed?
	How do you think your friends feel about your food allergy? Do they do anything to help?	Why? How does this make you feel? How do your friend's attitudes make you feel? Do they understand? Is there anything else they could do? Do you feel supported? Has anyone ever been mean about your FA?
Holidays	How do you manage your FA if on holiday?	Abroad vs in UK? Parent involvement? Do eating habits have to change? Do you worry more? Does it affect your holiday?
	Have you ever had a reaction on holiday?	What happened? How did you/family manage it? How did it make you feel? Do you want more holidays? Are you worried?
Risks	Have you taken more responsibility for your FA as you've gotten older?	Why? Easy/hard? How do you feel about this? How do you think parents feel? What responsibilities? Buy own food? Do you think this is good/bad?
	Do you ever eat food you might be allergic to?	What foods? Why? With friends/parents? Buying packaged food vs restaurant? How often? What do you think about? Past experience?
	How do you feel about 'may contain' labels?	Accurate? Do you eat them anyway? Any particular brands you're more confident with? Why?
	How do you feel if you take a risk?	Scared? Empowered? In what situation is taking a risk okay/why? If you're only allergic to nuts – do you think other allergies are any different?
	How do you feel about the future?	Secondary school, college, university, moving out etc?
Improving understanding	Is it easy to talk about your FA?	Easier with different people? Any bits you don't like talking about? Do you talk to anyone if you are struggling?

	Do you think people understand FA?	Is there anything they don’t know? Ignorance? Misinformation?
	Is there anything you wish other people knew about FA?	Friends/school/restaurant/community? More education?
	Do you have any ideas what could improve attitudes to FA?	More education? Not discriminating? Alternate menus in more places? More awareness?
Concluding questions	Is there anything about your FA we haven’t covered that you would like to talk about?	
	Is there was one thing someone could do to help you manage your FA better what would it be?	

Appendix 2.11: Example of coding



downplays FA + AAI?

AAI

INTERVIEWER: Yeah. Do you think you'd be okay if you had to use it?

ARIA: Not really. ← AAI would be difficult to use

changes mind?

INTERVIEWER: No? That's fine, that's quite normal. So, how do you feel about that?

ARIA: I feel fine with it. It's not really a big thing. ← feels OK about AAI use

INTERVIEWER: How do you feel about the needle?

ARIA: Oh, it's horribly scary. I had a practice one and they replaced the needle with a really short, like, pointed bit of plastic. So, it's horrible. ← likes tester pen less than actual AAI?

use of training pen

Commented [NKL(S7]: Doesn't like the AAI, worried about the needle, doesn't like the tester

INTERVIEWER: Yeah, it's not the best, is it? So, if it came down to it and you were having a reaction, would you rather use the EpiPen yourself or would you rather Mummy or someone else help you out with it.

believes someone else could do it better

external locus?

ARIA: I'd rather someone else do it because I wouldn't be strong enough to jab it into myself. ← worries about being able to administer

Commented [NKL(S8]: Not confident with AAI

would rather someone else do it as he believes she cannot use AAI herself

INTERVIEWER: Yeah, that's fair.

speed? use?

reaction

ARIA: I wouldn't be thinking straight. ← doesn't believe she could use AAI

INTERVIEWER: Yeah, you've got enough going on with everything else.

ARIA: Yeah.

home

INTERVIEWER: Yeah? So, is there anything that your family do to help you feel safer at home since you found out?

ARIA: Yes. Mummy's not allowed peanuts in the house anymore.

changes to make Ari feel safer
↳ adjustment to FA

home is safe

INTERVIEWER: How does that make you feel? Do you feel safer?

ARIA: Yeah, I feel much better because she had them all the time. And when I didn't know, I always used to smell them and I would soon start coughing and Mummy just thought I just had a cold or something but... yeah.

Commented [NKL(S9]: Better without the allergen in the house

even the smell bothers her

outside home & place

INTERVIEWER: Yeah, that's fine then. Is anything more difficult when you're not at home, then?

ARIA: Not really.

confident outsid of home - does believe outside much different

Study 3: Adolescents without FA beliefs: Qualitative study

Appendix 3.1: Ethics approval

Life and Health Sciences Ethics Committee's Decision Letter

To: Dr Rebecca Knibb, Dr Richard Cooke, Kristina Newman

Cc: [redacted]

[redacted] Life and Health Sciences Ethics Committee

From: [redacted]

Immediate Past Chair, Life and Health Sciences Ethics Committee

Date: 26/1/2017

Subject: **Project #1039: Exploring attitudes, beliefs and understanding of food allergy in children and adolescents**

Thank you for your submission. The information for the above proposal has been considered by the Immediate
Past Chair of the LHS Ethics Committee.

Please see below for details of the decision and the approved documents.

Reviewer's recommendation: Approved

Please see the tabled list below of approved documents:

Documentation	**Version/s**	**Date**	**Approved**
Participant information sheet- parent	https://www.ethics.aston.ac.uk/sites/ethics/files/ethics/knibbr/school_parent_info_sheet.doc	01/12/16	✓
Participant information sheet- adolescents	https://www.ethics.aston.ac.uk/sites/ethics/files/ethics/knibbr/school_adolescent_info_sheet.doc	01/12/16	✓
Consent form- parents	https://www.ethics.aston.ac.uk/sites/ethics/files/ethics/knibbr/ consent_form_-_parents.docx	01/12/16	✓
Consent form- adolescents	https://www.ethics.aston.ac.uk/sites/ethics/files/ethics/knibbr/ consent_form_-_adolescents.doc	01/12/16	✓
Risk Assessment	https://www.ethics.aston.ac.uk/sites/ethics/files/risk_assesse nt_form_knewman_0.docx	11/11/16	✓
Interview schedule	https://www.ethics.aston.ac.uk/sites/ethics/files/ethics/knibbr/draft_interview_schedule.docx	01/12/16	✓
Interview schedule- non-allergic	https://www.ethics.aston.ac.uk/sites/ethics/files/ethics/knibbr/draft_interview_schedule_-_non-allergic.docx	01/12/16	✓
Questionnaire	https://www.ethics.aston.ac.uk/sites/ethics/files/ethics/knibbr/demographic_questionnaire.doc	01/12/16	✓
Letter from schools	https://www.ethics.aston.ac.uk/sites/ethics/files/ethics/knibbr/l etter_from_schools.doc	01/12/16	✓

After starting your research please notify the LHS Research Ethics Committee of any of the following:

Substantial amendments. Any amendment should be sent as a Word document, with the amendment highlighted. The amendment request must be accompanied by all amended documents, e.g. protocols, participant information sheets, consent forms etc. Please include a version number and amended date to the file name of any amended documentation (e.g. “Ethics Application #100 Protocol v2 amended 17/02/12.doc”).

New Investigators

The end of the study

Please email all notifications and reports to [redacted] and quote the original project reference number with all correspondence.

Ethics documents can be downloaded from: [redacted]
Please note that these documents can ONLY be opened using Mozilla Firefox or the latest Internet Explorer version (IE9).

Statement of Compliance

The Committee is constituted in accordance with the Government Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK. In accord with University Regulation REG/11/203(2), this application was considered to have low potential risk and was reviewed by three appropriately qualified members, including the Chair of the Life and Health Sciences Ethics Committee.

Yours sincerely,

[redacted]

[redacted]
Immediate Past Chair, LHS Ethics Committee

Appendix 3.2: Ethics amendment approval

Life and Health Sciences Ethics Committee's Decision Letter

To: Kristina Newman, Dr Rebecca Knibb

Cc: [redacted]

Administrator, Life and Health Sciences Ethics Committee

From: [redacted]

Deputy Chair, Life and Health Sciences Ethics Committee

Date: 21/1/2020

Subject: **Project #1039:**
Exploring attitudes, beliefs and understanding of food allergy in children and adolescents

---

Thank you for your amendment submission. The amendment for the above study has been considered by the Chair of the LHS Ethics Committee.

Please see below for details of the decision and the approved documents.

Reviewer's recommendation: Favourable opinion

Please see the tabled list below of approved documents:

Documentation	**Version/s**	**Date**	**Approved**
Adolescent information sheet	4	12/7/17	✓
Parent information sheet	4	12/7/17	✓
Social media advert	NA	12/7/17	✓
Poster	NA	12/7/17	✓

After starting your research please notify the LHS Research Ethics Committee of any of the following:

Substantial amendments. Any amendment should be sent as a Word document, with the amendment highlighted. The amendment request must be accompanied by all amended documents, e.g. protocols, participant information sheets, consent forms etc. Please include a version number and amended date to the file name of any amended documentation (e.g. "Ethics Application #100 Protocol v2 amended 17/02/12.doc").

New Investigators

The end of the study

Please email all notifications and reports to [redacted] and quote the original project reference number with all correspondence.

Ethics documents can be downloaded from: [redacted]. Please note that these documents can ONLY be opened using Mozilla Firefox or the latest Internet Explorer version (IE9).

Statement of Compliance

The Committee is constituted in accordance with the Government Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK. In accord with University Regulation REG/11/203(2), this application was considered to have low potential risk and was reviewed by three appropriately qualified members, including the Chair of the Life and Health Sciences Ethics Committee.

Yours sincerely,

[redacted]

[redacted]
Deputy Chair, LHS Ethics Committee

Appendix 3.3: Recruitment email to schools

Hello,

My name is Kristina Newman. I am a PhD student at Aston University, and I am studying the attitudes, beliefs and understanding of children and adolescents towards food allergies. I am currently running a study with the allergy clinics in Leicester and with the charity Midlands Asthma and Allergy Research Association (MAARA), which has been approved by the ethics committee at Aston University.

