A Feasibility Randomised Control Trial of a Cognitive Behavioural Therapy Online Group Intervention to Improve the Psychological Wellbeing of Young People Aged 11-17 with Food Allergy.

### By

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Submitted in partial fulfilment of the degree of Doctor of Psychology (Clinical Psychology)

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# Declaration

I confirm that the submitted work is my own work and that I have clearly identified and fully acknowledged all material that is entitled to be attributed to others (whether published or unpublished) using the referencing system set out in the programme handbook/other programme research guidance. I agree that the University may submit my work to means of checking this, such as the plagiarism detection service Turnitin® UK. I confirm that I understand that assessed work that has been shown to have been plagiarised will be penalised.

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Date: 18/07/2022

# Publications / Presentations arising from the MRP

The first study in this thesis, alongside similar projects for adults with food allergy and parents of children with food allergy, was presented at the World Allergy Organisation and British Society for Allergy and Clinical Immunology 2022 conference (oral and poster presentation). The researcher was awarded the Allied Health Barry Kay award for best abstract presentation.

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## **Overview of portfolio**

It is well documented that young people living with food allergy can have heightened levels of anxiety and their quality of life is significantly impacted. Although limited studies have investigated the effectiveness of psychological interventions for parents of children with food allergy, empirical evidence is sparse for interventions supporting young people's psychological wellbeing. Part One of this portfolio presents a Randomised Controlled Trial (RCT) to investigate the feasibility, acceptability, and preliminary efficacy of a low intensity Cognitive Behavioural Therapy (CBT) online, group workshop. The findings suggested recruitment was successful, justifying a need for psychological support for young people with food allergy. Food allergy-related quality of life impairment was reduced in the intervention group compared to the control at both the one-month and three-month follow-up time points. Other measures of worry and coping did not show differences between groups. The goalbased outcomes demonstrated trends of improvement toward participants' subjective goals and participants' workshop feedback found the intervention to be acceptable. Overall, the intervention showed promising feasibility, acceptability, and preliminary signals of efficacy. Results are interpreted within the feasibility design and recommendations are made for future research. Part Two of this portfolio presents a reflexive thematic analysis of young people with food allergy to answer the question of what needs to change to improve their psychological wellbeing. Three themes were generated: psychological impact should be talked about, improvements in safety and risk management, and interpersonal relationships and understanding. This provided a helpful insight into what young people find beneficial for their wellbeing to guide implications across various systems.

### Part 1 - First Empirical Paper

A Feasibility Randomised Control Trial of a Cognitive Behavioural Therapy Online Group Intervention to Improve the Psychological Wellbeing of Young People Aged 11-17 with Food Allergy.

Word count: 8,416

### Abstract

It is well documented that young people living with food allergy can have heightened levels of anxiety and a significant impact on quality of life. Although limited studies have investigated the effectiveness of psychological support for parents of children with food allergy, empirical evidence is sparse for interventions supporting young people's psychological wellbeing. There is suggestion in the literature of the benefits of a cognitive behavioural based intervention to support this patient group. This study used a randomised controlled trial (RCT) design to investigate the feasibility, acceptability, and preliminary efficacy of a low intensity Cognitive Behavioural Therapy (CBT) group workshop. Participants were a sample of 52 young people aged 11-17 with food allergy and were allocated to either the intervention group or a control group who did not receive an intervention until after the completion of the study. The intervention consisted of two threehour sessions spaced one-week apart and were facilitated by two trainee clinical psychologists via an online platform. Participants completed measures of food allergy related quality of life, worry, adherence to food allergy self-care behaviours and coping strategies at baseline, one-month and three-months post intervention. Those in the intervention group also completed goal-based outcome measures and a workshop feedback form. Recruitment was successful, justifying a need for psychological support for young people with food allergy. Although attrition did occur at baseline, very few participants were lost to follow-up in each group. There were no demographic differences found between those who dropped out and those who completed the study. For food allergy related quality of life, the impact was reduced in the intervention group compared to the control at both the one-month (Hedges g =0.70, 95% CI [0.01, 1.40]) and three-month (Hedges g = 1.23, 95% CI [0.51, 1.96]) followup. No differences were found on other measures of worry, coping and adherence to food allergy specific self-care behaviours between groups. However, the goal-based outcomes

demonstrated trends of improvement towards participants' subjective goals. Quantitative and qualitative analysis of the workshop feedback form found the intervention to be acceptable and supportive to participants. Overall, the intervention showed promising feasibility, acceptability, and preliminary signals of efficacy. Results are interpreted within the feasibility design and recommendations are made for future research.

## Introduction

Food allergy is an increasing public health concern, with Westernised countries reporting a prevalence of diagnosed allergies of up to 10%, most notably among younger children (Loh & Tang, 2018). Over the last few decades, the number of people diagnosed with food allergy has been increasing, as has the awareness of the psychological burden of living with food allergy. The symptoms lie on a spectrum, from a mild reaction to fatal anaphylaxis as a possible result of exposure. Therefore, avoidance of the allergen and having access to emergency medication (e.g., adrenaline auto-injectors) remains the primary care for management (Muraro et al., 2014a). Research has also identified that children and young people are the age group most at risk for fatal anaphylaxis to food (Turner et al., 2015), which can result in a significant impact on quality of life for those with an allergy and their family (Cummings et al., 2010).

Having a food allergy is related to an increased risk of anxiety in young people (Ferro et al., 2016). This anxiety was found to persist across longitudinal assessments at aged 14 and 21 and was attributed to the lifelong fears of coming into contact with their allergen and subsequent reactions. Reaching adolescence comes with increasing independence and for those with food allergy it also is a transitional period wherein parents start to give more responsibility for the management of their food allergy to the young person. This negotiation and power imbalance can create further conflict and increased anxiety for both the parent and the young person (DunnGalvin et al., 2009). In addition, the dietary and social restrictions accompanying the management of food allergy can result in children feeling socially isolated or even bullied (Ravid et al., 2012; Muraro et al., 2014b). Research has also shown that adolescents with food allergy are up to four times as likely to have symptoms of depression which persist into young adulthood (Ferro et al., 2016). Considering the social pressures of adolescence, research has found that young people can sometimes feel concerned that if they

were to disclose their allergy this could negatively impact friendships and therefore choose not to (Fenton et al., 2013).

Anxiety is a normal part of human experience as it is an appropriate response to uncertain or unpredictable situations. However, when anxiety is excessive it can cause great distress and interfere with daily functioning (Gross & Hen, 2004). Cognitive models of anxiety describe it as the results of an interpretation of a situation as a threat, and those diagnosed with general anxiety disorder can report high levels of threat despite the absence of objective risk or danger (Milne et al., 2019). Food allergy related anxiety is influenced by the perception of experiencing a severe reaction and the ability to cope with a reaction successfully (de Holanda et al., 2021). For this specific anxiety, there is an ever-present objective risk that does require vigilance and avoidance. With regards to the management of an allergy, some level of anxiety is adaptive as anxious children are less likely to take risks in terms of exposure to the allergen compared to those who are less anxious (Mandell et al., 2005). However, sometimes the anxiety around a fatal reaction can result in avoidance of social situations, not allowing age-appropriate outings or having an excessively restricted diet which could have implications for children's growth and development (Klinnert & Robinson, 2008; Polloni et al., 2013). Walkner et al. (2015) referred to the optimal emotional response being that of 'relaxed readiness' to allow for effective food allergy management whilst minimising more maladaptive aspects of anxiety such as hypervigilance or avoidance.

Considering the 'relaxed readiness' response, interventions for young people with food allergy should aim to recognise, normalise, and support levels of anxiety that can allow for more adaptive coping strategies (Polloni & Muraro, 2020). DunnGalvin et al. (2009) identified three categories of coping strategies that young people start to use which were avoidant, minimisation and adaptive. Avoidant strategies appeared to be associated with high levels of anxiety and low self-efficacy to manage both the emotional impact of living with

food allergies and relationships with others. Young people with more avoidant coping strategies (such as avoiding social events or places where they could be exposed to the allergen) have been found to have higher trait anxiety, believed to be linked to years of fear of exposure to their allergen (Polloni et al., 2017). Cognitive minimisation involved a rejection of the identity of having a food allergy and appeared to be motivated by peer acceptance rather than allergy self-care. Adaptive strategies related to more positive cognitive, emotional or behaviour strategies which supported them to be more independent and self-manage. Coping skills that are developed in adolescence tend to persist into adulthood and those which are more constructive have a positive impact on wellbeing as well as adherence to medical advice (Schmidt et al., 2003). Therefore, an intervention to target a reduction in maladaptive coping techniques and increase adaptive cognitive behavioural problem-solving approach may prove beneficial.

A recent systematic review into the effectiveness of interventions to improve selfmanagement for young people with allergic conditions found all interventions that met their criteria to be for asthma, highlighting the need for specific interventions for those with food allergies (Knibb et al., 2020). A feasibility study on group CBT with parents of children with food allergy provided a signal of efficacy and called for more research on group CBT for similar populations (Vreeken-Ross et al., 2021). CBT for young people with food allergies has been derived from ideas such as those summarised in a review which highlighted the physiological, cognitive, and behavioural aspects of anxiety in relation to anaphylaxis (Manassis, 2012). They described how the physiological symptoms of anxiety (such as dizziness, nausea, or hyperventilation) can be confused with an anaphylaxis response. They called for both psychoeducation on being able to identify different psychological symptoms as well as further support in relaxation techniques. Given the worries are more likely to be around life-threatening high-risk events, cognitive strategies aimed at empowering the child's

own ability to manage this risk were deemed more helpful. They also acknowledged the behavioural aspect of unnecessary excessive avoidance and the benefit of graded returns to feared situations. Building on these suggestions, further recommendations to help this population included enhancing self-esteem and addressing cognitive distortions and anxiety not directly related to their food allergy (Monga & Manassis, 2006).

CBT has shown to be effective in supporting young people with health conditions in managing distress, increasing competence in mastering the challenges of adolescence and improvement in coping skills (Christie & Wilson, 2005; Morey & Loades, 2021; Rechenberg & Koerner, 2021). A recent meta-analysis also found preliminary evidence that brief CBT interventions can benefit young people who experience anxiety in the context of living with a physical health condition (Catanzano et al., 2020). Although little is known about CBT for children with food allergies, interventions using CBT for parents of children with food allergies, interventions using CBT for parents of children with food allergies, interventions using levels of worry and anxiety and improving quality of life (Boyle et al., 2017; Knibb, 2015; Sugunasingha et al., 2020; Vreeken-Ross et al., 2021).

Boyle et al. (2017) found a single session intervention reduced anxiety in mothers of children with food allergy in the long term. In addition, CBT as a single session intervention has been shown to reduce anxiety in young people (Schleider & Weisz, 2017). As the literature has highlighted feelings of not being understood by peers and feeling different, it may be beneficial to offer young people the opportunity to meet others in a similar situation. Group interventions are recommended for young people as it can be reassuring that their concerns are shared, and discussions can promote more adaptive ways of coping (Manassis, 2012). Research with younger children emphasised the benefits of creating a safe environment for children to connect and share similar experiences of living with food allergy (LeBovidge et al., 2008). It was suggested that older children may benefit from groups aimed at coping

skills such as managing stress, assertiveness and problem solving. Given this, it was hypothesised that young people with food allergies may benefit from a brief group intervention using principles from CBT to guide them in specific food allergy related contexts. Research has highlighted that food allergy impacts various aspects of psychological wellbeing, but this study will focus on developing an intervention based on the 'relaxed readiness' anxiety response in the hope to improve understanding of specific food allergy anxiety and quality of life in young people with food allergies.

The research question central to this study is 'Is a CBT-based intervention feasible and acceptable for young people to manage the ongoing impact of food allergy related anxiety and general wellbeing?'. The overall aim of this study was to test the feasibility and preliminary efficacy of an online CBT workshop to support young people with food allergy and anxiety through a randomised controlled trial (RCT). This study examined the feasibility in terms of recruitment, retention, and acceptability of the workshop as well as preliminary efficacy to reduce symptoms of anxiety and improve food allergy related quality of life. Changes between groups were assessed descriptively to provide a signal of efficacy recommended for feasibility trials to inform the potential for further, potentially larger scale studies.

## Methods

### Design

This study was a parallel groups feasibility RCT to explore a CBT-based group workshop for young people with food allergy and self-reported anxiety, compared to a control group. A waitlist control group was chosen due to there not currently being an active control intervention to compare to. A 1:1 ratio of randomisation was chosen.

As per the aims of a feasibility design, this study reports on the acceptability of recruitment and protocol generally, and whether a signal of efficacy was found. The CONSORT extension for randomised pilot and feasibility trials guidance was followed (Eldridge et al., 2016). The study was prospectively registered on an international register of trials (clinicaltrials.gov; Identifier: NCT04770727).

Ethical approval was given by The University of Surrey Ethics Committee (EGA Ref No: FHMS 20-21 002, Appendix A).

### **Participants**

The target population was young people aged 11-17 with food allergy and self-reported anxiety in relation to managing their food allergy. The original age range for this study was 12-17. However, during the recruitment process, parents of young people aged 11 expressed interest in the study and so it was discussed in supervision to extend the age to include those aged 11 given they were at the same developmental stage as those already included. An amendment was approved by the University of Surrey ethics committee (Appendix B).

Participants were recruited online via social media websites and recruitment was supported by the Anaphylaxis Campaign who allowed study advertisement on their social media channels (Appendix C). Participants were required to be willing and able to engage with the content of the workshops and were excluded if they were currently receiving psychological input in relation to their food allergy (Table 1).

For pilot and feasibility studies, the recommended sample size is to have a minimum of 12 participants in each group (Julious, 2005). The anticipated sample size was 15-20 participants in each arm to allow for attrition and determine the feasibility, acceptability, and signal efficacy of the intervention. Therefore, the aim was to recruit 30-40 participants. These rates were tracked and reported.

#### Table 1

	Inclusion Criteria		Exclusion Criteria
1.	Children and young people aged 11- 17 years with food allergy.	1.	Child does not speak English.
2.	To have reported anxiety or worry in relation to management of food allergy.	2.	Currently under a mental health team and receiving ongoing psychological input.
3.	Able to attend the one-day workshop at the University of Surrey to complete the intervention in full (or online alternative).	3.	Receiving ongoing psychological input in relation to their food allergy.
4.	Able and willing to engage and understand the content of the workshop.	4.	Does not have the capacity to provide informed assent/consent and/or consent not gained from caregivers.
5.	Willing and able to comprehend English and provide assent/consent.		

Inclusion and Exclusion Criteria for Participants

# Procedure

After an expression of initial interest by a potential participant (or their parent/caregiver), a participant information sheet was sent to the email address provided (Appendix D & E) along with an invitation to a screening telephone conversation. This included a detailed explanation of the study, what participation would involve, how the randomisation would work and provided the opportunity for any questions to be asked. In addition, potential participants were checked that they met the inclusion criteria through self-report. Both caregivers and the young person were invited to attend the screening conversation. At any point in the study, if participants were not eligible or decided not to continue, they were sent an information sheet with resources on how to seek psychological support and were encouraged to email the

researcher if they had any questions on this (Appendix F). For those still interested after the telephone conversation, consent and assent forms were then sent for both the young person and their caregiver to complete for their respective parts in the study (Appendix G - I). Once consent was received, baseline measures were sent out to all participants. Participants were required to enter a unique identification code, to ensure that the measures could be linked when they were completed post intervention.