I am writing to you to ask if your school would consider supporting me in my research. We are interested in talking to children with and without food allergy as this will help us find out what all young people think. We are looking to recruit approximately 40 secondary school students (aged 11-16 years) to take part in an interview to talk about their thoughts on food allergies. They do not need to have an allergy to take part.

The interview is not compulsory and the students would be free to withdraw at any time. Any identifiable information such as names would be replaced by pseudonyms to keep the students anonymous. Interviews could be conducted however best suited the students including Skype, a phone call or face-to-face in a safe place. Parental and student consent would both be required before any interview was arranged. The interview would be arranged in the student's own time so not to interfere with their education.

If you are willing to help, I would only ask that you pass on a letter to the students inviting them to take part. A letter specifically for parents is also available. Both letters explain the study and its process and provide contact details should any student wish to take part.

It is completely fine if no students choose to take part, as this is completely voluntary. I have included the information sheets below should you wish to read them.

Thank you for taking the time to read this email and considering my research.

Kristina Newman
PhD student
[redacted]
[redacted]
School of Life and Health Sciences
Aston University
Aston Triangle
Birmingham
B4 7ET

Appendix 3.4: Letter from consenting schools

School of Life and Health Sciences
Aston University
Aston Triangle
Birmingham
B4 7ET
[redacted]

Dear Parent

We are helping Aston University in Birmingham with a study to look at attitudes children and adolescents have towards food allergy. This is being funded by Midlands Asthma and Allergy Research Association and Aston University. We are writing to you as your child is aged 11-16 and attends a secondary school in the Midlands and we would be very grateful if you would consider taking part.

Food allergy seems to be on the increase, and yet there is not much research that looks at how children and adolescents feel about food allergies and their attitudes towards it. So we can develop ways in which we can help children and teenagers manage their food allergy and increase education around food allergy, it is important to understand what attitudes children and adolescents have to food allergies. We can then develop questionnaires that reliably measure this and find ways to help them manage better.

If you have a child aged 11 to 16 years, the team would like to talk to them about what they think about food allergies. Interviews can take place at your home, at the University, in another quiet and safe location or can be done over the telephone or by Skype. The study follows the British Psychological Society requirements regarding ethics and also conforms to the regulations outlined in The Data Protection Act (1998). The study has received ethical approval from Aston University Research Ethics Committee.

This research is being conducted as part of a PhD project. Further information about this study can be found in the enclosed information sheets. If you have any questions about the research please contact Kristina Newman (PhD student) on [redacted] Dr Rebecca Knibb on [redacted]. If you would like to take part, please email or phone Kristina Newman or complete the tear off slip at the bottom of this letter and post it to Aston University in the envelope provided.

In return for your help each participating child will receive £10 in book tokens or Love to Shop vouchers.

Thank you for taking the time to consider this request.

Yours sincerely

Researcher: Kristina Newman
[redacted]

My name is ___________________________ and I would like to take part in this research.

Please contact me on (telephone number) ____________________________

Best time of day to call _____________________________

Please email me at ______________________________

Appendix 3.5: Social media advert

Twitter/Facebook:

Can you help? Do you know any 11-16 year olds in the Midlands who wouldn't mind a chat about food allergies? £10 voucher as a thank you!

Are you aged 11-16 years?

Would you like a £10 Love to Shop/Book voucher?

A research study looking into food allergies is recruiting for interviews. You do not need a food allergy to take part.

Interviews are likely to last 30-60 minutes and can be done over the phone, Skype or a place of your choice.

You will receive a £10 love to shop or book voucher for your time.

If you are interested please contact Kristina:

[redacted]

Thank you!

Appendix 3.6: Information sheet for adolescents

School of Life and Health Sciences
Aston University
Aston Triangle
Birmingham
B4 7ET
[redacted]

Attitudes, beliefs and understanding of children and adolescents with food allergy

INFORMATION SHEET for ADOLESCENTS

My name is Kristina Newman. I am a PhD student at Aston University, and I am looking at how adolescents view having a food allergy. I am writing to ask if you would like to help us find out more about how children and young people understand and view food allergies.

Before you decide whether you want to help us, we would like to tell you what this study is all about and why we are doing it. Please read this letter and think carefully before deciding. If you have questions or there are any bits that you do not understand please get in touch with me or ask your parents or guardian. **My contact details are at the top of this letter.**

What is the study about?

We are interested in finding out how children and teenagers feel about food allergies. By asking you to tell us what you think and feel about food allergies, we can then help develop a questionnaire for young people of all ages to complete and this can help us understand a bit more about how other children and teenagers feel about food allergies. We can then try and help children and young people who may be finding it difficult to live with their food allergy and help inform young people who do not know much about food allergies.

Why have I been chosen?

You have been asked to take part in this study because you live in the Midlands and are aged 11-16 years.

Do I have to take part?

You can decide if you want to take part in the study. You don't have to, it is your choice. If you don't want to take part nobody will be upset with you. If you do decide to do the study you can stop doing it whenever you want and nobody will mind. It is fine if you do or do not have a food allergy.

What will happen if I take part?

We would like you to talk us about your thoughts on food allergies and how you feel about it. You can either come to the University or we can come to your house. We can also talk to you over the telephone if you would like to, or by Skype. We will tape this on a special piece of equipment called a Dictaphone. We will ask you if you are happy for us to use your words when we write about the study, but your name will be removed so you won't be identified. In total, this will take up to an hour.

What are the benefits of taking part?

By looking at how children and teenagers feel about food allergies, we hope to be able to develop a questionnaire that will help us understand this. We hope that this will then help people like your doctor to help children and teenagers who are finding it tricky to manage their food allergy or your teachers help to explain to other young adults about food allergies.

What are the disadvantages of taking part?

There are no disadvantages or risks to taking part. If you decide during the interview that you want to stop or take a break, you can do this at any time.

Who will see my answers to the questions?

Only the people helping to run this study will see your answers.

What will happen to the results of the study?

The information you give us will be looked at by Kristina Newman and Dr. Rebecca Knibb. We will also write a report of the study, which will be published. The information we collect will also be written up as part of a project called a PhD. We can send you a copy of the report if you would like them. Your name will not be in anything we publish.

Will anything about the research upset me?

There are no right or wrong answers for this study and we won't ask you anything that will upset you. But if you do get upset for any reason you can stop anytime you like and nobody will mind.

What if there is a problem?

If you are worried about anything and want to make a complaint about anything to do with this study, please speak to the research team and we will do our best to answer your questions. You can ring Dr Rebecca Knibb on [redacted]. If she cannot help you and you still have any worries about how the study has been conducted, then you can contact the Secretary of the University Research Ethics Committee, [redacted]

Did anyone check this study is ok to do?

Before we are allowed to do a study, it has to be checked by a group of people called a Research Ethics Committee. They check the study is fair. This study has been checked by the Aston Ethics Committee.

What do I do next?

Talk to your mum and dad, or the person who looks after you and see if you would like to take part. You can also talk to us if you want to take part by ringing us on the number which you will find on the bottom of this information sheet. If you want to take part, please keep this letter.

Thank you for taking the time to read this letter.

Kristina Newman (PhD Student)

Appendix 3.7: Information sheet for parents

School of Life and Health Sciences
Aston University
Aston Triangle
Birmingham
B4 7ET
[redacted]

Attitudes, beliefs and understanding of children and adolescents with food allergy

INFORMATION SHEET FOR PARENTS

My name is Kristina Newman. I am a PhD student at Aston University, and I am studying how the attitudes, beliefs and understanding of adolescents towards food allergies. I am inviting your child to take part in a study we are running with the allergy clinics in Leicester and with the charity Midlands Asthma and Allergy Research Association (MAARA).

Before you decide if you would like your child to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. If anything is not clear and you would like some more information you can get in touch with me on the above number or email address. Please take your time to decide whether or not you wish to take part.

Thank you for reading this.

The purpose of the study:

Food allergy seems to be on the increase, and yet there is not much research that looks at how children and adolescents view the risk of food allergy and their associated attitudes. We would like to find out how children and adolescents both with and without food allergies see food allergies and develop questionnaires that reliably measure their attitudes towards food allergy. We hope that this will help health care professionals develop ways in which children can be supported to understand and manage their food allergy and be used in interventions to improve attitudes towards food allergy and investigate how best to educate others about food allergies.

Why has my child been chosen and what would we need to do?

Your child has been asked to take part in the study because they live in the Midlands and are aged between 11 and 16 years. It does not matter whether your child does or does not have a food allergy as this will allow us to compare attitudes between food allergic and non-food allergic adolescents. If your child would like to take part we would like to interview them about their attitudes towards food allergies. For the interviews you could come to Aston University, or we could come to your house or another quiet location of your choosing. We can also do interviews over the telephone or by Skype. We will tape the interviews and will ask you if you are happy for us to use your child's words when we write about the study (with your child's name removed). In total this will take about 45 minutes to an hour.

Does my child have to take part?

No, it is up to your child to decide whether or not to take part. If they decide to take part you will be asked to keep this information sheet and to sign a consent form, which says you are happy for your child to take part. If your child decides to take part and wishes to stop the interview at any point, they may do so and withdraw (stop taking part) from the study without giving a reason.

If after taking part in the interview your child wishes to withdraw from the study, they are free to withdraw at any time up to two weeks after taking part in the interview and without giving a reason. Just contact us and we will destroy all the information you gave us.