Participants were then randomised into groups. Randomisation was carried out using an automated randomisation system accessed via the web (https://www.sealedenvelope.com/) using block sizes of four and six. Once recruitment had resulted in approximately 10 participants being in each treatment arm, a date for the workshop was decided and those in the intervention group were sent an email informing them of the dates of the workshop and a brief introduction to CBT. Those in the control group were sent an email informing them they were in the control group and reminding them of the dates when they will be asked to complete the post intervention measures. To reach the required total number of participants, two sets of workshops were run.

After attending the workshop, the intervention group had additional goal-based outcome measures to complete and were also asked to complete a feedback form on the acceptability of the workshop. All participants were then sent the outcome measures at the two post intervention time points: one-month and three-months following the workshop. Following completion of the three-month outcome measures, those in the control group were sent the workshop materials in a self-help booklet format. As it was low-intensity CBT, they were expected to access the self-help material in the workbook independently. Support on accessing the materials was offered to all of those in the control arm however, no participant expressed a need for this.

#### Measures

Outcome measures were collected using Qualtrics, an online secure data collection platform. Links to complete these were sent via email. Additional reminder emails and phone calls were sent to participants to encourage completion of data.

**Demographic Questionnaire.** A demographic questionnaire was developed for the study following consultations with food allergy researchers (Appendix J). At baseline, participants answered 18 questions about their characteristics including food allergy specific questions such as age of diagnosis and history of anaphylaxis reactions.

Quality of Life. Reported change in the primary outcome, food allergy-related quality of life was measured using FAQLQ-CF: Food Allergy Quality of Life Questionnaire – Child Form ( $\leq$ 12 years) or FAQLQ-TF: Food Allergy Quality of Life Questionnaire – Teenager Form (13-17 years). Caregivers were also asked to fill out FAQLQ-PF: Food Allergy Quality of Life Questionnaire – Parent Form ( $\leq$ 12 years) or FAQLQ-PFT: Food Allergy Quality of Life Questionnaire – Parent Form (13-17 years). The raw FAQLQ scores of 0 to 6 were recoded as 1 ("no impairment") to 7("maximal impairment") as done by Flokstra-de Blok et al. (2008).

*FAQLQ-CF* (Flokstra-de Blok et al., 2009, Appendix K). This includes 24 items regarding the impact on quality of life on a Likert scale from 1 (no impairment) to 7 (extremely impaired). There are four subscales: Allergen Avoidance, Risk of Accidental Exposure, Emotional Impact, and Dietary Restrictions. The measure has strong internal consistency (Cronbach's alpha=0.94) and cross-sectional validity (Flokstra-de Blok et al., 2009).

*FAQLQ-TF* (Flokstra-de Blok et al., 2008, Appendix L). This includes 23 items regarding the impact on quality of life on a Likert scale from 1 (no impairment) to 7 (extremely impaired). There are three subscales: Allergen Avoidance and Dietary

Restrictions, Risk of Accidental Exposure, and Emotional Impact. FAQLQ-TF has excellent internal consistency (Cronbach  $\alpha = .92$ ), good construct validity and can discriminate between young people who differ in the number of food allergies. In addition, it shows convergent/discriminant validity which highlights the importance of having a disease-specific measure of quality of life for young people with food allergies (Flokstra-de Blok et al., 2008).

*FAQLQ-PF* (DunnGalvin et al., 2008, Appendix M) includes 30 questionnaire items that are scored on a seven-point Likert scale from 1 (no impact on QoL) to 7 (extreme impact on QoL). Subscales address general emotional impact, food anxiety and social and dietary limitations. It is sensitive to change and has excellent longitudinal reliability and validity in a food-allergic patient population (DunnGalvin et al., 2010).

*FAQLQ-PFT* (Hamp et al., 2008, Appendix N) includes 27 items scored on a sevenpoint Likert scale from 1 (no impact on QoL) to 7 (extreme impact on QoL). Within this study, this measure had excellent internal constancy with this population (Cronbach's  $\alpha$  = .91).

Levels of Worry and Coping Skills. General levels of worry were assessed using the Penn State Worry Questionnaire for Children (PSWQ-C; Chorpita et al., 1997, Appendix O). Which assesses general characteristics of worry in children and young people aged 7 to 17. The 14 items are rated using a self-report 4-point Likert rating scale from 0 (never) to 3 (always) with three questions reverse scored. Summed together, the total score ranges from 0-42 with higher scores indicating higher levels of worry. The measure has demonstrated favourable psychometric properties (Cronbach  $\alpha = 0.89$ ) in a large community sample with high convergent and discriminative validity (Chorpita et al., 1997).

The Coping Strategies Inventory (CSI; Tobin, 1991, Appendix P) assesses coping thoughts and behaviours in response to a specific stressor. A 32-item shortened version was developed from the highest factor loadings and best alpha coefficients from the original 72-item version.

The shortened version correlates well with other measures of children's coping and has been used often in paediatric literature. The subscales are categorized into engagement strategies (approach related actions that are viewed as limiting long-term psychological and physiological impact of stressors) and disengagement strategies (avoidance of stressors to produce desirable short-term effects but lead to long-term problems). The internal consistency estimates for this scale ranged from .70 to .94 and test-retest reliability within stressor of r=.67-.83 (Blount et al., 2008). Within the current study, this measure continued to have good internal constancy with this population (Cronbach's  $\alpha = .81$  to .83).

Adherence to Food Allergy Specific Self-Care Behaviours. To understand food allergy specific adaptive behaviours, a self-care scale from Jones et al. (2013) was used (Appendix Q). Responses are measured on a 5-point scale anchored 1 (never true) and 5 (always true), with higher scores representing greater adherence (Cronbach's  $\alpha$  =.65).

**Goals Based Outcome Measure.** After completing the workshop, participants were sent a Qualtrics link to complete their goals and goal-based outcomes (Adapted from Law & Jacob, 2013, Appendix R) which were revisited at the one-month and three-month follow-up. They were asked to identify up to three goals and rate them in accordance with how close they are to achieving it from 0 (no progress towards goal) to 10 (goal has been reached fully). This measure was developed from the belief that the most important measure of change is that which the young person has chosen to make themselves (Law and Jacob, 2015).

**Feedback on Workshop.** A 10-item questionnaire was developed to collect participant feedback on the workshop after it was completed (Appendix S). The questionnaire consisted of a mix of Likert scale responses (e.g. How much do you agree or disagree with the statement '*Support for managing anxiety for young people with food allergies is useful*'?) and open-ended questions (e.g., What part(s) of the group did you find most useful?) where participants could report their views of the workshop and tell the researcher about their

thoughts on the content and delivery. The questionnaire was developed based on previous feedback forms including those looking at change following taking part in therapy (Elliott & Rodgers, 2008; Ruffles et al., 2020).

### **Public Patient Involvement (PPI)**

Before starting to design the intervention, the researcher attended the Anaphylaxis Campaign group conference for support group leaders. This provided up-to-date information on what the charity was doing and what they planned to do, as well as the opportunity to talk with the parents and speakers at the conference about what is missing in terms of support for young people with allergies.

Following this, the content of the workshop was created in consultation with members of the Anaphylaxis Campaign support groups which included both parents and young people. This influenced the intervention development to ensure the specific expereiences of young people with food allergy was represented and the language was deemed accessible. During the charity's 'Anaphylaxis Awareness Week' the researcher presented a webinar on managing wellbeing in relation to food allergy which resulted in further understanding of the need for psychological support in this population.

### The Intervention

Building on the previous research, the intervention was based on principles from CBT. The course was designed to be delivered as 'low-intensity' and to give young people various strategies to take away to try themselves after. The workshop was facilitated by two trainee clinical psychologists with the allocated trainee researching the client group taking the lead on facilitating the workshop, supported by a trainee researching caregivers of those with food allergies or adults with food allergies.

The intervention consisted of two three-hour workshops delivered over an online platform. Paediatric psychology services in response to COVID-19 restrictions have shown that groups can be successfully transferred online if sufficient thought and creativity are involved in the preparation (Flannery et al., 2021). The workshop was facilitated alongside a PowerPoint which provided opportunities for demonstrations, polls, and group discussions. All participants also received the corresponding workbook and extra worksheets which had the content of each part along with exercises and space to make notes. In creating the workbook, attention was given to ensure they were clear and in accessible language to the target age group. The workshop content was based on strategies researched to be effective for anxiety and developed under supervision of a reader in health psychology and a clinical psychologist specialising in CBT. The content is summarised in Table 2 below.

#### Table 2

Workshop Parts	Focus of Session
Day 1	
Part 1: Cognitive Behavioural	• Introduction to CBT and understanding the idea that our thoughts, physical symptoms, and
Therapy (Based on Padesky &	behaviour can all influence one another and therefore contribute to keeping unbeloful
Mooney, 1990)	feelings, such as anxiety, going.
	Using an example to demonstrate the CBT 5- area model.
Part 2: Psychoeducation on	• Normalising the experience of anxiety, including explaining its role as a helpful survival
Anxiety	mechanism.
(Based on Farrand, 2020)	• Introduction to parts of the brain involved in anxiety: survival brain, emotional brain and thinking brain. Explaining the 'fight or flight' response and considering what situations may trigger this.
	• Venn diagram of the overlap between the physical symptoms of anxiety and food allergy,

Content of the Workshop and Corresponding Workbook

Part 3: Worry and the Worry Tree ( <i>Based on Butler &amp; Hope, 2007;</i> <i>Stallard, 2019</i> )	<ul> <li>whilst highlighting the importance of following a safety plan if a symptom is 'tricky' or confusing (Albert, 2019).</li> <li>Explaining the CBT skills help us to experience anxiety at a manageable level using a scale from 0% of the time worrying to 100%.</li> <li>Explanation of the difference between hypothetical and practical worries, using food allergy related examples.</li> <li>The worry tree and a case example to demonstrate how it can be used.</li> <li>How to let practical worries go: worry time, worry notepad, distraction, mindfulness and visualisation.</li> <li>Practical problem solving to find solutions (D'zurilla &amp; Goldfried, 1971).</li> </ul>
Day 2	
Part 4: Negative Thinking	• Negative automatic thoughts can influence what
(Based on Greenberger & Padesky,	so being able to recognize and identify our negative thoughts is the first step towards not
2016; Stallard, 2019)	<ul> <li>Negative thoughts is the first step towards not letting them impact how we feel as much.</li> <li>Negative thinking styles in relation to food allergy including black and white thinking, prediction, mind reading and more.</li> <li>How to overcome them: tracking, recognising thinking styles and coming up with a more balanced thought.</li> <li>Using an example to consider how to come up with a more balanced, alternative thought.</li> <li>Noticing the positives by considering our</li> </ul>
Part 5: Assertiveness	<ul> <li>Normalising that young people may find it</li> </ul>
(Based on Beaumont & Welford,	<ul><li>difficult to talk to others about their allergy.</li><li>Discussion of the difference between passive and</li></ul>
2020)	assertive communication. Explaining different tips to communicate assertively and using these to create an 'assertive script' to explain their allergy others.
	• Top tips for ordering an allergy-safe takeaway from #SpeakUpForAllergies campaign (Food Standards Agency, 2021).
Part 6: Behaviour	• Explaining the relationship between avoidance and anxiety.
(Based on Clark & Salkovskis,	<ul> <li>Safety behaviours: those which are helpful in managing food allergy and unbeloful in</li> </ul>
2009)	managing anxiety.

•	• Using graded exposure to help break the cycle of
	avoidance in manageable steps. Using case
	examples to create fear ladders.
Part 7: Relaxation	• Relaxation helps us to generally feel calm and
	can also help when we feel anxious to prevent
(Based on Stallard, 2019)	being caught up in the vicious cycle of worry.
•	• Demonstration of techniques including relaxed
	breathing, balloon breathing, square breathing,
	and progressive muscle relaxation.
•	• Grounding techniques help to 'step back' from
	the anxiety and bring our focus back into the
	present moment. Demonstration of the 5,4,3,2,1
	technique and how to make a more personalised
	box of grounding ideas.
Part 8: Bringing it all Together	• Summarising the content and asking them to
	consider what they would like to change or
(Based on Brosan et al., 2013)	techniques they would like to try.
•	• Explanation of SMART goals and how to turn
	techniques from the workshop into both short-
	term and long-term SMART goals.
	• Considering obstacles and booking in reviews of
	goals.

# Ethical Considerations

The workshops were always run by two facilitators to provide support in managing group dynamics and participant distress if it were to arise. All participants were also provided with support resources as well as having the email for the lead researcher and reminded that if they had any questions or concerns, they could get in contact. Additional reminders were given to workshop participants to maintain the confidentiality of others within the group.

All data collection and storage adhered to the Data Protection Act (2018) and the General Data Protection Regulation (GDPR) principles (Spencer & Patel, 2019). In addition, from the design to the writing of this study, the British Psychological Society Code of Human Research Ethics was followed so that it was in line with the principles of ethical human research (Oates, 2021).

## Analysis Strategy

**Feasibility of the Workshop.** In line with expected practice for feasibility studies, descriptive statistics for the intervention and control group are presented alongside demographic information (Eldridge et al., 2016). The recruitment rates, retention rates and any reasons that were gathered for dropping out of the study are presented.

**Preliminary Efficacy.** Quantitative data gathered from baseline, one-month and three-month post intervention was analysed. Given the feasibility approach, significance testing was not undertaken as it was not the aim of the study. Scores on the outcome measures are presented in terms of means and standard deviations. The mean change scores over time were calculated for both follow-up points compared to the baseline scores as baseline differences between intervention and control groups varied significantly (PSWQ: t(45) = 2.23, p=0.03). The differences in mean change scores between the intervention and control group were analysed and Hedge's g effect size was calculated with 95% Cis; values of 0.2, 0.5 and 0.8 were considered small, medium, and large, respectively (Cohen, 1988). Hedge's g was chosen over Cohen's d effect size given the sample sizes varied across the time points due to participant completion. For the goal-based measure, trends of change from baseline to follow-up are detailed.

Acceptability of the Workshop. Quantitative data from the feedback questionnaire were presented as frequencies. The written comments from the open questions were analysed using content analysis guided by Erlingsson and Brysiewicz (2017). Inductive content analysis was chosen as it can be used to summarise the content of written material to make numerical comparisons with relative ease across all the feedback given (Patton, 1990). The qualitative data from each question was merged and statements that related to the acceptability of the workshop were extracted as codes. These codes were then organised into subcategories and following this into categories which related to different aspects of

acceptability. If a participant said something that fell into the same subcategory multiple times, this was only counted once within the sub-category.

## Results

### **Participants**

Recruitment took place from January to July 2021. In this time, ninety-three young people or their parents contacted the researcher for further information on the study. Despite both parents and the young person being invited to the screening calls, there was only a few instances where the young person was present. Exclusion from screening occurred if they did not respond to the researcher, did not meet inclusion criteria (Table 1), were not UK-based or the young person did not want to take part after the parents expressed interest on their behalf. Following the screening calls, fifty-two participants completed consent forms for the research. Of these, twenty-six were allocated to the control and intervention groups respectively.

In the control group, six (23%) did not complete baseline questionnaires in full but three completed them partially which provided demographic information. Within the intervention group, all completed their baseline questionnaires: two participants (8%) could not attend the workshop, two participants (8%) dropped out either during or after part one of the workshop after expressing that they were not anxious, and three (12%) did not attend with no further contact. As 19 engaged with both parts of the workshop, this meant that 73% completed the treatment as a feasibility indicator.