Whether you decide to take part or not will not affect the standard of care that you or your child receives at the clinic.

What are the benefits of taking part?

By looking at how children and adolescents feel about food allergies and their attitudes towards it, we hope to be able to develop a questionnaire that will be able to reliably measure the attitudes your child has towards food allergies. We hope that this will help health care professionals develop ways in which children can be supported to manage and understand their food allergy and the questionnaires will be able to measure whether this works.

Will I be reimbursed for my time?

If you travel to Aston University to take part in interviews we can refund your travel and car park expenses.

What are the disadvantages of taking part?

There are no disadvantages or risks to taking part. If your child decides during the interview that they want to stop or take a break, they can do this at any time.

What will I need to do if I decide to allow my child to take part?

If you would like to take part, please get in touch with Kristina Newman by email on [redacted] Or you can complete the tear off slip at the bottom of the attached letter and post it to the Aston University in the enclosed envelope. We will then get in touch with you to arrange an interview.

INFORMATION ABOUT THE CONDUCT OF THE STUDY

Will the information I give in this study be kept confidential?

Yes, all information collected from your child for the study will be kept strictly confidential. That means that no one outside of the research team will see any of the information you give us. Each person taking part in the study will be given a code or study number that we will use when looking at what your child has said in the interview. Information will be kept in a locked filing cabinet and on a password protected computer at Aston University for 7 years and then it will be destroyed. The procedures for handling, processing, storage and destruction of the questionnaire data collected during the study are compliant with the Data Protection Act 1998.

If your child tells us something which we feel is putting them at risk we may need to talk to you about this or to your doctor, but we will talk to you about that before we talk to anyone else.

What will happen to the results of the study?

The information you and your child give us will be looked at by Kristina Newman and Dr. Rebecca Knibb. The information you provide will help us to develop a food allergy attitudes scale, a questionnaire that will measure how your child views their food allergy. Data we collect will also be written up as part of a PhD. We can send you a copy of the report if you would like them. Your child's name will not be in anything we publish.

What if there is a problem?

If you have any concerns or complaints about anything to do with this study, please speak to the research team and we will do our best to answer your questions. You can ring Dr Rebecca Knibb on [redacted]
If she cannot help you and you still have any worries about the way in which the study has been conducted, then you should contact the Secretary of the University Research Ethics Committee, [redacted]

Who has reviewed the study?

This study has been looked by the Life and Health Sciences ethics committee at Aston University. These are a group of people who check research to make sure that it protects the safety, rights, wellbeing and dignity of anyone who takes part.

Can I get more information?

If you are interested in taking part in this study but would like some more information before you decide, please talk to Dr Rebecca Knibb or email us. Or please feel free to talk to your child's consultant at your clinic. If you would like to talk to an independent person about taking part in this study or about research in general in Psychology at Aston University please contact the Director of the Aston Research Centre for [redacted]

Thank you for taking time to read this information sheet.

Yours sincerely

Kristina Newman	Dr Rebecca Knibb
PhD Student	Chief Investigator

Research Team:
Kristina Newman (PhD Student), Dr Knibb (chief investigator/supervisor), Dr Richard Cooke (co-investigator/supervisor)

Appendix 3.8: Consent form for adolescents

maaRa
MIDLANDS ASTHMA & ALLERGY RESEARCH ASSOCIATION

Aston University
Birmingham

Ethics Approval Number_____________

Participant ID number______________

Attitudes, beliefs and understanding in children and adolescents with food allergy

STATEMENT OF INFORMED CONSENT FOR TEENAGERS

	Please initial each box to indicate you have read the statement:
I agree to take part in an interview for this research study looking at attitudes of children and adolescents towards food allergy.	☐
I have read the study information (version____) and know who to contact should I have any questions about taking part in the study.	☐
I understand that taking part in the study is voluntary, and that I am free to withdraw at any time after taking part. I do not have to give any reasons or explanations for doing so. I have been provided with details of who I should contact if I wish to withdraw.	☐
I agree for my interview to be recorded and understand that it will be kept confidential and saved using a participant number.	☐
I agree for direct quotes to be used from the interview and understand that any quotes will be anonymised, and my name will not be used in any publications from this research.	☐
I understand that all data I provide will be kept confidential and stored securely on a password protected computer. Any hard copies of data will be stored in a locked filing cabinet.	☐
I am happy to be contacted again about this research study.	☐

________________________	________________________	______________
Name of Participant	Signature	Date
________________________	________________________	______________
Researcher	Signature	Date

Appendix 3.9: Consent form for parents

maara
MIDLANDS ASTHMA & ALLERGY RESEARCH ASSOCIATION

Aston University
Birmingham

Ethics Approval Number_____________

Participant ID number______________

Attitudes, beliefs and understanding in children and adolescents with food allergy.

STATEMENT OF INFORMED CONSENT FOR PARENTS OF CHILDREN AGED 11-16 YEARS

Please initial each box to indicate you have read the statement:

I agree for my child to participate in this research study to explore attitudes of children and adolescents towards food allergy. ☐

I and my child have read the study information (version _______) and know who to contact should we have any questions about participation in the study. ☐

I understand that my child's participation in the study is voluntary, and that they are free to withdraw at any time after taking part. We do not have to give any reasons or explanations for doing so. We have been provided with details of who to contact if we wish to withdraw. ☐

I understand that all data my child provides will be kept confidential and stored securely on a password protected computer. Any hard copies of data will be stored in a locked filing cabinet. ☐

_________________________ _________________________
Name of Child Name of person giving consent for child

____
Relationship to child

____
Signature Date

_________________________ _________________________
Researcher Signature Date

Appendix 3.10: Demographics form

Attitudes, beliefs and understanding of food allergy in children and adolescents

Demographics and food allergy questionnaire for children and adolescents to complete.

Researcher names: Kristina Newman; Dr Rebecca Knibb, [redacted]

Participant ID number_____

Please answer the following questions. If there is anything you don’t want to answer or don’t know the answer too, please skip the question and go to the next one. If you need help with any questions you could ask your mum or dad or the person who looks after you.

- Gender: Male [ ] Female [ ]
- Age: ……………………..
- How many food allergies do you have? ....
- Do you have any of the following:

▪ Asthma	YES	[ ]	NO	[ ]
▪ Eczema	YES	[ ]	NO	[ ]
▪ Hay fever	YES	[ ]	NO	[ ]

- What are you allergic to? *(tick as many as apply)*

▪ Peanut	[ ]	• Fish	[ ]
▪ Other nuts	[ ]	• Shellfish	[ ]
▪ Type of nuts ……………………..		• Latex	[ ]
▪ Cow’s milk	[ ]	• Tree pollen	[ ]
▪ Egg	[ ]	• Grass pollen	[ ]
▪ Soya	[ ]	• Other	[ ]
If other please specify:			

- Have you had any allergies to foods which you can now eat?

▪ Egg	YES	[ ]	NO	[ ]
▪ Milk	YES	[ ]	NO	[ ]
▪ Other	YES	[ ]	NO	[ ]
If other please say what allergies they have outgrown:				

- What medicine do you have for your food allergy? (*tick as many as apply)*

▪ Antihistamines	[ ]
▪ Adrenaline injection (Emerade, Epi-Pen or JEXT)	[ ]
▪ None	[ ]

- Which of the following symptoms do you get? *(tick as many as apply)*

▪ Wheals/lumps on skin	[ ]	▪ Reflux/heartburn	[ ]
▪ Rash	[ ]	▪ Blocked up nose	[ ]
▪ Atopic dermatitis/eczema	[ ]	▪ Irritable or itchy nose	[ ]
▪ Itchy skin	[ ]	▪ Runny nose	[ ]
▪ Dry skin	[ ]	▪ Throat tightening/difficulty swallowing	[ ]
▪ Scabby skin	[ ]	▪ Breathing difficulties	[ ]
▪ Face swelling	[ ]	▪ Tight chest	[ ]
▪ Tingling/sore mouth	[ ]	▪ Asthma	[ ]
▪ Swelling of lips or tongue	[ ]	▪ Wheeze/coughing	[ ]
▪ Vomiting	[ ]	▪ Blue around the lips	[ ]
▪ Bloated stomach	[ ]	▪ Collapse/faint	[ ]
▪ Stomach pain	[ ]	▪ Other	[ ]
▪ Diarrhoea	[ ]	▪	
If other please specify:			

- Have you ever been to hospital with an allergic reaction to food?

  YES [ ]   NO [ ]

- Have you seen a doctor about your food allergy/allergies?

  YES [ ]   NO [ ]

- If you have seen a doctor, how did the doctor test for food allergy?