Twenty of the control participants were sent the questionnaires at the follow-up time points and 17 (85%) completed the one-month questionnaires and 18 (90%) completed the threemonth questionnaires. Nineteen of the workshop participants were sent the questionnaires at

the follow-up time points and 17 (89%) completed both the one-month and three-month questionnaires. The questionnaires were sent out via email and almost all participants required a reminder to complete the questionnaires after a week of receiving them (either via email or telephone call). Some participants needed numerous reminders ( $\leq$  5) and clinical judgement was used to determine how many were appropriate. Of those that attended the workshop, all were sent the feedback questionnaire and 15 (79%) completed this. Figure 1 illustrates the number of participants at each stage of the research and data collection presented in a CONSORT flow diagram (Eldridge et al., 2016).

## Figure 1

CONSORT Diagram



# **Demographic Data**

Fifty-two participants were recruited between the age of 11 and 17. Table 3 shows the

demographic data for those that completed this baseline information, which included twenty-

six in the intervention group and twenty-three in the control group.

### Table 3

	Whole Sample (N=49)	Control (N=23)	Workshop Intervention (N=26)
Gender, $n$ (%)			
Female	32 (65)	13 (57)	19 (73)
Male	15 (31)	10 (44)	5 (19)
Non-binary / third gender	1 (2)	0 (0)	1 (4)
Prefer not to say	1 (2)	0 (0)	1 (4)
Ethnicity, <i>n</i> (%)			
White	39 (80)	19 (83)	20 (77)
Asian or Asian British	3 (6)	3 (13)	0 (0)
Black, African, Caribbean or	0 (0)	0 (0)	0 (0)
Black British Minod on Multiple Ethnic	$\zeta(12)$	1 (4)	5 (10)
	0(12)	1 (4)	5 (19)
Fijian	1 (2)	0 (0)	1 (4)
- 1,1411	1 (2)	0(0)	1 (1)
Age, Median (IQR)	13 (3)	13 (2)	13.5 (4)
Approximate age of Diagnosis	1 (4)	2(4)	1 (5)
in years, Median (IQR)			
Number of Siblings, Median	1(1)	1(1)	1(1)
(IQR)			
Number of food allergies,	3 (4)	3 (3)	3 (4)
Median (IQR)			
Nut, <i>n</i> (%)	45 (92)	19 (83)	26 (100)
Milk, <i>n</i> (%)	17 (35)	9 (39)	8 (31)
Egg, <i>n</i> (%)	22 (45)	9 (39)	13 (50)
Wheat, <i>n</i> (%)	5 (10)	3 (13)	2 (8)
Soya, <i>n</i> (%)	5 (10)	2 (9)	3 (12)
Sesame, $n$ (%)	13 (27)	5 (22)	8 (31)
Fish, <i>n</i> (%)	8 (16)	3 (13)	5 (19)
Shellfish, <i>n</i> (%)	6 (12)	2 (9)	4 (15)
Fruits, <i>n</i> (%)	8 (16)	2 (9)	6 (23)
Previous Psychological	19 (39)	10 (44)	9 (35)
Support, $n(\%)$			
Other physical health	28 (57)	13 (57)	15 (58)
conditions, <i>n</i> (%)			

Demographic Data for the Control and Intervention Groups

Have a EpiPen for their food	48 (98)	22 (96)	26 (100)
allergy, <i>n</i> (%)			
Have an Anaphylaxis	43 (88)	20 (87)	23 (89)
management plan, n (%)			
Used EpiPen trainer device, n	44 (90)	20 (87)	24 (92)
(%)			
Received training to use	47 (96)	22 (96)	25 (96)
EpiPen, $n$ (%)			
Wouldn't leave house without	43 (88)	21 (91)	22 (85)
EpiPen, $n$ (%)			
Had to use EpiPen, $n$ (%)	13 (27)	4 (17)	9 (35)
Had EpiPen administered by	16 (33)	5 (22)	11 (42)
someone else, $n$ (%)			
Been to hospital with an	35 (71)	16 (70)	19 (73)
allergic reaction to food, <i>n</i> (%)			
Had an Anaphylaxis Reaction,	36 (74)	16 (70)	20 (77)
<i>n</i> (%)			
Number of Anaphylaxis	1 (2)	1 (3)	1 (2)
reaction, Median (IQR)			

Tests of difference were also performed on baseline characteristics between those who completed the study (n = 37) and those who had not completed and dropped out of the study (n = 12). 'Non-completers' included those who didn't complete the baseline measures in full from the control group (n = 3), those who dropped out or did not attend the workshop in the intervention group (n = 7), and those who did not complete questionnaires at both follow-up time points from both the control and intervention (n = 2). Three additional participants from the control did not complete their baseline information but this included the demographic questionnaires so they could not be compared. Completion rates were not found to significantly differ across the intervention and control groups ( $\chi 2$  (1) = 0.94, p = 1.000). A series of fisher's exact analyses and *t* tests were conducted to assess pre-test differences between completers versus non-completers (Table 4). No significant differences were found on any of the demographics including gender, ethnicity, age, age diagnosed, number of allergies and if they had had an anaphylaxis reaction. Independent sample t tests also showed no significant difference between completers and non-completers on baseline outcome measures that were completed.

#### Table 4

	Completers $(n-37)$	Non-Completers $(n-12)$	P value for difference
Gender $n(%)$	(n-37)	(n-12)	0.42
Fomala	25 (68)	7 (58)	0.42
N-1-	25 (08)	1 (38)	
Male	11 (30)	4 (33)	
Non-binary / third gender	1 (3)	0(0)	
Prefer not to say	0 (0)	1 (8)	
Ethnicity, n (%)			0.77
White	29 (78)	10 (83)	
Asian or Asian British	3 (8)	0 (0)	
Black, African, Caribbean or	0 (0)	0 (0)	
Black British			
Mixed or Multiple Ethnic Groups	6 (16)	2 (17)	
Fijian	1 (3)	0 (0)	
Age, Median (IOR)	13 (4)	12.5 (2)	0.07
Approximate age of Diagnosis in years, <i>Median (IQR)</i>	1 (3.5)	1.25 (4)	0.60
Number of food allergies, <i>Median</i> ( <i>IQR</i> )	3 (4)	3 (3)	0.97
Had an Anaphylaxis Reaction, <i>n</i> (%)	29 (78)	7 (58)	0.28

Demographic Data for Study Completers and Non-Completers

# **Preliminary Efficacy**

As there are age-specific FAQLQ measures, the overall means were combined whilst the subscales were analysed separately by age (11-12 years [CF] and 13-17 years [TF]). The intervention demonstrated a medium effect size reduction in impairment in FAQLQ at 1 month (Hedges g = 0.70, 95% CI [0.01, 1.40]) (Table 5). At three months, the effect of the intervention was more prominent (Hedges g = 1.23, 95% CI [0.51, 1.96]).

When looking at the subscales, the change was most evident for those aged 13-17 as the intervention demonstrated a large effect size reduction in impairment in FAQLQ at 3 months (Hedges g = 1.40.95% CI [0.47, 2.34]). The intervention showed large effect size reduction in the subscales of *Allergy Avoidance and Dietary Restriction* (Hedges g = 2.06,95% CI [1.03, 3.10]) and *Emotional Impact* (Hedges g = 1.05,95% CI [0.15, 1.94]). For those aged

11-12, the intervention showed a large effect size reduction in impairment on the subscale of *Dietary Restriction* at 3 months (Hedges g = 1.44. 95% CI [0.19, 2.69]). Although other subscales showed medium to large effect sizes, their confidence intervals crossed zero at the 95% confidence interval, and so did not indicate a signal of efficacy.

The remainder of the measures (PSQW-C & CSI) also had effect sizes that crossed zero. The adherence items appeared to approach ceiling across both groups (Hedges g = 0.28, 95% CI [-0.39, 0.95]).

# Table 5

Descriptive Statistics, Mean Change from Baseline to Follow-Ups, and Effect Size of the Difference Between Intervention and Control Group

	Inte	rvention		Con	trol		Analysis	
	n	M (SD)	Mean observed change from baseline (SD)	n	M (SD)	Mean observed change from baseline (SD)	Mean observed change difference	Hedges g effect size (95%CI)
FAQLQ-CF & FAOLO-TF								
Baseline	26	5.80 (0.73)		21	5.30 (1.26)			
1 month	17	5.37 (0.96)	0.49 (0.68)	17	5.38 (1.07)	-0.07 (0.86)	0.56	0.70 (0.01, 1.40)*
3 month	17	5.16 (0.94)	0.70 (0.68)	18	5.46 (1.14)	-0.19 (0.73)	0.89	1.23 (0.51, 1.96)*
FAQLQ-CF								
Baseline	9	5.97 (0.48)		9	5.00 (1.41)			
1 month	5	5.58 (0.84)	0.28 (0.58)	8	5.34 (1.31)	-0.19 (0.99)	0.47	0.51 (-0.63, 1.64)
3 month	5	5.22 (0.69)	0.66 (0.80)	8	5.32 (1.33)	-0.17 (0.91)	0.83	0.88 (-0.29, 2.05)
FAQLQ CF AA								
Baseline	9	6.02 (0.72)		9	5.00 (1.65)			
1 month	5	5.57 (1.16)	0.17 (0.82)	8	5.50 (1.66)	-0.34 (1.16)	0.51	0.45 (-0.68, 1.58)
3 month	5	5.23 (0.87)	0.51 (1.06)	8	5.38 (1.50)	-0.21 (1.16)	0.73	0.60 (-0.54, 1.75)
FAQLQ CF RAE								
Baseline	9	5.82 (0.52)		9	5.22 (1.58)		a <b>1-</b>	
1 month	5	5.12 (0.27)	0.52 (0.61)	8	5.38 (1.12)	0.05 (0.96)	0.47	0.51 (-0.62, 1.65)
3 month	5	4.88 (1.24)	0.80 (1.41)	8	5.35 (1.38)	0.08 (0.97)	0.73	0.58 (-0.56, 1.72)
FAQLQ CF EI	0	(15 (0 (2)))		0	5 15 (1 50)			
	9	0.15(0.03)	0.27(0.50)	9	5.15(1.59)	0.17(1.05)	0.20	0.21(0.01, 1.22)
1 month	5	5.90 (0.89)	0.37(0.30)	ð	5.23(1.43)	0.17(1.05) 0.25(1.02)	0.20	0.21 (-0.91, 1.33)
	3	5.77 (0.79)	0.0 (1.21)	0	5.15 (1.05)	0.23 (1.02)	0.55	0.50 (-0.85, 1.42)
Receive	0	5 87 (0 50)		0	1 67 (1 35)			
1 month	5	5.67 (0.50)	0.13(1.00)	8	4.07(1.55) 5 23 (1.45)	0.56(1.07)	0.70	0.62(0.52, 1.76)
3 month	5	4.93(1.23)	0.13(1.00) 0.77(1.05)	8	5.23(1.43) 5 40 (1 50)	-0.30(1.07)	1 50	1 44 (0 19 2 69)*
	5	1.95 (1.12)	0.77 (1100)	0	5.10 (1.50)	0.75 (0.91)	1.00	1.11 (0.1), 2.0))
Raseline	17	5 71 (0.83)		12	5 52 (1 56)			
1 month	12	5 28 (1 03)	0.58(0.72)	9	5 42 (0 90)	0.04(0.76)	0.54	0.70(-0.19, 1.59)
3 month	12	5 14 (1 06)	0.50(0.72) 0.72(0.66)	10	5 58 (1.03)	-0.21(0.61)	0.93	1 40 (0 47 2 34)*
FAOLO-TF AADR	12	5.11 (1.00)	0.72 (0.00)	10	5.50 (1.05)	0.21 (0.01)	0.95	1.10 (0.17, 2.51)
Baseline	17	5.97 (0.83)		12	5.78 (1.14)			
1 month	12	5.32 (1.14)	0.74 (0.92)	9	5.68 (0.97)	0.01 (0.54)	0.73	0.90 (-0.01, 1.81)
3 month	12	5.22 (1.08)	0.88 (0.54)	10	5.77 (1.06)	-0.12 (0.36)	1.00	2.06 (1.03, 3.10)*
FAQLQ-TF EI			, , ,					· · · · ·
Baseline	17	5.42 (1.03)		12	5.07 (1.11)			
1 month	12	5.26 (1.21)	0.21 (0.57)	9	5.16 (0.96)	-0.13 (1.03)	0.34	0.41 (-0.46, 1.28)
3 month	12	4.93 (1.19)	0.5 (0.66)	10	5.36 (1.13)	-0.43 (1.04)	0.93	1.05 (0.15, 1.94)*
FAQLQ-TF RAE								
Baseline	17	5.37 (0.97)		12	5.51 (1.57)			
1 month	12	5.25 (1.10)	0.5 (0.92)	9	5.30 (1.04)	0.24 (1.19)	0.26	0.24 (-0.63, 1.11)
3 month	12	5.25 (1.28)	0.49 (1.09)	10	5.52 (1.39)	-0.18 (1.12)	0.67	0.58 (-0.27, 1.44)
FAQLQ Parent								
Baseline	26	5.54 (0.75)		20	5.14 (1.13)			
1 month	18	5.49 (1.11)	0.06 (0.99)	17	5.32 (1.12)	-0.22 (0.62)	0.27	0.32 (-0.35, 0.99)
3 month	19	5.12 (1.10)	0.48 (0.77)	18	4.98 (1.39)	0.17 (0.68)	0.31	0.42 (-0.23, 1.07)
PSWQ								
Baseline	26	28.27 (9.25)		21	22.62 (7.85)			
1 month	17	25.59 (8.08)	1.06 (4.16)	17	22.76 (6.94)	0.29 (5.1)	0.76	0.16 (-0.51, 0.83)

3 month	17	25.41 (7.94)	3.00 (4.89)	18	24.28 (8.61)	-1.06 (6.74)	4.06	0.67 (-0.01, 1.35)
CSI Engagement								
Baseline	26	40.42 (10.02)		20	36.05 (12.45)			
1 month	17	47.65 (13.73)	-6.00 (10.62)	17	40.82 (14.65)	-4.71 (13.95)	-1.29	-0.10 (-0.77, 0.57)
3 month	17	45.71 (16.29)	-3.71 (16.00)	18	38.83 (16.54)	-3.22 (19.20)	-0.48	-0.03 (-0.69, 0.64)
CSI Problem Solving								
Baseline	26	9.42 (4.20)		20	9.55 (4.30)			
1 month	17	12.59 (5.12)	-2.00 (5.84)	17	10.82 (4.85)	-1.00 (3.97)	-1.00	-0.20 (-0.87, 0.48)
3 month	17	12.26 (5.21)	-1.94 (5.64)	18	9.78 (4.68)	-0.22 (5.16)	-1.72	-0.31 (-0.98, 0.36)
CSI Cognitive								
Restructuring								
Baseline	26	8.65 (2.90)		20	8.30 (3.34)			
1 month	17	10.88 (3.97)	-2.29 (2.97)	17	9.82 (4.25)	-1.47 (3.34)	-0.82	-0.25 (-0.93, 0.42)
3 month	17	10.53 (4.35)	-1.65 (4.68)	18	9.94 (4.87)	-1.67 (5.12)	0.02	0.00 (-0.66, 0.67)
CSI Express								
Emotions								
Baseline	26	10.19 (3.95)		20	8.55 (3.44)			
1 month	17	10.71 (4.10)	-0.88 (5.38)	17	9.06 (3.53)	-0.76 (3.29)	-0.12	-0.03 (-0.70, 0.65)
3 month	17	10.59 (4.26)	-0.76 (3.83)	18	8.78 (4.44)	-0.39 (5.39)	-0.38	-0.08 (-0.74, 0.59)
CSI Social Contact								
Baseline	26	12.15 (5.25)		20	9.65 (4.85)			
1 month	17	13.47 (5.25)	-0.82 (4.11)	17	11.12 (5.02)	-1.47 (7.37)	0.65	0.11 (-0.57, 0.78)
3 month	17	12.35 (5.34)	0.65 (6.42)	18	10.33 (5.18)	-0.94 (7.66)	1.59	0.22 (-0.45, 0.88)
CSI Disengagement								
Baseline	26	41.54 (8.82)		20	41.45 (14.19)			
1 month	17	36.94 (13.39)	6.24 (10.90)	17	42.06 (14.86)	-1.35 (11.60)	7.59	0.66 (-0.03, 1.35)
3 month	17	39.24 (14.50)	4.29 (13.50)	18	41.67 (11.55)	0.50 (13.30)	3.79	0.28 (-0.39, 0.94)
CSI Problem								
Avoidance								
Baseline	26	8.69 (3.70)		20	9.35 (4.42)			
1 month	17	9 82 (3 50)	-0.76(3.91)	17	11 18 (4 59)	-1 71 (4 87)	0.94	0 21 (-0 47 0 88)
3 month	17	9 29 (3 92)	-0.65(3.51)	18	10.78 (3.46)	-1 11 (4 89)	0.46	0.21(-0.56, 0.77)
CSI Wishful	17	).2) (3.)2)	0.05 (5.50)	10	10.70 (3.10)	1.11 (1.05)	0.10	0.11 ( 0.50, 0.77)
Thinking								
Baseline	26	14.00 (4.53)		20	13.15 (3.96)			
1 month	17	12 00 (5 33)	2 24 (5 62)	17	13.06 (5.32)	-0.24 (4.60)	2 47	0 47 (-0 21 1 15)
3 month	17	12.00(5.05) 12.35(5.05)	1.88(6.05)	18	12 61 (4 33)	0.44(4.54)	1 44	0.17 (0.21, 1.13) 0.26 (-0.40, 0.93)
CSI Self Criticism	17	12.35 (3.05)	1.00 (0.05)	10	12.01 (1.55)	0.11(1.51)	1.11	0.20 ( 0.10, 0.93)
Basalina	26	8 02 (4 21)		20	8 35 (4 00)			
	20	8.92 (4.21) 7.04 (4.44)	200(2(4))	20	8.33 (4.09)	0.50(2.02)	2.50	0(7(0)) 0 12()
1 month	17	7.94 (4.44)	2.00 (3.64)	1/	8.70 (5.49)	-0.59(3.92)	2.59	0.67 (-0.02, 1.36)
3 month	1/	9.47 (5.60)	1.00 (4.81)	18	7.94 (4.07)	0.67 (4.45)	0.33	0.07 (-0.59, 0.73)
CSI Social								
Withdrawai	26	0.02 (2.20)		20	10 (0 (5 20)			
Dasenne	∠0 15	9.92 (3.39)	0.04 (1.10)	20	10.00 (3.39)	1 10 // /*	1.50	
1 month	17	7.18 (3.61)	2.76 (4.10)	17	9.12 (4.27)	1.18 (4.49)	1.59	0.36 (-0.32, 1.04)
3 month	17	8.12 (3.22)	2.06 (4.18)	18	10.33 (5.64)	0.50 (6.38)	1.56	0.28 (-0.39, 0.95)
Adherence items								
Baseline	26	4.70 (0.33)		21	4.52 (0.51)			
1 month	17	4.54 (0.47)	0.21 (0.43)	17	4.24 (0.53)	0.33 (0.67)	0.33	0.07 (-0.59, 0.73)
3 month	17	4.72 (0.40)	0.04 (0.37)	18	4.63 (0.38)	-0.10 (0.39)	1.56	0.28 (-0.39, 0.95)

\*Indicates confidence interval that does not contain the value 0.

Note:

- *FAQLQ* Food Allergy Quality of Life Questionnaire, *CF* Child Form, *TF* Teenage Form, *AA* Allergen Avoidance, *RAE* Risk of Accidental Exposure, *EI* Emotional Impact, *DR* Dietary Restrictions (for all FAQLQs, higher scores indicate more impaired quality of life). *PSWQ* Penn State Worry Questionnaire Child Form (higher scores indicate higher levels of worry). .
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- *CSI* Coping Strategies Inventory. More adaptive coping is achieved by higher scores on engagement (problem solving, cognitive restructuring, express emotions & social contact) and lower scores on disengagement (problem avoidance, wishful thinking, self-criticism, social withdrawal).
- Adherence items Adherence to food allergy specific self-care behaviours (higher scores suggesting greater adherence out of 5).

# Goal Based Outcomes

Where a young person gave more than one goal (maximum three), the average rating across these goals is given (Table 6). Goals generally were either specific skills from the workshop they wanted to put into practice or around feeling more confident and independent in managing their allergies. Specific skills goals included: 'To use the worry tree when I feel anxious to identify whether worries are hypothetical or practical and help let worries go', 'allocate a 'worry time' in the afternoon after school to reflect on allergy anxiety', 'create an assertive script to tell waiters in a restaurant about my allergies', 'identify and reduce negative thinking patterns', 'to practise breathing techniques and grounding exercises every evening to feel more relaxed and calm generally, and also when dealing with stressful situations'. Goals more generally on feeling more confident in the management of their allergy included: 'be more assertive and speak up more about allergies so that I feel more confident and safe', 'to be more open about my allergies around friends', 'travel without my parents', 'try new restaurants', 'learn how to confidently cook allergy friendly food'. As can be seen below, there was a general tendency for young people to rate themselves as being closer to achieving the goals they set at the one-month time point, which was either maintained or improved upon at three months.

#### Table 6

Young Person	<b>Post</b> <b>Workshop</b> (Out of a possible 10)	<b>1 Month</b> (Out of a possible 10)	Trend in Score	<b>3 Months</b> (Out of a possible 10)	<b>Trend in Score</b> (From most recent score)
1	6.33	7.00	Improved +0.67	10.00	Improved +3.00
2	4.33	8.67	Improved +4.33	9.00	Improved +0.33
3	5.00	7.00	Improved +2.00	8.00	Improved +1.00
4	7.00	7.00	No Change	7.00	No Change
5	4.00	4.67	Improved +0.67	6.33	Improved +1.67
6	6.00	6.50	Improved +0.50	9.50	Improved +3.00
7	3.00	4.00	Improved +1.00	7.00	Improved +3.00
8	5.00	6.67	Improved +1.67	7.33	Improved +0.67
9	7.00			8.33	Improved +1.33
10	0.00	4.33	Improved +4.33	7.00	Improved +2.33
11	1.00	5.00	Improved +4.00	10.00	Improved +5.00
12	6.00	8.00	Improved +2.00		N/A
13	1.00	9.00	Improved +8.00	9.00	No Change
14	2.67	6.67	Improved +4.00	7.67	Improved +1.00
15	1.50	5.00	Improved +3.50	6.50	Improved +1.50
16		2.67	N/A	8.00	Improved +5.33
17		0.00	N/A	7.50	Improved +7.50
18		6.00	N/A		
19			N/A	8.67	N/A
Average	3.99	5.77	Improved +2.62	8.05	Improved +2.29

Goal Based Outcome Scores for Intervention Participants Over Time

# Feedback on Acceptability

Ratings of acceptability for the workshop were completed by 15 out of the 19 that attended the workshop (Table 7). Overall, the feedback suggested that all either somewhat or strongly agreed that support for managing anxiety for young people with food allergies is useful. The ratings suggest that, to some degree, those that completed the workshop, found it to be beneficial and supportive and most felt it helped manage worry/anxiety in relation to food allergy. One participant who rated 'neither agree nor disagree' also stated they felt they
already knew the information from the workshop, which could be why they did not feel like it

provided any additional information on managing food allergy related anxiety.

Finally, 12/15 rated that they would be likely to continue to use the information and skills

they had gained from the workshop.

### Table 7

Ratings of Acceptability of the Workshop

How much do you agree or disagree with the statement 'Support for managing anxiety for young people with food allergies is useful'?

Strongly Agree	Somewhat Agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
73% (11)	27% (4)	0%	0%	0%

Acceptability ratings for the workshop: Please indicate how strongly you agree or disagree with each of the following statements. In general, I found taking part in the group workshop...

Beneficial	Strongly Agree	Somewhat Agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
	40% (6)	60% (9)	0%	0%	0%
Supportive	Strongly Agree	Somewhat Agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
	73% (11)	27% (4)	0%	0%	0%
Enjoyable	Strongly Agree	Somewhat Agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
	27% (4)	40% (6)	33% (5)	0%	0%
Helped you manage worry/anxiety in relation	Strongly Agree	Somewhat Agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
to your roou allergy	40% (6)	53% (8)	7% (1)	0%	0%

How likely are you to continue to use information / skills that you gained from the workshop (e.g. worry management strategies) going forwards?

Extremely	Somewhat	Neither likely	Somewhat	Extremely
likely	likely	nor unlikely	unlikely	unlikely
47% (7)	33% (5)	13% (2)	13% (1)	

Content analysis identified codes which were extracted from the data set as a whole which were organised into 23 subcategories and four subsequent wider categories based on the acceptability of the workshop (Table 8). The most common positive feedback was that the workshop was useful, and they wouldn't change the content or how it was presented. After this, helpful aspects included using examples of how to apply the strategies to allergy related situations and normalising their experiences. The most common skill that young people took away from the workshop was a general understanding of anxiety and how to manage it. Following this, they reported the distinction between hypothetical and practical worries using the worry tree was beneficial. Future considerations were most commonly around the length of the workshop in terms of either having shorter sessions or more breaks. In addition, it was highlighted that it would have been helpful to have a separate group for older teenagers where they could discuss activities more relevant to them such as drinking, dating etc. Finally, there were a few items that were categorised into 'not helpful' which appeared to be more of an individual experience and so may be useful to consider in future screening or planning of the workshop.

#### Table 8

Categories	Subcategories with examples	Frequency
Positive Feedback	No part of the group wasn't useful	9
	I think all can be used appropriately and can be worked on for in	
	the future.	
	No change to group content / presentation	8
	It was clearly presented and lots of detailed slides and good	
	interaction skills.	
	Examples used in workshop useful	5
	Showing examples of dealing with allergy anxieties.	
	Normalising	5
	It demonstrated that we were not alone and sharing experiences in	
	itself was helpful.	
	Helpful	4
	I also really liked how well everything was explained and how	
	friendly it was. It has helped me a lot.	
	Length and timing ok	4
	Perfect timing and I found the length of the group just right.	

Content Analysis of Intervention Participant Responses to Feedback Questionnaire

	Breaks helped engagement	2
	I found the sessions long however having the breaks made it more	
	enjoyable and easier to help concentrate.	
	Interactive	2
	I think the polls are really good and keep us interactive.	
Skills Taking Away	Understanding and managing worries (worry toolbox)	9
from Workshop	The focus on developing coping mechanisms to deal with anxiety	
	around our allergies.	
	Worry tree (hypothetical and practical worries)	8
	trying to come up with practical things I can do to reduce my risk of	
	an allergic reaction in situations I can control, and noticing when	
	I'm stressed out and about when there's nothing I can really do.	
	Relaxation & Grounding	5
	The methods to relax like the balloon breathing method and muscle	
	relaxation.	
	Negative Thinking Styles	5
	Having negative thinking styles explained.	
	Assertiveness	3
	Being assertive about allergies.	
	Distraction	2
	Some distraction techniques.	
	Writing worries down	2
	Keeping a worry journal.	
Future	More, shorter sessions	5
Considerations	Shorter and more sessions as it can get tiring nearing the end.	
	More Breaks	3
	I think I would also have benefitted from more frequent breaks just	
	to make sure I'd really taken the content in.	
	In Person	2
	I know there was no way it could have been in person, but I think	
	that would have helped me engage more.	
	Older teens	2
	<i>My anxiety, I think, comes more from situations that are relatively</i>	
	new to me as I'm getting older, such as parties where alcohol may	
	be involved.	
Not Helpful	Similar workshops in school	2
	It was sort of like the thing we do in PSHE at school.	_
	Exposure	1
	Breathing Exercises	1
	Explaining CBT	1
	<i>Explanations at the beginning about cognitive behavioural therapy.</i>	

# Discussion

This study aimed to investigate the feasibility and acceptability of creating a low intensity

CBT-based workshop for young people with food allergies and explore preliminary outcomes

as a signal of efficacy and usefulness of the workshop. The intervention and research were

deemed feasible as recruitment targets were reached with high retention and completion rates of outcome measures for both the intervention and control groups. Food allergy related quality of life improvement in the intervention group provided a signal of efficacy. In addition, the intervention group also demonstrated improvements toward their personalised goals. Feedback on the workshop suggested participants found it to be acceptable.

Regarding feasibility of recruitment, this was successful within the time frame and of those who were screened, the research consent rate (70%) was higher than a similar feasibility study recruiting 15-18-year-olds from a Child and Adolescent Mental Health Service (CAMHS) waiting list to a one-day CBT workshop at 42% (Loucas et al., 2020). This demonstrated there is a need within the community to justify psychological support for young people with food allergies. Attrition occurred across both groups at the baseline stage, with one of the biggest known factors being the dissonance between parents and child motivation. Specifically, parents would report that their child was anxious about their food allergy and/or would want to take part in the study, when in fact their child reported the opposite. Whilst parents report high levels of anxiety around living with food allergy, young people have described anaphylaxis as 'no big deal' and a relatively low impact on their day-to-day lives, with some describing their parents' worry as irritating (Akeson et al., 2007; Stensgaard et al., 2017). In this study, the screening calls typically took place with the parent, with the researcher speaking to the young person on only a few instances before the study, despite this being routinely available as an option. This dissonance may be reduced in future research by making it more of a mandatory part of the screening process that the young person is at least present during the screening calls, so the researcher is aware of how the young person understands what taking part in the research involves.

Although there was attrition at the baseline stage of the study, loss to follow-up remained at an acceptable level as 89% in the intervention and 85% - 90% in the control group returned

their outcome measures. However, this was not without repeated reminders for participants to complete the sets of outcome measures. There was no evidence of differential attrition by group and those that dropped out did not differ significantly on various demographics and baseline outcome measures to those that did not drop out.

The study showed promising preliminary findings for the efficacy of the food allergy specific measure across the follow-up periods. Although this study was small, there was a large effect size for the mean change in reduction of the impact on food allergy related quality of life in the intervention group compared to the control. These results suggest that the workshop was able to support areas previously identified in the literature and provided a signal of efficacy for further similar interventions.

However, regarding the measures of coping and worry, a signal of efficacy was not observed and so the mechanism behind the improvements in quality of life is still in question. As noted by Blount et al. (2008) the full potential for coping measures to yield practical and clinical implications in paediatric psychology is yet to be fully realized. In addition, it may be that levels of worry wouldn't be expected to reduce due to their protective nature in allergy management and there are other mechanisms influencing quality of life (Avery et al., 2003). In parents, it has been acknowledged that self-efficacy in the management of their child's food allergy can explain variance in quality of life and therefore this may have been a more helpful mechanism to measure in young people (Knibb et al., 2016).