  Skin prick tests [ ] Blood tests [ ] Food challenge [ ]

  Other please state……………………………………………………………

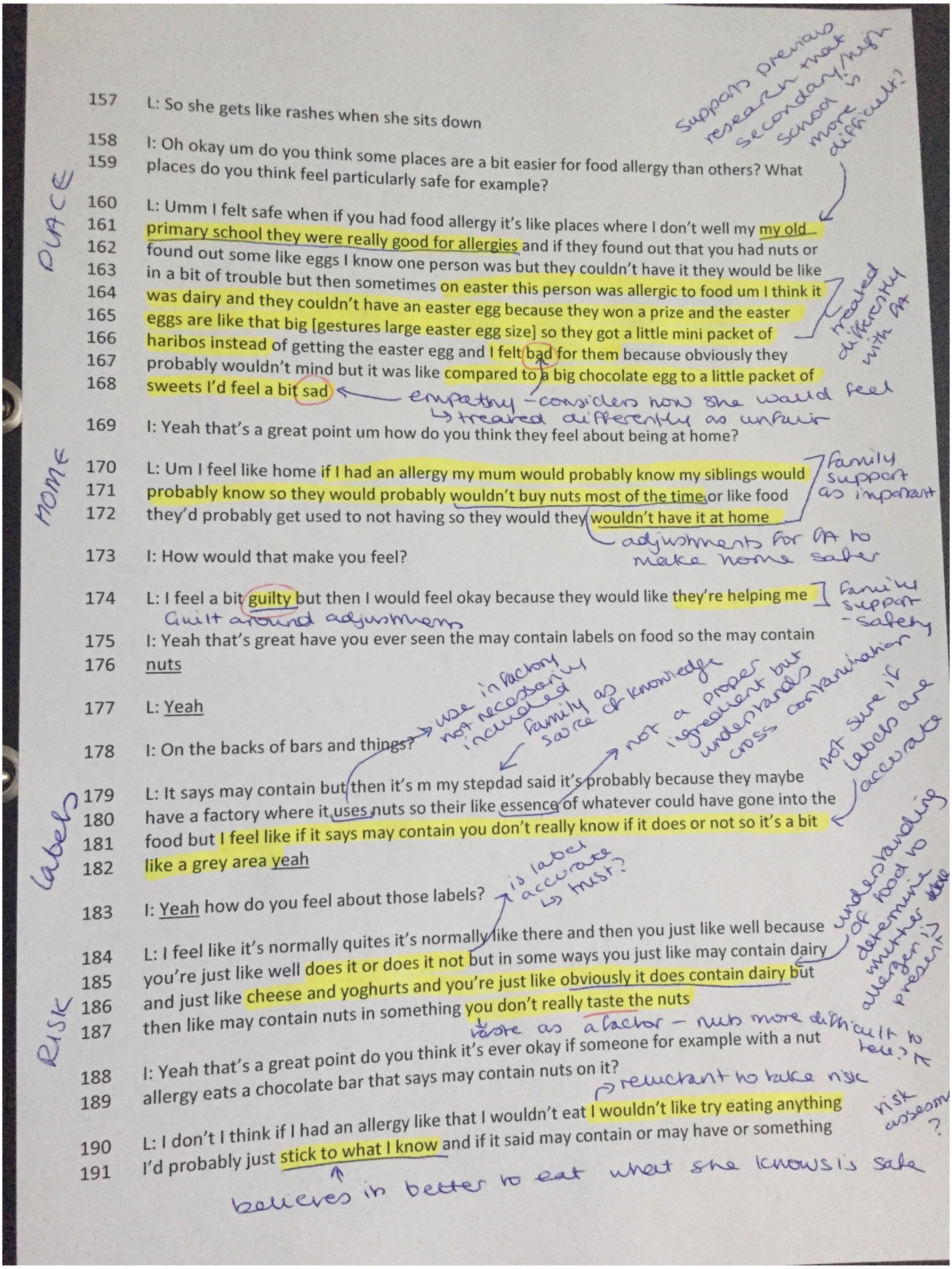
Appendix 3.11: Interview schedule

Interview schedule - Children/adolescents with no food allergy

Topic	Question	Prompts
Food Allergy	Can you tell me a bit about yourself?	Family/school/hobbies
	Do you know anyone with a food allergy (FA)?	No one/family/friend/acquaintance
	What do you know about FA? Can you tell me what you think an allergy is? What are the most common foods to be allergic to?	Symptoms/reaction/medication/what foods are most likely to be allergens
	How do you feel about FA?	Not bothered/exaggerated/confusing/scary/sad
AAIs	Do you know what medication is used to help people with FA?	Antihistamines/AAI/no cure/just avoid food
	Do you know what an AAI is?	Have you ever seen one? How is it used? How do you feel about them? Is it scary/interesting/weird?
	How would you feel if you had to carry one around?	Annoying/not bothered/necessary
	What would you do if someone you knew had a reaction? How would you feel?	Panic/call an adult/use AAI/ask for help/nothing/just watch/call ambulance
School	What do you think it's like to have FA at school?	Easy/hard? Lunchtimes? Any dangers? Do you know if your school has FA policy?
	How do you think other people react to someone with FA?	Teachers/friends/bullies/parents/staff/cooks
	What do you think about someone with FA coming on a school trip?	Snacks on bus/eating with others/no problem/shouldn't come as it's dangerous/would ruin the fun?
	Do you think there are any challenges having FA at school?	Why? What could help? Bullying?
Social life/friend's houses	What sort of social life do you think someone with FA has?	Why? Going out to eat/cinema/depends where?
	What if a party has a food that someone is allergic to? If it was you, how would you feel?	Should they remove it? Is it dangerous if they don't eat it? Should they come?
	Would you eat food you know someone was allergic to while in the same room?	Why? Far enough away/don't want to make them uncomfortable?
	How can friends affect someone with a FA?	Support/discrimination? Would FA teen eat risky foods?
	How would you feel if a friend asked about allergies when you were out eating a meal?	Fine with it/wasting time/uncomfortable/eat it anyway? What if they had to send food back?
	How would you feel if you had to ask about FA whenever you went out to eat?	Frustrated/not bothered/scared/worried
Holidays?	What challenges could there be for someone with FA on holiday?	Menu/different languages/different culture

	How do you feel about allergy free options? Should every restaurant do them?	Yes to keep safe/no not everyone has allergies? Why? Expensive?
	Do you think some places are easier for people with FA than others? Why?	Home as safe, holidays as scary
Labels	How do you feel about 'may contain' labels?	Accurate? Supermarkets don't want to be sued? Protection? Good to know?
	Is it okay if someone with FA eats a food with a 'may contain' label?	Yes/no/why? Their choice/no it's dangerous? Would it make you uncomfortable?
Anaphylaxis	Do you know what anaphylaxis is?	Test knowledge, allergic reaction
	How would you feel if you might react to something like that?	Scared/worried, can't imagine
Increasing understanding	Is it easy to talk about FA?	Why? What could make it easier?
	Is there anything you wish you knew about FA or that you think others should know?	More awareness/information/education?
	Do you think you understand FA? Or would you like to know more about it?	What would you like to know more about? Where could you get information? Should your school organise something?
	Is there anything that could improve attitudes to FA or make it more normal?	More awareness/education?
Concluding questions	Is there anything about FA we haven't covered that you would like to talk about?	
	Is there was one thing someone could do to help someone manage their FA better what would it be?	

Appendix 3.12: Example coding



L: So she gets like rashes when she sits down

I: Oh okay um do you think some places are a bit easier for food allergy than others? What places do you think feel particularly safe for example?

PLACE

L: Umm I felt safe when if you had food allergy it's like places where I don't well my my old primary school they were really good for allergies and if they found out that you had nuts or found out some like eggs I know one person was but they couldn't have it they would be like in a bit of trouble but then sometimes on easter this person was allergic to food um I think it was dairy and they couldn't have an easter egg because they won a prize and the easter eggs are like that big [gestures large easter egg size] so they got a little mini packet of haribos instead of getting the easter egg and I felt bad for them because obviously they probably wouldn't mind but it was like compared to a big chocolate egg to a little packet of sweets I'd feel a bit sad

Supports previous research that secondary/high school is more difficult?

treated differently with FA

empathy – considers how she would feel
↳ treated differently as unfair

I: Yeah that's a great point um how do you think they feel about being at home?

HOME

L: Um I feel like home if I had an allergy my mum would probably know my siblings would probably know so they would probably wouldn't buy nuts most of the time or like food they'd probably get used to not having so they would they wouldn't have it at home

Family support as important

adjustments for FA to make home safer

I: How would that make you feel?

L: I feel a bit guilty but then I would feel okay because they would like they're helping me

Guilt around adjustments

Family support – safety

I: Yeah that's great have you ever seen the may contain labels on food so the may contain nuts

L: Yeah

I: On the backs of bars and things?

labels

L: It says may contain but then it's m my stepdad said it's probably because they maybe have a factory where it uses nuts so their like essence of whatever could have gone into the food but I feel like if it says may contain you don't really know if it does or not so it's a bit like a grey area yeah

use in factory not necessarily included

Family as source of knowledge

not a proper ingredient but understands cross contamination

not sure if labels are accurate

I: Yeah how do you feel about those labels?

is label accurate
↳ trust?

RISK

L: I feel like it's normally quites it's normally like there and then you just like well because you're just like well does it or does it not but in some ways you just like may contain dairy and just like cheese and yoghurts and you're just like obviously it does contain dairy but then like may contain nuts in something you don't really taste the nuts

understanding of food to determine whether allergen is present

taste as a factor – nuts more difficult to tell?

I: Yeah that's a great point do you think it's ever okay if someone for example with a nut allergy eats a chocolate bar that says may contain nuts on it?

L: I don't I think if I had an allergy like that I wouldn't eat I wouldn't like try eating anything I'd probably just stick to what I know and if it said may contain or may have or something

reluctant to take risk

risk assessment ?

believes in better to eat what she knows is safe

Study 4: Development of AFAB scales

Appendix 5.1: Letter from clinic

University Hospitals of Leicester NHS
NHS Trust

Aston University
Birmingham

Clinic Address

[Date]

Dear Parent/guardian

Re: Attitudes and beliefs about food allergy.

We are helping Aston University in Birmingham with a study to look at how children and adolescents view their food allergy. This research is being conducted as part of a PhD project and is being funded by the Midlands Asthma and Allergy Research Association. We are writing to you as your child is aged 11 to 16 years and has had a diagnosis of food allergy. We would be very grateful if you would consider taking part.