Furthermore, the goal-based outcomes showed promising trends as young people felt they were able to meet goals they had set for themselves which included both increasing helpful coping strategies and feeling more confident in managing their allergy. Seeing change in goals a young person sets for themselves is viewed as the most important change, possibly due to the sense of empowerment and self-efficacy it provides (Law & Jacob, 2015). As the

CSI coping measure focuses on a single event, it may be the difference of being able to consider changes in coping as a whole or the more subjective nature of how the strategies are phrased within goal-based outcomes that helped young people to identify change more readily. Finally, both the worry and coping skills measures were not food allergy specific and therefore may not have captured the unique experiences of living with a food allergy. Other food allergy specific measures have been developed for other populations, such as food allergy anxiety scale and COPE inventory for adults (de Holanda et al., 2021, 2022). These were developed as generic instruments do not assess the specific influence of food allergy on anxiety. It was acknowledged that having separate evaluation of the influence of food allergy can improve referrals, target patient education, and improve care. Therefore, young people would also benefit from having measures that could help understand the specific role of food allergy in psychological wellbeing.

Both quantitative and qualitative feedback suggested high levels of acceptability for the intervention as all those that provided feedback agreed that interventions for food allergy and anxiety support is useful and that the workshop was beneficial and supportive. All but one participant agreed that the workshop helped them manage worry in relation to their food allergy and 12 (80%) rated it as likely they will continue to use what they had learnt. As well as taking away specific tools or psychoeducation, another benefit of the workshop was being with other young people with a food allergy and not feeling alone. Normalization is an established benefit of group therapy (Mensenkampff et al., 2015). As young people with food allergy may not have come across others with an allergy, the workshop created a space for them to share similar experiences and individual coping strategies. Those who didn't rate it as likely they would use something they had learnt had expressed that the workshop included content that they had previously come across. This may be something to consider exploring further in future screening so that young people are more aware of what it would involve.

Across the age range, the young people that took part in the workshop felt the content, delivery and presentation of the material was acceptable. However, two participants highlighted that being older and at a stage transitioning to adulthood brings new challenges to navigate such as dating, going to parties with alcohol, and attending university. Although it wasn't the aim of the workshop in this intervention, the Food Allergy Research & Education 'teen corner' highlights the importance of open conversations on these topics and it would be beneficial to explore in future adaptions of the workshop for more specific lifestyle elements (FARE, n.d).

This study took place within the context of the ongoing COVID-19 pandemic, which had a significant impact on the wellbeing of young people as they couldn't attend school, socialise and services providing support were no longer available as they once were (Corr et al., 2021). However, as there was a control condition, this allowed for comparisons between groups and minimised the influence of this on the results of this study. Given the restrictions in place of face-to-face contact, like many mental health support providers within the UK, it was delivered remotely over video instead of in person. Previous research has highlighted video delivered therapy helps to overcome barriers and increase access to psychological interventions (Varker et al., 2019). Psychological services for food allergy are viewed as 'the unmet need' as there are very few specialist services for this population (Knibb et al., 2019). Therefore, delivering this intervention online provided a service to populations where there is currently little available to them and is relevant to the future delivery of healthcare services. The flexibility of the online delivery meant that only two participants couldn't attend due to scheduling conflicts. There was a trade-off between facilitator availability and ensuring that the duration didn't result in 'zoom fatigue' and so two half-day workshops were delivered in this study (Fauville et al., 2021). From the qualitative group feedback, most that attended the workshop found this acceptable with the use of interactive examples, polls and videos aiding

engagement. However, some young people suggested they would have preferred it delivered over more frequent, shorter sessions which would be beneficial to explore the feasibility of future workshops.

To the researcher's knowledge, this is the first study that looked to create a CBT-based intervention for young people with food allergy using a feasibility RCT design. Therefore, a strength is that it adds to a currently very limited evidence base on the acceptability and efficacy of CBT in the context of paediatric food allergy.

#### Limitations

Various methods of data collection were utilised to triangulate as much information as possible on the feasibility, acceptability, and efficacy of the intervention. Although this is primarily a strength, it may have also come with bias from the researcher at interpretation of the findings. This is particularly relevant given the multiple roles the researcher held in also running the workshops. However, these biases were attempted to be actively addressed throughout the research process with the support of peer supervision.

The PSWQ-C was used an outcome measure given its ability to discriminate general anxiety from other anxiety disorders (Pestle et al, 2008). However, unlike the adult version of the measure, there is not a clear cut off for general anxiety and so further research would benefit from measures such as the Revised Children's Anxiety and Depression Scale (Chorpita et al., 2000) which looks at specific aspects of anxiety and low mood. This could aid further understanding of the mechanisms of change and if this relates to a wider psychological profile.

The sample of participants in this study was largely female (65%) and white (80%) and due to the virtual delivery of therapy, it was only available to those with devices at home where they could access the workshop. No demographic differences were observed between those

that dropped out and those who completed the study. A recent systematic review looked at demographic factors associated with anaphylaxis and reported that at  $\geq 10$  years, girls have comparable or even higher rates than boys (Wang et al., 2019). With regards to ethnicity, the true prevalence of food allergy is not known, but a study showed that South Asian Children living in the UK were more likely to have anaphylaxis compared to white children (Buka et al., 2015). In addition, a prospective study found 52.6% of a paediatric allergy clinic to be non-Caucasian and for this group to also have significantly more allergens per child compared to the Caucasian group (Dias et al., 2008). Psychological research having poor inclusion from non-white populations is not new. However, in developing future support for those with food allergy, this is something that needs to be considered to prevent those with higher rates of food allergy not being supported. For ethnically minoritised children of lower socioeconomic status, previous research has shown increased symptoms of social anxiety and anxiety overall (Goodwin et al., 2017). A number of possible explanations could influence the impact of food allergy in children of lower socioeconomic status including schools not having the resources to implement nut free policies, and instead results in the child being isolated; the financial burden of having to have a tailored diet for different family members; having access to resources that improve management of a food allergy. Therefore, in considering future psychological support for young people with a food allergy it is also important to consider the societal barriers in place that prevent a young person from feeling 'safe'.

The guidelines for feasibility studies have progressed since the writing of the protocol for this study and it is common practice to set progression criteria (Mbuagbaw et al., 2019). Guidelines for co-producing criteria for feasibility studies was set out by Young et al. (2019) in a health setting, albeit a different population as their study assessed the feasibility of an exercise intervention for people living with frailty. Their final progression criteria compared

to the results of the current study was promising as the 'GO criteria' of more than 50% of eligible patients recruited and 70% adherence to intervention were met. Accounting for those that dropped out prior to the workshop, the 80% outcome measure completion and less than 20% loss to follow-up criteria were also met. Future feasibility studies would benefit from following the mechanism to set tailored progression criteria.

#### **Directions for Future Research and Clinical Implications**

Regardless of the highlighted limitations, it is clear a workshop based on principles from CBT delivered remotely to young people with food allergy was found to be feasible and acceptable in terms of recruitment, retention, and outcome measure completion. The findings were promising in favour for the intervention and has warranted a larger scale RCT definitive trial to investigate these effects further. Given the impact of COVID-19 on the progression of virtually delivered psychological support, this intervention shows promise as a provision to meet the unmet need of young people with food allergy.

Future research would benefit from addressing some of the methodological limitations of the current study. This includes further careful consideration of intervention mechanisms which could be supported through public patient involvement. In addition, improvements could be made to the screening process by consistently including the young person more directly. As the view of the young person would be identified earlier in the process, it may have a positive influence on attrition throughout the study.

The workshop showed preliminary evidence that it improved food allergy related quality of life and participants were able to work towards personalised goals. However, such promising results were not seen in measures of worry and coping skills, therefore the mechanism for this change is not as clear. Young people with food allergy experience worry and coping in different ways to their peers considering they are faced with the threat of exposure to their

allergen daily. Therefore, it may be that these more general measures do not appropriately capture their unique experiences. As it was acknowledged in the workshop that anxiety is a helpful mechanism to manage food allergy, it may also be that levels of anxiety do not necessarily reduce and other areas such as resilience or self-esteem were improved. Future research would benefit from exploring this further through qualitative understanding of mechanisms of change and development of further measures to capture this.

This study also highlighted additional areas to consider, such as comparing online psychological support to in-person alternatives to further assess the benefits of the lower cost and more easily accessible intervention. Online groups being more widely available benefits young people with chronic health conditions who otherwise may be unable to access their nearest specialist psychological service (Flannery et al., 2021). As meeting others with food allergy was highlighted as a benefit of the workshops, further research using a three-armed trial which compared the workshops, self-help material and control groups could improve understanding of the influence of the CBT material alone compared to the group setting. Further, there is strong evidence in paediatric literature for the benefits of CBT and this is the model that research has focused on for psychological interventions in food allergy. However, there is also growing evidence for third wave cognitive behavioural therapies such as Acceptance and Commitment Therapy (ACT). This includes promoting improved diabetes management in adolescents and increasing engagement in meaningful activities in paediatric chronic pain (Hadlandsmyth et al., 2013; Pielech et al., 2017). Therefore, having a more detailed understanding of the mechanism of positive change would facilitate future new intervention directions.

Of those that completed the qualitative feedback, all found the workshop beneficial and supportive and most were able to take learning away to apply it to their goals. As such, this will have clinical implications as there are currently very few paediatric allergy psychological services within the UK. Given this was a low intensity, manualised CBT intervention it could benefit paediatric allergy teams in the development process of more tailored support for this population. Further research is needed in both community and clinical settings with this client group as psychological support has the potential to have a significant impact on the quality of life of young people with food allergy.

## **Conclusion**

In conclusion, a workshop based on principles from CBT delivered remotely to young people with food allergy was found to be feasible and acceptable. In addition, there is preliminary evidence that it can have beneficial effects on food allergy related quality of life and their individual goals. This contributes to the wider literature which has established the higher levels of worry and impact on quality of life in this population. Further research would benefit from addressing methodological issues as well as understanding more of the mechanisms of change. The findings from this study have warranted a larger scale RCT with a more diverse representation of participants to explore further the potential benefits of psychological support for this population.

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# Appendices

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Please note that identifiable information of the reviewers and supervisors has been redacted.

#### Appendix A

#### **Favourable Ethical Opinion Letter**

# RESEARCH & INNOVATION SERVICES

SURREY.AC.UK/RI



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ethics@surrey.ac.uk www.surrey.ac.uk

Holly Tallentire School of Psychology FHMS

03 November 2020

Dear Holly Tallentire,

#### EGA Ref No: FHMS 20-21 002 FHMS Project Title: Feasibility of a group intervention using Cognitive Behavioural Therapy (CBT) to reduce anxiety for children aged 12-17 with food allergy.

On behalf of the Ethics Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the submitted protocol and final supporting documentation listed in the table below.

Date of confirmation of ethical opinion: 3rd November 2020

This opinion is given on the understanding that you will comply with the relevant University policies, ethical and professional standards and any applicable regulatory requirements, and have completed all mandatory training provided by the University of Surrey.

If the project includes distribution of a survey or questionnaire to members of the University community, researchers are asked to include a statement advising that the project has been reviewed by the University's Ethics Committee.

However, please note all research activity must comply with current University guidance regarding the Covid19 pandemic:

https://www.surrey.ac.uk/coronavirus/research/research-university-ethics-committee-approval

If you wish to make any changes to the Protocol for this project, now or later, other than those permitted in the guidance provided in the above link, you must submit a Notification of Amendment form before any changes can be implemented. Please refer to the Guidance on Amendments which can be found on the Research Integrity and Governance Office webpages. Please note that the governance approval of this project is valid until the study end date provided.

Please be aware that the Committee will need to be notified of any incidents, deviations from protocol or adverse events that may potentially impact the research participants or your data integrity, and if the study is terminated earlier than expected with reasons. You should do this by contacting



ethics@surrey.ac.uk. Please be advised that the Ethics Committee and/or RIGO can audit research projects to ensure that researchers are abiding by the University requirements and guidelines.

This favourable ethical opinion is valid for the duration of the project. If you require an extension to the study end date, you must submit a notification of amendment. Please note that if the study is not completed within five years of the above date, you will be required to submit a new application to the Ethics Committee.

Please notify RIGO (ethics@surrey.ac.uk) when the research has been completed.

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

Document	Version	Date
SAGE ID 514292-514283-64967274	N/A	08 September 2020
Ethics and Governance Application form	1.0	29 September 2020
Queries Letter FHMS 20-21 002 EGA	N/A	29 October 2020
Protocol	3.0	29 October 2020
Data Management Flow Chart	1.0	29 September 2020
Data Management Plan	1.0	29 September 2020
Recruitment Poster	2.0	29 October 2020
Participant Information Sheet (12-17)	2.0	29 October 2020
Participant Information Sheet (caregiver)	2.0	29 October 2020
Parent Guardian Consent Form	2.0	29 October 2020
Consent Form + 16	2.0	29 October 2020
Consent and Assent Under 16s	2.0	29 October 2020
Food Allergy and Anxiety Workbook	2.0	29 October 2020





# Appendix B

# Extract from Notification of Amendment Form

Notification	of Amendment Form	n 🏂	SURREY SURREY	
Expected end date for data collection/participant recruitment	October 2021			
Brief description and reason for amendment		Supporting document(s)		
<ol> <li>Due to four parents of children aged interest to be potential participants. I supervisor, we agreed they would stil appropriate for the study. As at 11 th and so at the same stage development participants (Ages 12-17). Psychologic known to be critical to the development identity formation and so they would content.</li> </ol>	11 years expressing in discussion with my Il benefit and be ey are in key stage 3 ntally with the current cally, this period is ent of friendships and benefit from the	Document: 1. Changed from 12-17 to 11-17 across protocol 2. Recruitment poster 3. Information Sheet	Version & date v6 7/05/2021 v3 7/05/2021 v3 7/05/2021	
Declaration by Chief/ Principal Investigator				
<ul> <li>I confirm that I have read and will com</li> <li>Name of student: Holly Tallentire</li> <li>Signature: Amarca</li> </ul>	ply with the Code on Go	ood Research Practice.		

#### Appendix C

#### **Study Advertisement**



Thank you for your time. Holly Tallentire Trainee Clinical Psychologist

Recruitment Poster V3 7/05/2021 Study Title: Feasibility of a group intervention using Cognitive Behavioural Therapy (CBT) to reduce anxiety for children aged 11-17 with food allergy. This research has been approved by the University of Surrey ethics committee.

## **Appendix D**

### **Participant Information Sheet**

# PARTICIPANT INFORMATION SHEET

**Title of Study:** Feasibility of a group intervention using Cognitive Behavioural Therapy (CBT) to reduce anxiety in children aged 11-17 with a food allergy

University of Surrey Ref: 20-21 002 FHMS

## PLEASE KEEP A COPY OF THIS INFORMATION SHEET FOR YOUR RECORDS

### **Section: Taking Part**

#### **Introduction**

We would like to invite you to take part in a research project. Before you decide whether you would like to take part in this research study, it is important you read this information. Feel free to discuss this study with anyone you would like to, and please ask the research team any questions you have regarding the research study.

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

Research shows us that some young people with food allergies can also experience high levels of anxiety in relation to managing their allergy. The aim and objectives of this study are to evaluate a Cognitive Behavioural Therapy (CBT) based group workshop that has been designed to support young people manage their anxieties in relation to food allergies. We are specifically interested in if CBT tools and techniques can support young people in managing anxieties that come from living with a food allergy and if this can improve quality of life.

#### Who is responsible for this study?

This study is the responsibility of Holly Tallentire at the University of Surrey being supervised by **Example 1**.