Food allergy seems to be on the increase, and yet there is not much research that looks at how children and adolescents view their food allergy and how they manage it. So we can develop ways in which we can help children and teenagers manage their food allergy, it is important to understand attitudes towards food allergy and how children manage. A questionnaire to measure attitudes towards food allergy would help your child to let their clinician know in a quick and effective way how your child views their food allergy, which can affect how they deal with it. This would help to direct health care appropriately and would also help clinicians see if there are any interventions that could support your child manage their food allergy more effectively.

The research team have interviewed children and adolescents with food allergy and have developed a questionnaire about their attitudes and beliefs towards their food allergy. If your child is happy to take part, the research team would like your child to fill in the questionnaire. More information about the study and how to fill in the questionnaire can be found in the enclosed information sheet. We have also included an information sheet for your child to read. You and your child will also need to complete the enclosed consent/assent forms to say you are happy to take part. If it is easier, you can complete these forms and the questionnaires online at [web address].

The study follows the British Psychological Society requirements regarding ethics and also conforms to the regulations outlined in The Data Protection Act (1998). The study has received ethical approval from XXX NHS Research Ethics Committee.

This research is being conducted as part of a PhD project. If you have any questions about the research, please contact **Kristina Newman (PhD student) on** [redacted]. If your child would like to take part, please go to following web address [web address] or complete the enclosed questionnaires and consent forms and post them back to us.

Thank you for taking the time to consider this request.

Yours sincerely

Consultant
Email:

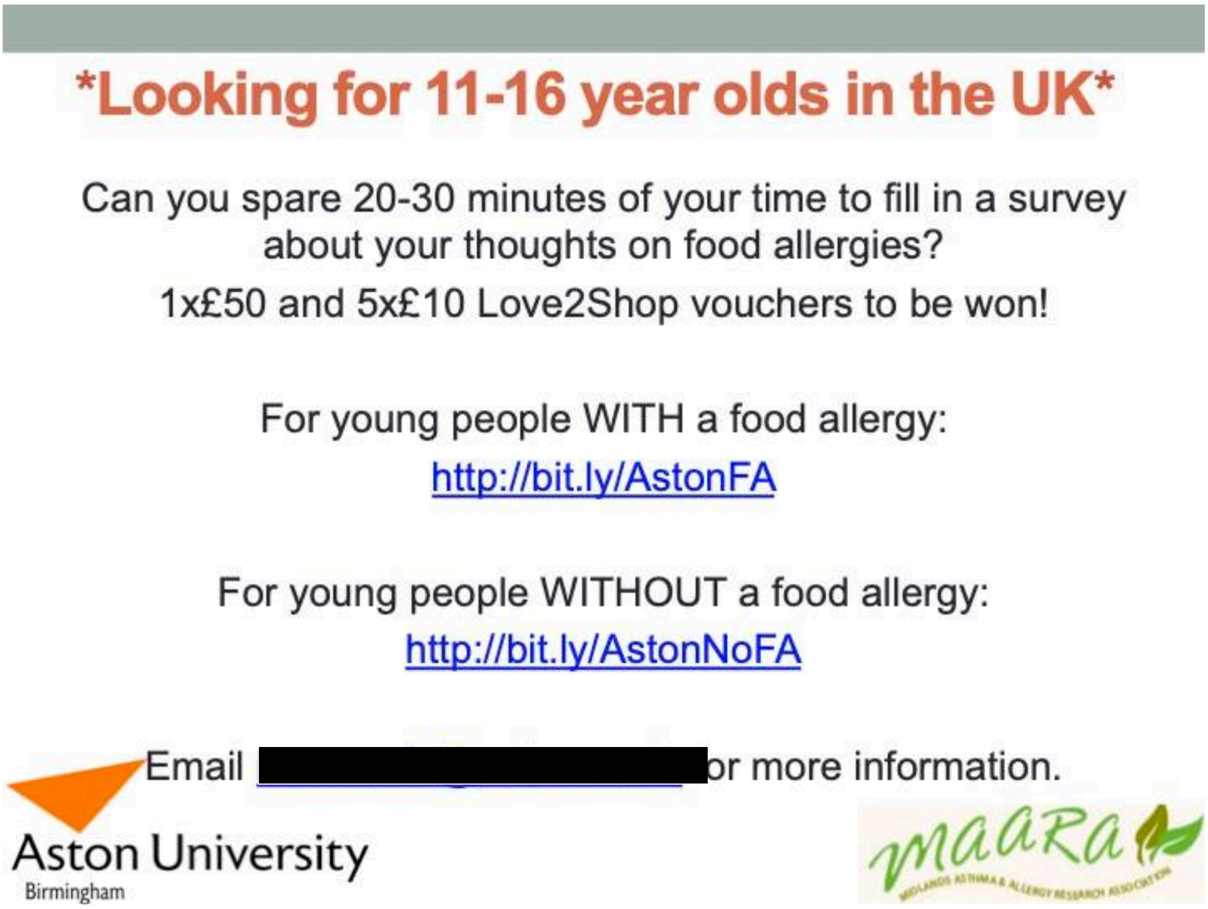
Appendix 5.2: Social media adverts

“What do UK 11-16-year olds think about #foodallergy? 🤔

I'm running a study to see what young people think about food allergies for my PhD. There are no wrong answers, it's confidential and there's a £50 Love2Shop voucher to be won!

Please RT/share/pass on to anyone who may be able to help!”

Advert 1:



Looking for 11-16 year olds in the UK

Can you spare 20-30 minutes of your time to fill in a survey about your thoughts on food allergies?

1x£50 and 5x£10 Love2Shop vouchers to be won!

For young people WITH a food allergy:

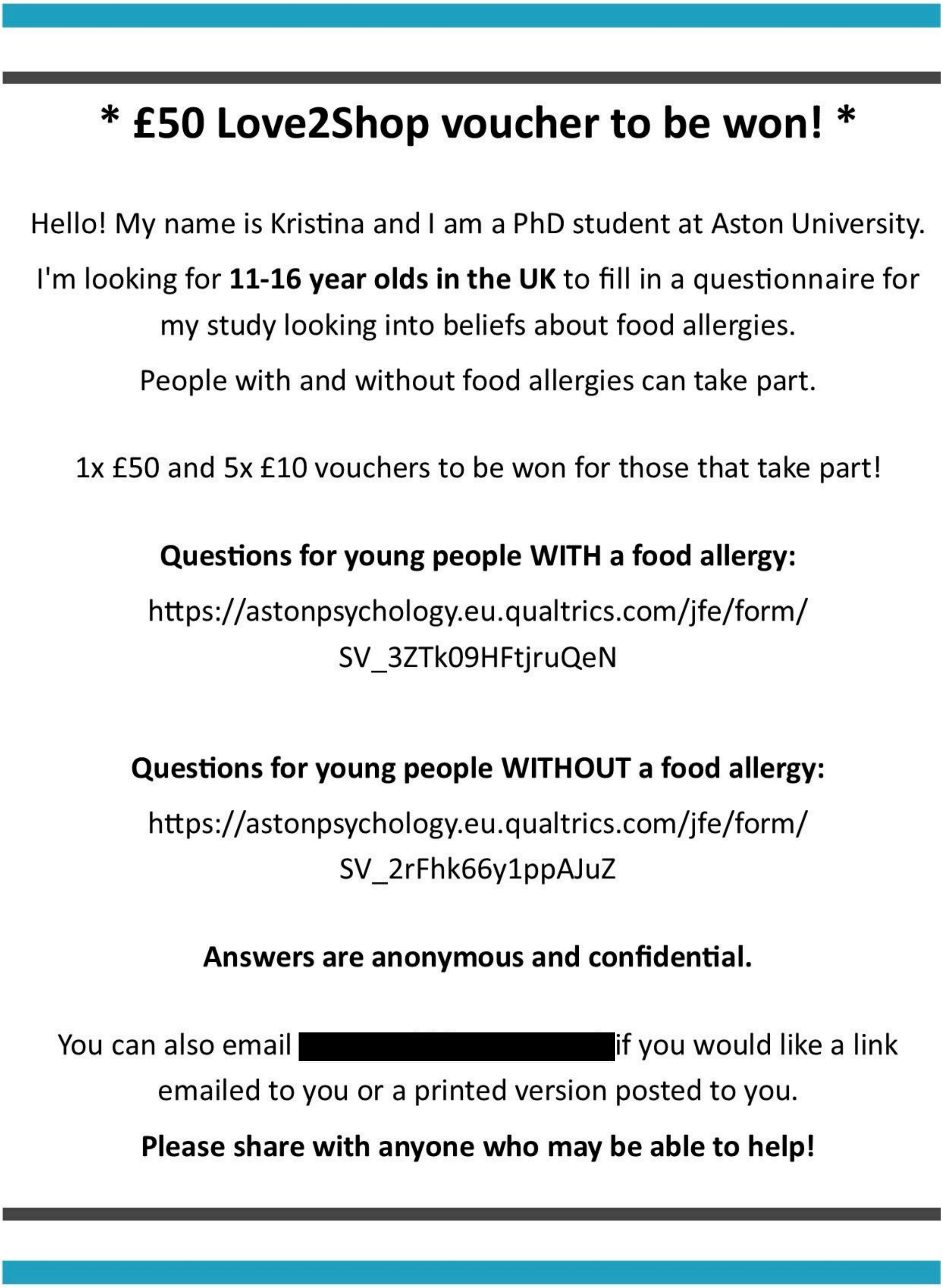
http://bit.ly/AstonFA

For young people WITHOUT a food allergy:

http://bit.ly/AstonNoFA

Email [redacted] or more information.