#### Why have I been invited to take part?

You are invited to participate in this study because you are between the ages of 11 and 17, have a food allergy and have expressed anxiety in relation to this allergy. Further inclusion criteria for this research are: you should be able to attend the one-day workshop at the University of Surrey to complete the intervention in full (or online); Willing and able to comprehend English and provide assent/consent (this means that you agree to take part in the study). If you are under 16 you will give 'assent' and your parents will give 'consent', whilst if you are 16+ you can give 'consent'.

#### Do I have to take part?

Participation is voluntary and you do not have to take part. We will describe the study in this information sheet and will give you seven days to read this, so you can decide whether you wish to take part in this study. Please contact us if there is anything that is not clear, or if you have any questions, or if you would like more information.

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

If you decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form to confirm your agreement to participate. You will be given a copy of this consent form to keep.

If you choose to take part, you will be randomly allocated to one of two groups (a bit like tossing a coin which means it happens by chance). So, you might be in the 'workshop group' and attend the workshop or you might be in the 'control group' and be asked to wait until after the three month follow up to then receive the workbook. We hope to be inviting 40 young people to take part in the research, with half of those in the 'workshop group'. The workshops will run with approximately 10-15 young people in each workshop, so we aim to run two workshops.

Your involvement in the study will last approximately 4 months. During this time, if you are in the 'workshop group' you will be asked to attend the one-day workshop at the University of Surrey and you will be invited to take part in a brief one-to-one follow-up interview at the three month follow up point. If you are in either the 'workshop group' or the 'control group' you will be asked to complete sets of questionnaires. We will use questionnaires to ask about you, which we will collect from both groups once you give your consent, before the workshop, one month after the workshop and three months after the workshop. We will also be asking your parent or guardian to complete some of these questionnaires at the same time. You can choose to complete these questionnaires online, over the phone or by post.

The workshop will include both educational and skills-based exercises with access to a complimentary workbook with the content of the workshop. The workshop will either be taking place at the University of Surrey, or online over Zoom given COVID-19 restrictions. Unfortunately, we cannot reimburse you for travel to attend the workshop. In the 'control group' you will not attend the workshop and you will receive the materials given out at the workshop once the evaluation is complete after the three month follow up.

If you take part in the workshop, at the one and three month follow up you will be offered a phone call to discuss how you are getting on since the workshop and answer any of your questions. At the three month follow up there will also be an optional individual interview which will focus on questions based around feasibility and acceptability of the workshop as well as asking about your experience of living with a food allergy. This interview will be recorded either through zoom or by a University audio recorder.

### What happens if I do not want to take part or if I change my mind?

You are free to withdraw from the study at any time, without giving a reason. Anonymised data (data which doesn't have anything to identify you as an individual) collected up until the point you withdraw will be used in analysis but no further data will be collected from you. You can withdraw from the study by getting in contact with a member of the research team whose details are below.

#### What will it look like if I take part?



#### What are the possible benefits in taking part?

Those who take part may benefit from anxiety management techniques delivered in the workshop or in the workshop materials that will be sent out to those in the 'control group' afterwards. It is hoped that this work will benefit those with food allergy who are also experiencing anxiety, by contributing to research in interventions in this area. Additionally, it will provide you with the opportunity to engage with other adolescents with food allergies and learn from each other.

#### Are there any potential risks involved?

When taking part in a psychological study there is always a chance that difficult feelings may arise. If for any reason you do become distressed during the research study and need support, please contact a member of the research team or one of the relevant services listed in the participant support sheet (attached). You can also see your GP if you experience any difficult feelings as a consequence of the research study.

#### How is the project being funded?

This research is a student project as part of a Doctorate in Clinical Psychology and the information we gather will be towards this qualification. No external funding has been received for this research.

#### Will my participation be kept confidential?

Your personal data will be accessed, processed and securely destroyed by members of the research team including the principal and co-investigators. In order to check that this research study is carried out in line with the law and good practice, it is possible that monitoring and auditing may be carried out by independent authorised individuals. Data collected during the study may be looked at by authorised individuals from the University of Surrey and from regulatory authorities, where it is relevant to your taking part in this research study. All will have a duty of confidentiality to you as a participant and we will do our best to meet this duty. We will anonymise any documents or records that are sent from the University of Surrey, so that you cannot be identified from them.

The data you provide will be anonymised and your personal data will be stored securely and separately from the anonymised data. Your name and address will be removed from all of the documents used in the study, and you will be assigned a numerical code. Any data traced back by this code will be stored separately so you will not be identifiable. Participants who decide to take part in the interviews will be audio recorded. This recording will be transcribed (written up), and all identifiable information will be removed. The research team may use direct quotes from the interviews in a report of the study results, but these will all be completely anonymised. You will not be identified in any reports/publications resulting from this research study and those reading them will not know who has contributed to the research study.

In certain exceptional circumstances where information arising from your participation indicates that you or others may be at significant risk of harm, the researcher may need to report this to an appropriate authority, in accordance with the UK General Data Protection Regulations (GDPR, 2018). This would usually be discussed with you first.

Examples of those exceptional circumstances when confidential information may have to be disclosed are:

- I (The researcher) believes you are at serious risk of harm, either from yourself or others
- I (The researcher) suspects a child may be at risk of harm
- You pose a serious risk of harm to, or threaten or abuse others
- As a statutory requirement e.g. reporting certain infectious diseases
- Under a court order requiring the University of Surrey to divulge information
- We are passed information relating to an act of terrorism

#### Will my data be shared or used in future research studies?

There is no intention to use the data generated from this study in future studies.

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

All of the results will be anonymised before being written up in reports. A final report summarising the main findings of the study will be produced and disseminated with participants who expressed a desire to receive this as well as study funders. The research findings will also be disseminated as a peer-reviewed scientific article and conference presentation with published findings maintaining participant confidentiality and anonymity.

#### Who has reviewed this study?

This research has been reviewed by an independent group of people, called an Ethics Committee. This study was reviewed and given a favourable ethical opinion by the University of Surrey Ethics Committee.

#### Section: Your personal data

#### What is personal data?

'Personal Data' means any information that identifies you as an individual. We will be collecting and using some of your personal data that is relevant to completing the study and this section describes what that means.

The information that we will collect will include your name, date of birth and contact details which is regarded as 'personal data' and gender, ethnic origin, and your health (both physical and psychological) which is regarded as a 'special category personal data'. We will use this information as explained in the 'What is the purpose of the study' section above.

#### Who is handling my personal data?

The University of Surrey, who has the legal responsibility for managing the personal data in this study, will act as the 'Data Controller' for this study. The research team will process your

personal data on behalf of the controller and are responsible for looking after your information and using it properly.

#### What will happen to my personal data?

As a publicly-funded organisation, we have to ensure that when we use identifiable personal information from people who have agreed to take part in research, that this data is processed fairly and lawfully. The University of Surrey processes personal data for the purposes of carrying out research in the public interest and special category data is processed on an additional condition necessary for research purposes. This means that when you agree to take part in this research study, we will use and look after your data in the ways needed to achieve the outcomes of the study.

Your personal data will be held and processed in the strictest confidence, and in accordance with current data protection regulations. When acting as the data controller, the University will keep identifiable information about you for 10 years after the study has finished after which time any identifiers will be removed from the aggregated research data.

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 decide to withdraw from the study, we will not be able to withdraw data collected up to that point. We will only keep and use the minimum amount of information about you that we have already obtained in order to complete the study.

If you wish to make a complaint about how we have handled your personal data, you can contact our Data Protection Officer Suzie Mereweather who will investigate the matter (<u>dataprotection@surrey.ac.uk</u>). 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) (<u>https://ico.org.uk/</u>).

You can find out more about how we use your information <u>https://www.surrey.ac.uk/information-management/data-protection</u> and/or by contacting <u>dataprotection@surrey.ac.uk</u>.

#### Section: Further information

#### What if you have a query or something goes wrong?

If you are unsure about something you can contact the research team for further advice using the contact details at the bottom of this information sheet.

However, if your query has not been handled to your satisfaction, or if you are unhappy and wish to make a formal complaint to someone independent of the research team, then please contact:

Research Integrity and Governance Office (RIGO)

**Research and Innovation Services** 

University of Surrey

Senate House, Guildford, Surrey, GU2 7XH

Phone: +44 (0)1483 689110

Email: rigo@surrey.ac.uk
The University has in place the relevant insurance policies which apply to this study. If you wish to complain or have any concerns about any aspect of the way you have been treated during the course of this study, then you should follow the instructions given above.

#### Who should I contact for further information?

If you have any questions or require more information about this study, please contact the research team using the following contact details:

Name: Holly Tallentire

Role: Trainee Clinical Psychologist

Email: h.tallentire@surrey.ac.uk



Thank you for reading this information sheet and for considering taking part in this research.

# Appendix E

# **Participant Information Sheet for Caregivers**

# **PARTICIPANT INFORMATION SHEET – Caregiver Form**

**Title of Study:** Feasibility of a group intervention using Cognitive Behavioural Therapy (CBT) to reduce anxiety in children aged 11-17 with a food allergy

University of Surrey Ref: 20-21 002 FHMS

# PLEASE KEEP A COPY OF THIS INFORMATION SHEET FOR YOUR RECORDS

# **Section: Taking Part**

#### Introduction

We would like to invite you to take part in a research project. Before you decide whether you would like to take part in this research study, it is important you read this information. Feel free to discuss this study with anyone you would like to, and please ask the research team any questions you have regarding the research study.

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

Research shows us that some young people with food allergies can also experience high levels of anxiety in relation to managing their allergy. The aim and objectives of this study are to evaluate a Cognitive Behavioural Therapy (CBT) based group workshop that has been designed to support young people manage their anxieties in relation to food allergies. We are specifically interested in if CBT tools and techniques can support young people in managing anxieties that come from living with a food allergy and if this can improve quality of life.

#### Who is responsible for this study?

This study is the responsibility of Holly Tallentire at the University of Surrey being supervised by

# Why have I been invited to take part?

You are invited to participate in this study because you are the caregiver of a child between the ages of 12 and 17 who has a food allergy and have expressed anxiety in relation to this allergy.

#### Do I have to take part?

Participation is voluntary and you do not have to take part. We will describe the study in this information sheet and will give you seven days to read this, so you can decide whether you wish to take part in this study. Please contact us if there is anything that is not clear, or if you have any questions, or if you would like more information.

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

If you decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form to confirm your agreement to participate. You will be given a copy of this consent form to keep.

If you, and your child, choose to take part, you will be asked to complete a questionnaire about your child's food allergy and how it impacts on them. Your child will be randomly allocated to one of two groups (a bit like tossing a coin which means it happens by chance). So, your child might be in the 'workshop group' and attend the workshop or your child might be in the 'control group' and be asked to wait until after the three month follow up to then receive the workbook. We hope to be inviting 40 young people to take part in the research, with half of those in the 'workshop group'. The workshops will run with approximately 10-15 adolescents in each workshop, so we aim to run two workshops.

Your involvement in the study will last approximately 4 months. During this time we will ask you to complete the questionnaire once you give your consent to take part in the research, before the workshop, one month after the workshop and three months after the workshop. You can choose to complete these questionnaires online, over the phone or by post.

# What happens if I do not want to take part or if I change my mind?

You (and your child) are free to withdraw from the study at any time, without giving a reason. Anonymised data (data which doesn't have anything to identify you as an individual) collected up until the point you withdraw will be used in analysis but no further data will be collected from you. You can withdraw from the study by getting in contact with a member of the research team whose details are below.

# What are the possible benefits in taking part?

It is hoped that this work will benefit those with food allergy who are also experiencing anxiety, by contributing to research in interventions in this area.

# Are there any potential risks involved?

When taking part in a psychological study there is always a chance that difficult feelings may arise. If for any reason you do become distressed during the research study and need support, please contact a member of the research team or one of the relevant services listed in the participant support sheet (attached). You can also see your GP if you experience any difficult feelings as a consequence of the research study.

# How is the project being funded?

This research is a student project as part of a Doctorate in Clinical Psychology and the information we gather will be towards this qualification. No external funding has been received for this research.

# Will my participation be kept confidential?

Your personal data will be accessed, processed and securely destroyed by members of the research team including the principal and co-investigators. In order to check that this research study is carried out in line with the law and good practice, it is possible that monitoring and auditing may be carried out by independent authorised individuals. Data collected during the study may be looked at by authorised individuals from the University of Surrey and from regulatory authorities, where it is relevant to your taking part in this research study. All will have a duty of confidentiality to you as a participant and we will do our best to meet this duty. We will anonymise any documents or records that are sent from the University of Surrey, so that you cannot be identified from them.

The data you provide will be anonymised and your personal data will be stored securely and separately from the anonymised data. Your name and address will be removed from all of the documents used in the study, and you will be assigned a numerical code. Participants who decide to take part in the interviews will be audio recorded. This recording will be transcribed (written up), and all identifiable information will be removed. The research team may use direct quotes from the interviews in a report of the study results, but these will all be completely anonymised. You will not be identified in any reports/publications resulting from this research study and those reading them will not know who has contributed to the research study.

In certain exceptional circumstances where information arising from your participation indicates that you or others may be at significant risk of harm, the researcher may need to report this to an appropriate authority, in accordance with the UK General Data Protection Regulations (GDPR, 2018). This would usually be discussed with you first.

Examples of those exceptional circumstances when confidential information may have to be disclosed are:

- The researcher believes you are at serious risk of harm, either from yourself or others

- The researcher suspects a child may be at risk of harm
- You pose a serious risk of harm to, or threaten or abuse others
- As a statutory requirement e.g. reporting certain infectious diseases
- Under a court order requiring the University of Surrey to divulge information
- We are passed information relating to an act of terrorism

#### Will my data be shared or used in future research studies?

There is no intention to use the data generated from this study in future studies.

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

All of the results will be anonymised before being written up in reports. A final report summarising the main findings of the study will be produced and disseminated with participants who expressed a desire to receive this as well as study funders. The research findings will also be disseminated as a peer-reviewed scientific article and conference presentation with published findings maintaining participant confidentiality and anonymity.

#### Who has reviewed this study?

This research has been reviewed by an independent group of people, called an Ethics Committee. This study was reviewed and given a favourable ethical opinion by the University of Surrey Ethics Committee.

#### Section: Your personal data

#### What is personal data?

'Personal Data' means any information that identifies you as an individual. We will be collecting and using some of your personal data that is relevant to completing the study and this section describes what that means.

The information that we will collect will include your name and contact details which is regarded as 'personal data'. We will use this information as explained in the 'What is the purpose of the study' section above.

## Who is handling my personal data?

The University of Surrey, who has the legal responsibility for managing the personal data in this study, will act as the 'Data Controller' for this study. The research team will process your personal data on behalf of the controller and are responsible for looking after your information and using it properly.

#### What will happen to my personal data?

As a publicly-funded organisation, we have to ensure that when we use identifiable personal information from people who have agreed to take part in research, that this data is processed fairly and lawfully. The University of Surrey processes personal data for the purposes of carrying out research in the public interest and special category data is processed on an additional condition necessary for research purposes. This means that when you agree to take part in this research study, we will use and look after your data in the ways needed to achieve the outcomes of the study.

Your personal data will be held and processed in the strictest confidence, and in accordance with current data protection regulations. When acting as the data controller, the University will keep identifiable information about you for 10 years after the study has finished after which time any identifiers will be removed from the aggregated research data.

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 decide to withdraw from the study, we will not be able to withdraw data collected up to that point. We will only keep and use the minimum amount of information about you that we have already obtained in order to complete the study.

If you wish to make a complaint about how we have handled your personal data, you can contact our Data Protection Officer Suzie Mereweather who will investigate the matter (<u>dataprotection@surrey.ac.uk</u>). 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) (<u>https://ico.org.uk/</u>).

You can find out more about how we use your information <u>https://www.surrey.ac.uk/information-management/data-protection</u> and/or by contacting <u>dataprotection@surrey.ac.uk</u>.

# Section: Further information

#### What if you have a query or something goes wrong?

If you are unsure about something you can contact the research team for further advice using the contact details at the bottom of this information sheet.

However, if your query has not been handled to your satisfaction, or if you are unhappy and wish to make a formal complaint to someone independent of the research team, then please contact:

Research Integrity and Governance Office (RIGO) Research and Innovation Services University of Surrey Senate House, Guildford, Surrey, GU2 7XH Phone: +44 (0)1483 689110 Email: <u>rigo@surrey.ac.uk</u>

The University has in place the relevant insurance policies which apply to this study. If you wish to complain or have any concerns about any aspect of the way you have been treated during the course of this study, then you should follow the instructions given above.

# Who should I contact for further information?

If you have any questions or require more information about this study, please contact the research team using the following contact details:

Name: Holly Tallentire

Role: Trainee Clinical Psychologist

Email: h.tallentire@surrey.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.

# Appendix F

# Additional Sheet with Information on Areas of Support

# Important Contacts – anxiety support

#### Contact your GP

They are your first port of call if you are feeling like you want further support, both for physical and mental health. GP can help you with things like:

- letting you know what support is available to you through the NHS or private services
- suggesting different types of treatment like counselling, medication or therapy
- offering regular check-ups to see how you're doing
- finding local support groups for your mental health
- explaining what the next steps are in getting you support

#### Text Young Minds: YM to 85258

Text the YoungMinds Crisis Messenger for free 24/7 support across the UK.

https://youngminds.org.uk/

#### Childline – call, chat or send an email

You can get in touch\_on **0800 1111** and you'll get through to a counsellor, they're there to listen and support you with anything you'd like to talk about. Childline is confidential and free from UK mobiles and landlines.

https://www.childline.org.uk/

#### The Mix – call, chat or send an email

The Mix offers support to anyone under 25 about anything that's troubling them. They have a free 121 webchat service and short-term counselling available.

https://www.themix.org.uk/

#### **Food Allergy Support**

#### Anaphylaxis Campaign: 01252 542029

They can help the allergic community and those who care for them on a variety of topics including; allergy care, labelling, legislation, food incidents and the physiological impact.

https://www.anaphylaxis.org.uk/

#### Allergy UK: 01322 619898

They can help with all sorts of things, including advising on your nearest NHS allergy clinic. The team includes in-house clinical experts who can help with more complex questions.

https://www.allergyuk.org/

# Appendix G

## **Consent & Assent Form for Young People Aged 11-15**

# **INFORMED CONSENT & ASSENT FORM**

## Thank you for considering taking part in this research.

# Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

**Title of Study:** Feasibility of a group intervention using Cognitive Behavioural Therapy (CBT) to reduce anxiety in children aged 11-17 with food allergy

University of Surrey Ref: 20-21 002 FHMS

The person asking for your consent must explain the project to you before you agree to take part. If you have any questions about the Information Sheet or their explanation, please ask the researcher before you make your decision. You will be given a copy of this Consent Form and the Information Sheet to keep and refer to at any time.

By **initialling** each box, you are consenting to this part of the study. Any un-initialled boxes will mean that you DO NOT agree to that part of the study and this may mean you are ineligible for the study.

Taking Part in The Study		
	Statement	Please Initial each box
1	I confirm that I have read and understood the information sheet dated <b>7/05/2021</b> <b>Version 3.0</b> for the above study. I have had the opportunity to consider the information and asked questions which have been answered so that I now understand.	
2	I understand that taking part is voluntary and that I am free to withdraw at any time during the study without giving any reason.	
3	I understand that information I provide may be subject to review by responsible individuals from the University of Surrey and/or other people that may monitor the research.	
4	I agree to take part in this study.	
5	I understand that information I provide will be used in various anonymised outputs including reports, publication, presentation, or on websites.	

6	I understand that my personal data, including this consent form, which link me to the research data, will be kept securely in accordance with data protection guidelines, and only be accessible to the immediate research team or responsible persons at the University.	
7	I understand any personal contact details collected about me, such as my phone number and address, will not be shared beyond the study team.	
8	I understand that my anonymity (others being able to identify you in the workshop) cannot be guaranteed in the group workshops, but participants will be asked to keep the discussions confidential (i.e. nothing personal about anyone will be shared outside of the workshop) and the research team will keep any information collected confidential.	
9	I agree to keep the discussions in the group workshop confidential and not share things about other workshop members.	
10	I consent to the processing of my special category data (ethnic origin; health) for the purposes stated in the information sheet.	
11	I understand that by agreeing to take part in this research my participation will involve being randomly allocated to the 'workshop group' or 'control group'.	
12	I confirm that I have been informed about confidentiality procedures and that my data will be kept confidential in most circumstances. I have been informed that confidentiality will only be broken if I share information that leads to significant concerns about my safety or the safety of others and there is a risk of harm.	
13	I understand that I can withdraw from the study. The anonymised data collected up to this point will be retained and used. No further data will be collected after this point.	

	Follow Up (optional)		
	Statement	Please Initial each box	
14	I give permission for the research team to contact me to take part in a follow up interview which will involve discussing the intervention and other things in relation to the psychological impact of living with food allergies and anxiety.		
15	If I choose to take part in the interview, I consent to my audio recording to be used for the purposes stated in the information sheet.		
16	I agree for the researchers to contact me to provide me with a study results summary afterwards and newsletter updates.		
17	I agree for the researchers to contact me if I do not attend the group workshop.		
18	I agree for my personal contact details to be stored by the research team who may wish to invite me to participate in follow-up studies to this project or in future studies being conducted at the University of Surrey.		

Signatures		
I confirm that I have read and understood the above and freely consent to my child participating in this study. I have been given adequate time to consider my participation		
Name of Parent/Guardian Signature Date		Date
Name of Researcher	Signature	Date

Signatures			
I confirm that I have read and understood the above and freely assent to participating in this study. I have been given adequate time to consider my participation			
Name of Participant	Signature	Date	

# Appendix H

## **Consent Form for Young People Aged 16+**

# **INFORMED CONSENT FORM**

# Thank you for considering taking part in this research.

# Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

**Title of Study:** Feasibility of a group intervention using Cognitive Behavioural Therapy (CBT) to reduce anxiety in children aged 11-17 with food allergy

University of Surrey Ref: 20-21 002 FHMS

The person asking for your consent must explain the project to you before you agree to take part. If you have any questions about the Information Sheet or their explanation, please ask the researcher before you make your decision. You will be given a copy of this Consent Form and the Information Sheet to keep and refer to at any time.

By **initialling** each box, you are consenting to this part of the study. Any un-initialled boxes will mean that you DO NOT agree to that part of the study and this may mean you are ineligible for the study.

Taking Part in The Study		
	Statement	Please Initial each box
1	I confirm that I have read and understood the information sheet dated <b>7/05/2021</b> <b>Version 3.0</b> for the above study. I have had the opportunity to consider the information and asked questions which have been answered so that I now understand.	
2	I understand that taking part is voluntary and that I am free to withdraw at any time during the study without giving any reason.	
3	I understand that information I provide may be subject to review by responsible individuals from the University of Surrey and/or other people that may monitor the research.	
4	I agree to take part in this study.	
5	I understand that information I provide will be used in various anonymised outputs including reports, publication, presentation, or on websites.	

6	I understand that my personal data, including this consent form, which link me to the research data, will be kept securely in accordance with data protection guidelines, and only be accessible to the immediate research team or responsible persons at the University.	
7	I understand any personal contact details collected about me, such as my phone number and address, will not be shared beyond the study team.	
8	I understand that my anonymity (others being able to identify you in the workshop) cannot be guaranteed in the group workshops, but participants will be asked to keep the discussions confidential (i.e. nothing personal about anyone will be shared outside of the workshop) and the research team will keep any information collected confidential.	
9	I agree to keep the discussions in the group workshop confidential and not share things about other workshop members.	
10	I consent to the processing of my special category data (ethnic origin; health) for the purposes stated in the information sheet.	
11	I understand that by agreeing to take part in this research my participation will involve being randomly allocated to the 'workshop group' or 'control group'.	
12	I confirm that I have been informed about confidentiality procedures and that my data will be kept confidential in most circumstances. I have been informed that confidentiality will only be broken if I share information that leads to significant concerns about my safety or the safety of others and there is a risk of harm.	
13	I understand that I can withdraw from the study. The anonymised data collected up to this point will be retained and used. No further data will be collected after this point.	

	Follow Up (optional)		
	Statement	Please Initial each box	
14	I give permission for the research team to contact me to take part in a follow up interview which will involve discussing the intervention and other things in relation to the psychological impact of living with food allergies and anxiety.		
15	If I choose to take part in the interview, I consent to my audio recording to be used for the purposes stated in the information sheet.		
16	I agree for the researchers to contact me to provide me with a study results summary afterwards and newsletter updates.		
17	I agree for the researchers to contact me if I do not attend the group workshop.		
18	I agree for my personal contact details to be stored by the research team who may wish to invite me to participate in follow-up studies to this project or in future studies being conducted at the University of Surrey.		

Signatures		
I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation		
Name of ParticipantSignatureDate		Date
Name of Researcher	Signature	Date

# Appendix I

# **Consent Form for Parent / Caregiver**

# **INFORMED CONSENT FORM**

Thank you for considering taking part in this research.

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

This form is for you to consent to completing the Food Allergy Quality of Life Questionnaire: Parent Form as part of the research.

**Title of Study:** Feasibility of a group intervention using Cognitive Behavioural Therapy (CBT) to reduce anxiety in children aged 11-17 with food allergy

# University of Surrey Ref: 20-21 002 FHMS

The person asking for your consent must explain the project to you before you agree to take part. If you have any questions about the Information Sheet or their explanation, please ask the researcher before you make your decision. You will be given a copy of this Consent Form and the Information Sheet to keep and refer to at any time.

By **initialling** each box, you are consenting to this part of the study. Any un-initialled boxes will mean that you DO NOT agree to that part of the study and this may mean you are ineligible for the study.

Taking Part in The Study		
	Statement	Please Initial each box
1	I confirm that I have read and understood the information sheet dated <b>7/05/2021</b> <b>Version 2.0</b> the above study. I have had the opportunity to consider the information and asked questions which have been answered satisfactorily.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time during the study without giving any reason.	
3	I understand that information I provide may be subject to review by responsible individuals from the University of Surrey and/or regulators for monitoring and audit purposes.	
4	I agree to take part in this study.	

5	I understand that information I provide will be used in various anonymised outputs including reports, publication, presentation, or on websites.	
6	I understand that my personal data, including this consent form, which link me to the research data, will be kept securely in accordance with data protection guidelines, and only be accessible to the immediate research team or responsible persons at the University.	
7	I understand any personal contact details collected about me, such as my phone number and address, will not be shared beyond the study team.	
8	I confirm that I have been informed about confidentiality procedures and that my data will be kept confidential in most circumstances. I have been informed that confidentiality will only be broken if I share information that leads to significant concerns about my safety or the safety of others and there is a risk of harm.	
9	I understand that I can withdraw from the study. The anonymised data collected up to this point will be retained and used. No further data will be collected after this point.	
10	I agree for my personal contact details to be stored by the research team who may wish to invite me to participate in follow-up studies to this project or in future studies being conducted at the University of Surrey	

Signatures		
I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation		
Name of Participant	Signature	Date
Name of Researcher	Signature	Date

# Appendix J

# **Demographic Information Gathered at Baseline**

#### **Demographic Information**

#### How old are you? (years)

How do you identify your gender?

- O Female
- O Male
- O Non binary / third gender
- O Prefer not to say
- O If you feel like the above do not apply to you, please enter how you identify your gender below:

#### How do you identify your ethnicity?

- O White
- O Asian or Asian British
- O Black, African, Caribbean or Black British
- O Mixed or multiple ethnic groups
- O If you feel like the above do not apply to you, please enter how you identify your ethnicity below:

#### How many siblings do you have?



- O Yes, please specify what kind of support:
- O No

# Have you ever accessed psychological therapy/support in the past?

- O Yes, please specify what kind of support:
- O No

Do you have any other physical health conditions?



- O Yes, please specify what:
- O No

#### How old were you when your allergy was diagnosed?

#### What type of food(s) is you allergic to? Tick as appropriate

- O Peanut
- O Nut
- O Milk
- O Egg
- O Wheat
- O Soya
- O Sesame
- O Fish
- O Shellfish
- O Fruits
- O Vegetables
- O Other

Please Specify if	
-------------------	--

#### What medicine do you have for your food allergy?

- O Antihistamines
- O Adrenaline auto-injector (Emerade, Epi-Pen, or Jext)
- O None

#### Have you used an auto-injector trainer or dummy device?

- O Yes
- O No

#### If you have an auto-injector, have you received training to use it?

- O Yes
- O No

#### If you have an auto-injector, in a typical week how many days would you go out without it?

'other':

#### Have you ever had to use an auto-injector?

- O Yes
- O No

#### Have you had an auto-injector administered by someone else (i.e. parent, doctor, teacher)?

- O Yes
- O No

#### Have you ever been to the hospital with an allergic reaction to food?

- O Yes
- O No

#### Have you ever had an anaphylaxis reaction (a severe allergic reaction)?

- O Yes, please tell us the number of reactions:
- O No
- O Unsure

#### Do you have an anaphylaxis management plan?

- O Yes
- O No

# Appendix K

# FAQLQ-CF

( nc	⊖ ot	Image: Constraint of the second secon		(;; ver	) Y		ex	dtrei	;;) remely			
Ho	w <u>troubles</u>	<u>some</u> is it, bec	cause of your food	l allergy,		©	0	0	٢	:	٢	0
13	that the i	ngredients of	a food change?									
14	4 that the label states: "May contain (traces of)"?											
15	5 that you have to explain to people around you that you have a food											
	allergy?											
16	that peop	ole around yo	u forget that you h	have a food alle	ergy?							
17	that othe	rs can eat the	e food you are alle	rgic to when yo	ou do things with							
	other peo	ople?										
18	that you don't know how things taste which you can't eat?											
						1						

Ho	w <u>frightened</u> are you because of your food allergy	$\odot$	٢	$\odot$	٢	٢	٢	0
10	of an allergic reaction?		п	п	п	п	п	П
20	of eating the wrong food by accident?							
21	to eat something you have never eaten before?							

Ans	swer the following questions:	$\odot$	٢	$\odot$	٢	٢	٢	0
22	How <u>concerned</u> are you that you will never get rid of your food allergy?							
23	How disappointed are you when people don't take your food allergy into							
	account?							
24	How disappointed do you feel because you have a food allergy?							