Advert 2:



* £50 Love2Shop voucher to be won! *

Hello! My name is Kristina and I am a PhD student at Aston University.

I'm looking for **11-16 year olds in the UK** to fill in a questionnaire for my study looking into beliefs about food allergies.

People with and without food allergies can take part.

1x £50 and 5x £10 vouchers to be won for those that take part!

Questions for young people WITH a food allergy:

https://astonpsychology.eu.qualtrics.com/jfe/form/SV_3ZTk09HFtjruQeN

Questions for young people WITHOUT a food allergy:

https://astonpsychology.eu.qualtrics.com/jfe/form/SV_2rFhk66y1ppAJuZ

Answers are anonymous and confidential.

You can also email [redacted] if you would like a link emailed to you or a printed version posted to you.

Please share with anyone who may be able to help!

Appendix 5.3: Questionnaire information sheet for adolescents

School of Life and Health Sciences
Aston University
Aston Triangle
Birmingham
B4 7ET
[redacted]

Attitudes, beliefs and understanding of food allergy in children and adolescents

INFORMATION SHEET FOR TEENAGERS – QUESTIONNAIRE DEVELOPMENT

My name is Kristina Newman. I am a PhD student at Aston University, and I am looking at the attitudes, beliefs and understanding of adolescents towards food allergies. If you are between 11 and 16 years of age you can take part in this study. **You don't have to have food allergy to take part.** Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read this information carefully and discuss it with others if you wish to. If anything is not clear and you need more information before you decide if you want to take part in the study or not, please get in touch with a member of the study team (details at the end of the information sheet).
Thank you for reading this.

The purpose of the study:

Food allergy seems to be on the increase, ~~and~~ yet there is not much research that looks at the views adolescents have about their food allergy. In the first phase of the study we interviewed young people to get a better understanding of their views of food allergy. From that information we developed a questionnaire and we are now asking young people to fill it in for us. We hope that this will help us and doctors and nurses develop ways in which young people with food allergies can be supported to understand and manage their food allergy better. **Everyone who takes part will be entered into a prize draw for Love to Shop or Book Vouchers.**

Why have I been chosen?

You have been asked to take part in the study because you either go to the allergy clinic at Leicester or you have seen an advert for the study.

What would I need to do?

As part of this study, we would like you to fill in some questionnaires for us. These will ask about your views about food allergies, how you feel in general and your views about health and illness. This will help us to check our questionnaire on your views about food allergies to see if it is reliable. Filling them in will take around 20 minutes. The easiest way to do this is to fill questionnaires in online, using a computer, a tablet or your phone.

If you are reading this online, you can find the questionnaires by clicking the bottom of the page. If you have been given this information in clinic or sent this information sheet and questionnaires by post, please fill in the questionnaires and post them back to us. Or you can go online and find the questionnaires here:

Questions for 11-16 year olds **with** food allergy can be found here:
http://bit.ly/AstonFA

Questions for 11-16 year olds **without** food allergy can be found here:
http://bit.ly/AstonNoFA

If you want us to send the questionnaires to you by post, just get in touch with us and we can send them to you.

We will also ask you if you would mind filling in another short questionnaire about your views on food allergies in a few weeks' time, so we can do a final check that our new questionnaire is reliable, but you don't have to do this if you don't want to.

Do I have to take part?

No, it is up to you to decide whether you want to take part or not. If you decide to take part, you are free to withdraw (stop taking part in the study) at any time without giving a reason. If you do take part in the study and change your mind, you can just contact us and we will destroy all the information you gave us, however any information that has already been analysed can't be withdrawn. Withdrawing from the study will **not** affect any health care you receive now or in the future.

What are the benefits of taking part?

By understanding your views about food allergies, we will be able to see if our questionnaire is reliable. We also hope that this will help us and doctors and nurses develop ways in which young people with food allergies can be helped to manage and understand their food allergy better.

What are the disadvantages or risks of taking part?

There are no risks in taking part but you may decide you don't want to answer some of the questions about food allergy. You will be able to stop answering questions at any time you wish and either take a break or decide you do not want to take part anymore. If there are any questions you don't want to answer you can skip the question and move on to the next one.

What do I need to do if I decide to take part?

Please let the person who looks after you know that you would like to take part. If you are reading this online, clicking to the next page will take you to a consent form. You will need to fill this in to tell us that you are happy to take part. If you are 15 years old or younger, the person who looks after you will also need to fill in a consent form to say they are happy for you to take part. You then just need to fill in the questionnaires.

If you have been sent this information sheet and questionnaires by post or they have been given to you in clinic, you can find the consent forms with the questionnaires. You will need to fill these in and post them back to us. Or you can find everything online at:

Questions for 11-16 year olds **with** food allergy can be found here:
http://bit.ly/AstonFA

Questions for 11-16 year olds **without** food allergy can be found here:
http://bit.ly/AstonNoFA

INFORMATION ABOUT THE CONDUCT OF THE STUDY

Will the information I give in this study be kept confidential?

Yes, all information collected from you will be kept strictly confidential. That means that no one outside of the research team will see any of the information you give us. Each person taking part in the study will be given a code or study number that we will use when looking at the information from the study. We will not ask for your name. Information will be kept in a locked filing cabinet and on a password protected computer at Aston University for 6 years and then it will be destroyed.

What will happen to the results of the study?

The information from the questionnaires will only be seen by members of the study team. We will write a report of the study which will be published, and the results will be written up as part of a PhD. We can send you a summary of the results if you would like them.

What if there is a problem?

If you are worried about anything to do with this study, please speak to the research team and we will do our best to answer your questions. You can ring Dr Rebecca Knibb or email her (phone number and email address are at the bottom of this information sheet). If she cannot help you and you still have any worries about the way in which the study has been conducted, then you should contact the Director of Governance of the University Research Ethics Committee, [redacted]

Who has reviewed the study?

This study has been looked by the Derby Research Ethics Committee. These are a group of people who check research to make sure that it protects the safety, rights, wellbeing and dignity of anyone who takes part.

<u>Can I get more information?</u>

If you are interested in taking part in this study but would like some more information before you decide, please talk to Dr Rebecca Knibb or email us. Or please feel free to talk to the person who looks after you, such as your mum or dad. If you would like to talk to an independent person about taking part in this study or about research in general in Psychology at Aston University please contact the Director of the Aston Research Centre for Children's and Young People's Health, [redacted] [redacted] If you would like independent advice on any aspect of this study, you can also contact the PILS (Patient Information and Liaison Service) at the Leicester Hospitals NHS Trust on [redacted].

Thank you for taking time to read this information sheet.

Research Team:

Kristina Newman PhD Student Aston University Aston Triangle Birmingham B4 7ET [redacted]	**Dr Rebecca Knibb** Chief Investigator Aston University Aston Triangle [redacted]	[redacted] Consultant Paediatrician Children's Allergy Service Leicester Royal Infirmary Leicester LE1 5WW

Study telephone number: [redacted]

Appendix 5.4: Questionnaire information sheet for parents

School of Life and Health Sciences
Aston University
Aston Triangle
Birmingham
B4 7ET
[redacted]

Attitudes, beliefs and understanding of food allergy in children and adolescents

INFORMATION SHEET FOR PARENTS - QUESTIONNIARES

My name is Kristina Newman. I am a PhD student at Aston University, and I am studying the attitudes, beliefs and understanding of adolescents towards food allergies. I am inviting your child to take part in a study we are running with [redacted] Research Association (MAARA). **Your child does not have to have a food allergy to take part.**

Before you decide if you would like your child to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. If anything is not clear and you would like some more information you can get in touch with me on the above number or email address. Please take your time to decide whether you wish your child to take part or not.

Thank you for reading this.

The purpose of the study:

Food allergy seems to be on the increase, yet there is not much research that looks at the views adolescents have about their food allergy. In the first phase of the study we interviewed young people with and without food allergies to get a better understanding of their views of food allergy. From that information we developed a questionnaire and we are now asking young people to fill it in for us. We hope that this will help us and doctors and nurses develop ways in which young people with food allergies can be supported to understand and manage their food allergy better. **Everyone who takes part will be entered into a prize draw for Love to Shop Vouchers.**

Why has my child been chosen?

Your child has been asked to take part in the study because they are aged between 11 and 16 years and they either go to a secondary school in the UK, attend the allergy clinic at Leicester or you have seen an advert for the study.

What would we need to do?

As part of this study, we would like your child to fill in some questionnaires for us. These will ask about their views about food allergies, how they feel in general and their views about health and illness. This will help us to check our questionnaire on their views about food allergies to see if it is reliable. Filling them in will take around 20 minutes. The easiest way to do this is to fill questionnaires in online, using a computer, a tablet or phone.

If you are reading this online, your child can find the questionnaires by clicking the bottom of the page. If you have been given this information in clinic or sent this information sheet and questionnaires by post, please ask your child to fill in the questionnaires and post them back to us. Or they can go online and find the questionnaires at:

Questions for 11-16 year olds **with** food allergy can be found here:
http://bit.ly/AstonFA

Questions for 11-16 year olds **without** food allergy can be found here:
http://bit.ly/AstonNoFA

If you want us to send the questionnaires to you by post, just get in touch with us and we can send them to you.

We will also ask your child if they would mind filling in another short questionnaire about their views on food allergies in a few weeks' time, so we can do a final check that our new questionnaire is reliable, but they don't have to do this if they don't want to.

Does my child have to take part?

No, it is up to your child to decide whether they would like to take part or not. If they decide to take part you will be asked to complete a consent form, which says you are happy for your child to take part. If your child decides to take part and wishes to stop at any point, they may do so and withdraw (stop taking part) from the study without giving a reason. If after taking part your child wishes to withdraw from the study, they are free to withdraw at any time without giving a reason. Just contact us and we will destroy all the information they gave us, however any information that has already been analysed can't be withdrawn.

Whether you decide to take part or not will not affect the standard of health care that you or your child receives.

What are the benefits of taking part?

By understanding your child's views about food allergies we will be able to see if our questionnaire is reliable. We also hope that this will help us and doctors and nurses develop ways in which young people with food allergy can be helped to manage and understand their food allergy better.

What are the disadvantages of taking part?

There are no risks in taking part but your child may decide they don't want to answer some of the questions about food allergy. They can stop answering questions at any time they wish and either take a break or decide they do not want to take part anymore. If there are any questions they don't want to answer they can skip the question and move on to the next one.

What will I need to do if I my child would like to take part?

If you are reading this online, clicking to the next page will take you to consent forms. If your child would like to take part your child will need to complete the online form to say that they are happy to take part. **If your child is 15 years old or younger, they will also need you to sign the form**. Your child will then just need to fill in the questionnaires.

If you have been given this information in clinic or sent this information sheet and questionnaires by post, you can find the consent forms with the questionnaires. You and your child will need to fill these in and post them back to us. Or you can find everything online at:

Questions for 11-16 year olds **with** food allergy can be found here:
http://bit.ly/AstonFA

Questions for 11-16 year olds **without** food allergy can be found here:
http://bit.ly/AstonNoFA

INFORMATION ABOUT THE CONDUCT OF THE STUDY

Will the information I give in this study be kept confidential?

Yes, all information collected from your child for the study will be kept strictly confidential. That means that no one outside of the research team will see any of the information you give us. Each person taking part in the study will be given a code or study number that we will use when looking at what your child has said. Information will be kept in a locked filing cabinet and on a password protected computer at Aston University for 6 years and then it will be destroyed. The procedures for handling, processing, storage and destruction of the questionnaire data collected during the study are compliant with the Data Protection Act 1998.

What will happen to the results of the study?

The information that your child gives us will be analysed by Kristina Newman and the research team. Data we collect will also be presented at conferences, published in journals and written up as part of a PhD. We can send you a copy of the report if you would like one. Your child's name will not be in anything we publish.

What if there is a problem?

If you have any concerns or complaints about anything to do with this study, please speak to the research team and we will do our best to answer your questions. You can ring [redacted] or email [redacted]. If she cannot help you and you still have any worries about the way in which the study has been conducted, then you should contact the Director of Governance of the University Research Ethics Committee, [redacted]

Who has reviewed the study?

This study has been looked by the Derby Research Ethics Committee. These are a group of people who check research to make sure that it protects the safety, rights, wellbeing and dignity of anyone who takes part.

Can I get more information?

If you are interested in taking part in this study but would like some more information before you decide, please talk to Dr Rebecca Knibb or email us. If you would like to talk to an independent person about taking part in this study or about research in general in Psychology at Aston University please contact the Director of the Aston [redacted]

If you would like independent advice on any aspect of this study, you can also contact the PILS (Patient Information and Liaison Service) at the Leicester Hospitals NHS Trust on [redacted].

Thank you for taking time to read this information sheet.

Research Team:

Kristina Newman PhD Student Aston University Aston Triangle Birmingham B4 7ET [redacted]	**Dr Rebecca Knibb** Chief Investigator Aston University Aston Triangle [redacted]	[redacted] Consultant Paediatrician Children's Allergy Service Leicester Royal Infirmary Leicester LE1 5WW

Study telephone number: [redacted]

Appendix 5.5: FA SCALE consent form for adolescents aged 16 years

University Hospitals of Leicester NHS
NHS Trust

maara
MIDLANDS ASTHMA & ALLERGY RESEARCH ASSOCIATION

Aston University
Birmingham

CONSENT FORM FOR YOUNG PERSON 16 YEARS OF AGE OR OVER - QUESTIONNAIRES

Project Title: Attitudes, beliefs and understanding of food allergy in children and adolescents

Name of Researcher: Kristina Newman

Name of Project Supervisor: Rebecca Knibb

Participant ID:

	Please initial each box to indicate if you agree with the statement:
I have read the study information (version________) and know who to contact should I have any questions about taking part in the study.	☐
I understand that taking part in the study is voluntary, and that I am free to withdraw (stop taking part) at any time. I do not have to give any reasons for this. I have been provided with details of who I should contact if I wish to withdraw.	☐
I am aware that any anonymised research data already analysed cannot be destroyed, withdrawn or recalled.	☐
I agree to take part in this study.	☐
I am happy to be contacted again about this study.	☐
I would like to receive a summary of the results of this project.	☐

Name of Participant ____________ Signature ____________ Date ____________

Researcher ____________ Signature ____________ Date ____________

If you would like to be contacted again about this study or get a summary of the results, please put your contact email address or telephone number here. We will store this separately from the study data.

Email/Telephone______________________________

1 copy for participant, 1 copy for researcher, 1 copy for patient records

Appendix 5.6: FA SCALE assent form for adolescents aged 11-15 years

ASSENT FORM FOR CHILDREN AND YOUNG PERSONS UNDER 16 YEARS – QUESTIONNAIRES

Project Title: Attitudes, beliefs and understanding of food allergy in children and adolescents

Name of Researcher: Kristina Newman

Name of Project Supervisor: Rebecca Knibb

Participant ID:

Child (or if unable, parent on their behalf) /young person **please initial all the ones you agree with:**

	Initials
I have read the study information (version________) and somebody has explained this project to me.	
I know who to contact should I have any questions about taking part in the study	
I have asked questions and they have been answered in a way that I understand.	
I understand that it is ok to stop taking part at any time and I do not have to give any reasons for this.	
I understand that everything I say will be kept safe and confidential.	
I agree to take part in this study.	
I am happy to be contacted again about this study.	
I would like to receive a copy of the results from this project.	YES/NO

PLEASE TURN OVER

If you don’t want to take part, do not sign your name.

If you do want to take part in this study, please sign your name and write today’s date.

Your name……………………………… Date……………………………………………….

Your Mum, Dad or the person who looks after you, needs to sign here to show that they are happy for you to take part in the research

-----------------------------	--------------------------------------	-----------
Parent/guardian name	Parent/guardian signature	Date

The researcher who explained this project to you needs to sign here too:

------------------------------	--------------------------------------	-----------
Researcher name	Parent/guardian signature	Date

If you and your child would like to be contacted again about this study or get a summary of the results, please put your contact email address or telephone number here. We will store this separately from the study data.

Email/Telephone_____________________________

1 copy for participant, 1 copy for researcher, 1 copy for patient records

Appendix 5.7: FA SCALE consent form for parents

University Hospitals of Leicester NHS Trust

MAARA Midlands Asthma & Allergy Research Association

Aston University Birmingham

CONSENT FORM FOR PARENTS OF CHILDREN UNDER 16 YEARS – QUESTIONNAIRES

Project Title: Attitudes, beliefs and understanding of food allergy in children and adolescents

Name of Researcher: Kristina Newman

Name of Project Supervisor: Rebecca Knibb

Participant ID:

Please initial each box to indicate you agree with each statement:

I and my child have read the study information (version ______) and know who to contact should we have any questions about participation in the study. ☐

I understand that my child's participation in the study is voluntary, and that they are free to withdraw at any time. We do not have to give any reasons or explanations for doing so. We have been provided with details of who to contact if we wish to withdraw. ☐

I am aware that any anonymised research data already analysed cannot be destroyed, withdrawn or recalled. ☐

I am happy for my child to be contacted again if my child agrees to this. ☐

I agree for my child to participate in this research study. ☐

Name of child	Name of person giving consent for child	
Relationship to child	Signature	Date

Name of researcher	Signature of researcher	Date

If you and your child would like to be contacted again about this study or get a summary of the results, please put your contact email address or telephone number here. We will store this separately from the study data.

Email/Telephone______________________________

1 copy for participant, 1 copy for researcher, 1 copy for patient records

Appendix 5.8 Demographics form for adolescents with FA

University Hospitals of Leicester NHS Trust

MAARA Midlands Asthma & Allergy Research Association

Aston University Birmingham

What are the attitudes, beliefs and understanding of food allergies in children and adolescents?

About you:
Circle the answer that best fits you.

My gender is:

Male	Female	Prefer not to say

My age (in years) is:

11	12	13	14	15	16

My ethnicity is:

- British
- White European
- Other European background
- Indian
- Pakistani
- Bangladeshi
- Other South Asian background
- Chinese
- Other East Asian background
- Black African
- Black Caribbean
- Other Black background
- Other/mixed ethnic group

Do you currently have a diagnosed food allergy?

Yes	No

What town or city do you live in?

____

<u>About your food allergy:</u>
You may want to ask your mum, dad or a guardian to help fill in some of these questions about your food allergy.

How many food allergies do you have?

____

Have you *<u>ever</u>* required treatment for any of the following?

Asthma	Yes	Maybe	No
Eczema	Yes	Maybe	No
Hay fever	Yes	Maybe	No

Do *<u>you</u>* have any relatives (e.g. mother, father, brother, sister) with food allergy?

____

What are you allergic to? Please tick as many as apply.

- Peanut [ ]
- Other nuts [ ]
  - **Type of nuts**: ____________________________
- Sesame seeds [ ]
- Cow’s milk [ ]
- Egg [ ]
- Soya [ ]
- Fish [ ]
- Shellfish [ ]

- Latex [ ]
- Tree pollen [ ]
- Grass pollen [ ]
- Other [ ]
    - **If other, please specify**: ________________________

Have you had any allergies to foods which you can now eat?

- Egg YES [ ] NO [ ]
- Milk YES [ ] NO [ ]
- Other YES [ ] NO [ ]

If other, please say what allergies you have outgrown?

____

What age were you when you first reacted to food? (If you are not sure, please put your closest guess.)

____

Has your food allergy been diagnosed by a healthcare professional? (e.g. doctor or allergist)

YES [ ] NO [ ] NOT SURE [ ]

How old were you when you were diagnosed (a doctor told me or my parents that I have food allergy)? If you have not been diagnosed by a doctor, leave this blank.

____

How was your food allergy diagnosed?

Skin prick tests [ ] Blood tests [ ] Food challenge [ ] History [ ]

Other please state……………….

Have you been prescribed by your doctor (for your food allergy):

- Adrenaline (e.g. Epi-Pen, JEXT) YES [ ] NO [ ]
- Antihistamine YES [ ] NO [ ]

Other, please state ______________________

How did you react during your *worst* ever reaction? (*Tick as many boxes as are appropriate)*

- Vomiting [ ]
- Abdominal (tummy) pain [ ]
- Rash [ ]
- Face swelling [ ]
- Tingling/sore mouth [ ]
- Swelling of lips or tongue [ ]
- Throat tightening/difficulty swallowing [ ]
- Breathing difficulties [ ]
- Wheeze [ ]
- Collapse/faint [ ]
- Other [ ]

If other please specify……………………………………………………

Have you ever had an anaphylactic reaction?

YES [ ] NO [ ] NOT SURE [ ]

What treatment did you take for your *worst* reaction? (*Tick as many boxes as are appropriate)*

- Antihistamines [ ]
- Adrenaline injection (e.g. Epi-Pen or JEXT) [ ]
- None [ ]
- Other (please specify) ___________________

Have you ever been to hospital with an allergic reaction to food?

YES [ ] NO [ ] NOT SURE [ ]

How many times approximately have you reacted to food? (If more than 20 just put 20.)

____

Is there anything else you would like to tell us about your food allergies?

Appendix 5.9: Demographic form for adolescents without FA

University Hospitals of Leicester NHS
NHS Trust

MAARA MIDLANDS ASTHMA & ALLERGY RESEARCH ASSOCIATION

Aston University
Birmingham

What are the attitudes, beliefs and understanding of food allergies in children and adolescents?

About you:

Circle the answer that best fits you.

My gender is:

Male Female Prefer not to say

My age (in years) is:

11 12 13 14 15 16

My ethnicity is:

- British
- White European
- Other European background
- Indian
- Pakistani
- Bangladeshi
- Other South Asian background
- Chinese
- Other East Asian background
- Black African
- Black Caribbean
- Other Black background
- Other/mixed ethnic group

What town or city do you live in?

____

If you had an allergy in the past that you have outgrown, what were you allergic to and how old were you when you outgrew it? (You can skip this if you have never had an allergy).

____

Appendix 5.14: Data protection statement

Data protection statement

In line with its obligations in relation to data and privacy law, and to comply with the General Data Protection Regulation (“GDPR”) and the Data Protection Act 2018 (“DPA”) Aston University is required to give you information in relation to your participation in research. This transparency statement provides that information. Aston University is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study. Aston University will process your personal data in order to register you as a participant and to manage your participation in the study. It will process your personal data on the grounds that it is necessary for the performance of a task carried out in the public interest (GDPR Article 6(1)(e). Aston University may process special categories of data about you which includes details about your health. Aston University will process this data on the grounds that it is necessary for statistical or research purposes (GDPR Article 9(2)(j)). Aston University will keep identifiable information about you for 6 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

You can find out more about how we use your information at [redacted]

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner’s Office (ICO).

Study 4a: The Adolescent FA Beliefs scale (AFAB)

Appendix 6.1: AFAB

We are interested in your own personal views of how you see your food allergy at the moment. Please circle the answer that best shows how much you agree or disagree with the following statements about your food allergy.

We want you to answer these questions on your own if you can, but you can ask your mum, dad or a guardian for help if you do not know what a question means.

A food allergy is a serious condition.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Food allergies and food intolerances are the same thing.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Symptoms of a food allergy are mild, like a rash or an upset stomach.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

A food allergy is a life-threatening condition.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Food allergies are common.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

You can grow out of food-allergies.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I will have my food allergy for the rest of my life.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

My food allergy has a big impact on my life.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

My food allergy is unpredictable (I don't know when I could have a reaction).

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Food allergy symptoms get better as you get older.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Living with a food allergy gets easier as you get older.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Primary school was easier than secondary school for managing my food allergy. (If you did not find out you had an allergy until secondary school, put whether you think it would have been easier in primary school).

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

My treatment will cure my food allergies.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I would not use an epi-pen if I had a reaction because I do not like needles.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

If I had a reaction to food, I could handle the situation.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

My actions (e.g. checking ingredients) affect how serious my food allergy is.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

It’s better to let my parent take responsibility for my food allergy (e.g. check labels and carry my adrenaline-pen).

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I think life is easy with a food allergy.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I think food allergies make new friendships difficult.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I think food allergies make romantic relationships (having a boyfriend or girlfriend) difficult.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I should always check ingredients in food.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I think my food allergy makes school difficult.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

School trips are hard with a food allergy.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I think restaurants understand food allergies well.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I think there are enough allergy-free/alternative options (e.g. dairy free milks like almond milk).

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I think food allergy seriousness is exaggerated.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I think schools could do more for people with a food allergy.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Some places are more difficult than others when trying to manage food allergy.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

My food allergy would not affect any holidays I have abroad.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I can handle having my food allergy.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

My food allergy is annoying.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

My food allergy makes me feel sad.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

My food allergy is scary.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I’m not worried about my food allergy.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Having a food allergy has changed my social life.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I think nuts should be banned in schools.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I think may contain (e.g. ‘may contain nuts’) labels are important.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I think may contain labels are always accurate.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I do not think may contain nuts labels need to say <u>which</u> nuts are included.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

If I eat something with a may-contain label on for something I am allergic to, nothing will happen.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Nut allergies are the most serious of food allergies.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

It’s easier to be born with a food allergy than find out you have it when you’re ta teenager.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

My food allergy is part of who I am.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I don’t think my food allergy will limit me in the future.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Study 4b: The Adolescent Food Allergy Beliefs scale: Peers without food allergy (AFAB-P)

Appendix 7.1: AFAB-P

We are interested in your own personal views of how you see food allergies at the moment. Please circle the answer that best shows how much you agree or disagree with the following statements about food allergies.

We want you to answer these questions on your own if you can, but you can ask your mum, dad or a guardian for help if you do not know what a question means.

A food allergy is a serious condition.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Food allergies and food intolerances are the same thing.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Symptoms of a food allergy are mild (e.g. like a rash or an upset stomach).

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

A food allergy is a life-threatening condition.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Food allergies are common.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

You can grow out of food-allergies.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Having food allergy has a big impact on someone’s life.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Food allergies are unpredictable (e.g. you don’t know when you could have a reaction).

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Living with a food allergy gets easier as you get older.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Primary school would be easier than secondary school for people with food allergies.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Treatment can cure food allergies.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I would not use an epi-pen if someone had a reaction because I do not like needles.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

If someone had a reaction to food, I could handle the situation.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Someone's actions (e.g. if they check ingredients) can affect how serious their food allergy is.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

It's better to let a parent take responsibility when you have a food allergy (e.g. check labels and carry my adrenalin-pen).

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I think life is easy with a food allergy.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I think food allergies can make new friendships difficult.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I think food allergies make romantic relationships (having a boyfriend or girlfriend) difficult.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

People with a food allergy should always check ingredients in food.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I think a food allergy would make school difficult.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

School trips would be hard with a food allergy.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I think restaurants understand food allergies well.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I think there are enough allergy-free/alternative options (e.g. dairy free milks like almond milk).

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I think food allergy seriousness is exaggerated.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I think schools could do more for people with a food allergy.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Some places are more difficult than others when trying to manage food allergy.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Food allergies would not affect any holidays abroad.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I could handle having a food allergy.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

If I had a food allergy, I would feel annoyed.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

If I had a food allergy, I would feel sad.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

If I had a food allergy, I would feel scared.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

If I had a food allergy, I would <u>not</u> feel worried.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Having a food allergy would change my social life.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I think nuts should be banned in schools.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I think may contain (e.g. ‘may contain nuts’) labels are important.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I think may contain labels are always accurate.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I do not think may contain nuts labels need to specify which nuts are included.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

If someone with a food allergy ate something with a ‘may-contain’ label on for something they were allergic to, nothing will happen.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Nut allergies are the most serious of food allergies.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

It’s easier to be born with a food allergy than find out you have it when you’re a teenager.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

If I had a food allergy it would be part of who I am

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

I don’t think food allergies limit people when they are adults.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	2	3	4	5

Appendix 7.2: Note before IPQ-B for adolescents without FA

For the next questionnaire, imagine that you have a food allergy and answer how you THINK you would feel. There are no wrong answers.

Appendix 7.3: Note before KidCOPE for adolescents without FA

The next questions are about you in general, so you do not have to think about food allergies.