The questions are about the influence of your food allergy on your quality of life. It is important that you fill in the answers yourself. You may ask your parents for help, but they are not allowed to tell you which answer to give. Answer every question by putting an 'x' in the proper box. You may choose from the following answers.











w <u>troublesome</u> do you find it, because of your food allergy, that you	$\odot$	$\odot$	٢	٢	٢	٢	0
must always watch what you eat?							
can eat fewer things?							
are limited in buying things you like?							
have to read labels?							
have to refuse food when you do things with others?							
can less easily stay for a meal with someone?							
can taste or try fewer things when eating out?							
have to tell beforehand about what you are not allowed to eat when							
eating out?							
have to check yourself whether you can eat something when eating out?							
hesitate eating certain foods when you don't know if it is safe?							
must watch out when touching certain foods?							
don't get anything when someone is giving treats at school?							
	must always watch what you eat? can eat fewer things? are limited in buying things you like? have to read labels? have to refuse food when you do things with others? can less easily stay for a meal with someone? can taste or try fewer things when eating out? have to tell beforehand about what you are not allowed to eat when eating out? have to check yourself whether you can eat something when eating out? hesitate eating certain foods when you don't know if it is safe? must watch out when touching certain foods? don't get anything when someone is giving treats at school?	w troublesome do you find it, because of your food allergy, that you       Image: Comparison of the second allergy and the second allergy a	w troublesome do you find it, because of your food allergy, that you <ul> <li>Imust always watch what you eat?</li> <li>Imust always watch what you eat?</li> <li>Imust always watch what you eat?</li> <li>Imust always watch what you like?</li> <li>Imust always to read labels?</li> <li>Imust always food when you do things with others?</li> <li>Imust always for a meal with someone?</li> <li>Imust always of the refuse food when eating out?</li> <li>Imust always to the refuse food whether you can eat something when eating out?</li> <li>Imust watch out when touching certain foods?</li> <li>Imust watch out when someone is giving treats at school?</li> </ul>	w troublesome do you find it, because of your food allergy, that you	w troublesome do you find it, because of your food allergy, that you       Image: Im	w troublesome do you find it, because of your food allergy, that you <ul> <li>w troublesome do you find it, because of your food allergy, that you</li> <li> <li> <li> <li> <li> </li> <li> </li></li></li></li></li></ul> must always watch what you eat? <ul> <li> <li> <li> <li> <li> <li> <li> <l< td=""><td>w troublesome do you find it, because of your food allergy, that youCCC<th< td=""></th<></td></l<></li></li></li></li></li></li></li></ul>	w troublesome do you find it, because of your food allergy, that youCCC <th< td=""></th<>

The following four questions are about the chance that you think you have of something happening to you because of your food allergy. Choose one of the answers. This is followed by two more questions about your food allergy. Answer every question by putting an 'x' in the box next to the proper answer.

nev (0% ch	0 ver ance)	1 very small chance	2 small chance	3 fair chance	4 big chance	big ice		6 always (100% chanc					
How b	ig do you	I think the char	ice is that you				0	1	2	3	4	5	6
1 wi 2 wi all	ll accider Il have a ergic?	tally eat somet severe reaction	hing to which y if you acciden	you are allergi tally eat some	c? thing to which	you are							
3 wi 4 car ea	will die if you accidentally eat something to which you are allergic? can <u>not</u> do the right things for your allergic reaction should you accidentally eat something to which you are allergic?												
5	i. How m becaus	any foods are y e of your food	eat 6. Ever How n do wit	yone does thin - playing with - going to a b - visiting, - staying ove eating out. nuch does your h others?	gs with of h friends, birthday p r with son <b>food alle</b>	ther oarty, meor	peop ne fo	ole, s ran t thi	neal	as; or you			
	almost none       so little I don't actually notice it         very few       very little         a few       little         some       moderately         many       a good deal         very many       a great deal         almost all       a very great deal												

# Appendix L

# FAQLQ-TF

The following questions concern the influence your food allergy has on your quality of life. Answer every question by marking the appropriate box with an 'x'. You may choose from one of the following answers.

0	1	2	3	4	5	6
not	barely	slightly	moderately	quite	very	extremely

		П
		_

0	0 1		2	3	4	í	5						6		
no	ot	barely	slightly	moderately	quite	ve	ery			extremely					
Ho	n <u>troubles</u>	<u>ome</u> is it, beo	cause of your fo	od allergy,			0	1	2	3	4	5	6		
13	that the ir	ngredients of	a food change?												
14	that the la	abel states: "	May contain (tra	aces of)"?											
15	5 that the labeling of the bulk packaging (for example box or bag) is different														
	than the individual packages?														
16	that you h	nave to expla	in to people aro	und you that you ha	ive a food										
	allergy?														
17	that durin	ng social activ	ities others can	eat the food to whi	ch you are										
	allergic?														
18	that during social activities your food allergy is not taken into account														
	enough?														

How <u>frightened</u> are you because of your food allergy	0	1	2	3	4	5	6
19 of an allergic reaction?							
20 of accidentally eating the wrong food?							
21 to eat something you have never eaten before?							

22 How <u>discouraged</u> do you feel during an allergic reaction?			
23 How <u>disappointed</u> are you when people don't take your food allergy into			

The following four questions are about the chance that you think you have of something happening to you because of your food allergy. Choose one of the answers. This is followed by two more questions about your food allergy. Answer every question by putting an 'x' in the box next to the proper answer.

(0%	0 1 2 3 4 never very small small fair great very % chance) chance chance chance chan								5 ery great al hance (1009						
Ho	w great do y	ou think the ch	ance is that y	ou			0	1	2	3	4	5	6		
1	will accidentally eat something to which you are allergic?														
2	will have a	severe reaction	if you accider	tally eat somet	hing to which y	/ou are									
	allergic?														
3	will die if ye	ou accidentally e	eat something	to which you a	re allergic?										
4	can not effectively deal with an allergic reaction should you accidentally eat														
	something to which you are allergic?														
							1								

5. How many products must you avoid because	6. How great is the impact of your food allergy
of your food allergy?	on your social life?
almost none	negligibly small
very few	very small
🗆 a few	🗆 small
some	moderate
many	🗆 great
very many	very great
almost all	extremely great

# Appendix M

# FAQLQ-PF

		SECTION A : For all age groups	No	otata	ш		1	Extre	emelv	Ŧ
Bec	ause of food allergy	y, my child feels	_	0	1	2	3	4	5	6
1	Anxious about food									
2	Different from other	children								
3	Frustrated by dietary	restrictions								
4	Afraid to try unfamili	iar foods								
5	Concerned that I am	worried that he/she will have a reaction to food								
			I	I						
			1	Not a	t all			Ex	trem	ely
Be	cause of food allerg	y, my child		0	1	2	3	4	5	6
6	Experiences physical	l distress								
7	Experiences emotion	ual distress								
8	Has a lack of variety	in his her diet								
			No	otata	all			Ex	trem	ely →
Be	cause of food allerg	y, my child has been negatively affected by		0	1	2	3	4	5	б
9	Receiving more atter	ntion more attention than other children of his/her age								
10	Having to grow up n	nore quickly than other children of his/her age								
11	His/her environment	being more restricted than other children of his/her age								
			1	Not a	t all			I	Extre	mely
				_						
Be	cause of food allerg	y, my child's social environment is restricted bec	ause	0	1	2	3	4	5	б
of	limitations on									
12	Restaurants we can s	afely go to as a family								
13	Holiday destinations	we can safely go to as a family								
				'						
			Not	at all				E.	rom	ala:
				at au				La	. em	<b>→</b>
Be	cause of food allers	y, my child's ability to take part has been		0	1	2	3	4	5	б
lin	nited	,,,		ľ	-	-	-	•	-	-
14	In social activities in	other people's houses ( <i>sleepovers, parties, playtime</i> ) 3								

SECTION B.: For children aged 4 to 12 years.								
		Not a	tall			1	Extre	melv
	-							<b>→</b>
Because of food allergy, my child's ability to take part has been		0	1	2	3	4	5	б
limited								
15 In preschool/school events involving food ( class parties/treats/lunchtime)								
	r	Not a	t all			I	Extre	mely
								•
Because of food allergy, my child feels		0	1	2	3	4	5	б
16 Anxious when going to new places								
17 Concerned that he/she must always be cautious about food								
18 'Left out' in activities involving food								
19 Upset that family social outings (sating out, celebrations, days out) have been limited by feed allocations.								
20 Anxious about accidentally eating an ingredient to which he/she is allergic								
21 Anxious when eating with unfamiliar adults/children								
22 Frustrated by social restrictions								
	N	ot at	all			E	xtre	mely
								-
Because of food allergy, my child		0	1	2	3	4	5	б
23 Is more anxious in general than other children of his/her age								
24 Is more cautious in general than other children of his/her age								
25 Is not as confident as other children of his/her age in social situations								
26 Wishes his/her food allergy would go away								
		-						
SECTION C : For children aged 7 to 12 years								
	Not	t at al	u			Ex	trem	ely
								-
Because of food allergy, my child feels		0	1	2	3	4	5	б
27 Worried about his/her future(opportunities, relationships)								
28 That many people do not understand the serious nature of food allergy								
29 Concerned by poor labelling on food products								
30 That food allergy limits his/her life in general								
4		-						

	SECTION D: For all age groups							
Pa	rt 2 : You and your child's worries about food safety	0	) = (   = 1	extro very	eme unl	ly u likel	nlik ly	ely
Ple: on t	ise answer the following questions with reference to the 6-point scale he right	2 3 4	i = 1 i = 1 i = 0	som likel quit	ewh y e lik	at u xely	nlik	ely
Q1.	What chance <b>do you think</b> your child has of?	5 6	i = 1 i = 6	ery extr	like eme	ely ly li	kely	,
	Question			б-р	oint	Sca	le	
Т	accidentally ingesting the food to which they are allergic ?	0	1	2	3	4	5	•
2	having a severe reaction if food is accidentally ingested ?							
3	dying from his/her food allergy following ingestion in the future ?							
	offectively treating him/hercelf, or receiving offective treatment	╟						
4	for the second s			1	1	1		

# Q2. What chance does your child think he/she has of .....?

	Question			б-ро	int	Scal	le	
		0	1	2	3	4	5	б
Т	accidentally ingesting the food to which they are allergic ?							
2	having a severe reaction if food is accidentally ingested ?							
3	dying from his/her food allergy following ingestion in the future ?							
4	effectively treating him/herself, or receiving effective treatment from others (including Epipen administration), if he/she accidentally ingests a food to which he/she is allergic ?							

# Appendix N

# FAQLQ-PFT

# Food Allergy Quality of Life Questionnaire – Parent Form - Adolescents Aged 13-17

Instructions for participants

- The following are all scenarios that parents have told us affect their adolescent's quality of life because of food allergy.
- Please indicate how much of an impact each scenario has on your teenager's quality of life by placing a tick or a cross in one of the boxes number 0-6.
- If you believe the scenario has no impact please choose 0 (not at all). It is important that you answer all the questions to help us understand the impact of food allergy on the quality of life of teenagers.

Response choice 0 = not at all

- 1 = barely
- 2 = slightly
- 3 = moderately

4= quite a bit

- 5 = very much
- 6 = extremely
  - All information given is confidential
  - The questionnaire will only be identified by a code number

	- ·		cop	1100	01101	00	_	
	Question	0	1	2	3	4	5	6
		Not at all	Barely	Slightly	Moderately	Quite a bit	Very much	Extremely
1.	My teenager always eats the same foods because of food allergy							
2.	My teenager has a restricted diet because of food allergy							
3.	My teenager cannot experiment with different foods on holiday because of food allergy							
4.	My teenager misses out because of food allergy							
5.	My teenager is more cautious generally because of food allergy							
6.	My teenager sticks to foods he/she knows							
7.	My teenager has to be more sensible that his/her peers because of food allergy							
8.	My teenager takes more of an interest in food because of food allergy							
9.	My teenager reads the label on everything he/she eats							
10.	My teenager is frustrated about food labelling							
11	My teenager is more wary of situations because of food allergy							
12.	My teenager feels different because he/she cannot eat what his/her friends can eat							
13.	My teenager feels anxious in restaurants							
14.	My teenager finds it difficult to ask about food ingredients in restaurants							
15.	My teenager avoids telling people about his/her food allergy until he/she knows them well							
16.	My teenager gets irritated by his/her food allergy							
17.	My teenager worries as he/she always has to carry a bag because of his/her medication							

# Response choice

	Question	0	1	2	3	4	5	6
		Not at all	Barely	Slightly	Moderately	Quite a bit	Very much	Extremely
18.	School trips away are not easy for my teenager							
19.	My teenager worries that he/she can only eat in a limited range of restaurants							
20.	My teenager has been really scared by having a reaction							
21.	My teenager feels nervous around the food they are allergic to because of food allergy							
22.	My teenager gets frightened about food allergy							
23.	I feel my teenager has had to grow up more quickly because of food allergy							
24.	My teenager has to be more responsible than other teenagers							
25.	My teenager has been teased because of food allergy							
26.	My teenager gets frustrated because of food allergy							
27.	My teenager feels different to other teenagers because of food allergy							

# Appendix O

# **PSWQ-C**

#### PSWQ-C

<u>Directions</u>. This form is about worrying. Worrying happens when you are scared about something and you think about it a lot. People sometimes worry about school, their family, their health, things coming up future, or other kinds of things. For each sentence that you read, circle the answer that best tells how true that sentence is about you.

1.	My worries really bother me.	never true	sometimes true	most times true	always true
2.	I don't really worry about things.	never true	sometimes true	most times true	always true
3.	Many things make me worry.	never true	sometimes true	most times true	always true
4.	I know I shouldn't worry about things, but I just can't help it.	never true	sometimes true	most times true	always true
5.	When I am under pressure, I worry a lot.	never true	sometimes true	most times true	always true
б.	I am always worrying about something.	never true	sometimes true	most times true	always true
7.	I find it easy to stop worrying when I want.	never true	sometimes true	most times true	always true
8.	When I finish one thing, I start to worry about everything else.	never true	sometimes true	most times true	always true
9.	I never worry about anything.	never true	sometimes true	most times true	always true
10.	I've been a worrier all my life.	never true	sometimes true	most times true	always true
11.	I notice that I have been worrying about things.	never true	sometimes true	most times true	always true
12.	Once I start worrying, I can't stop.	never true	sometimes true	most times true	always true
13.	I worry all the time.	never true	sometimes true	most times true	always true
14.	I worry about things until they are all done.	never true	sometimes true	most times true	always true

#### **Appendix P**

#### **Coping Strategies Inventory – Short Form**

Once again, take a few minutes to think about <u>your chosen event</u>. As you read through the following items please answer them based on how you handled your event.

Please read each item below and determine the extent to which you used it in handling your chosen event.

- A. Not at all
- B. A little
- C. Somewhat
- D. Much
- E. Very much
- 1. I worked on solving the problems in the situation.
- 2. I looked for the silver lining, so to speak; I tried to look on the bright side of things.
- 3. I let out my feelings to reduce the stress.
- 4. I found somebody who was a good listener.
- 5. I went along as if nothing were happening.
- 6. I hoped a miracle would happen.
- 7. I realised that I was personally responsible for my difficulties and really lectured myself.
- 8. I spent more time alone.
- 9. I made a plan of action and followed it.
- 10. I looked at things in a different light and tried to make the best of what was available.
- 11. I let my feelings out somehow.
- 12. I talked to someone about how I was feeling.
- 13. I tried to forget the whole thing.
- 14. I wished that the situation would go away or somehow be over with.

- 15. I blamed myself.
- 16. I avoided my family and friends.
- 17. I tackled the problem head on.
- 18. I asked myself what was really important, and discovered that things weren't so bad after all.
- 19. I left my emotions out.
- 20. I talked to someone that I was very close to.
- 21. I didn't let it get to me; I refused to think about it too much.
- 22. I wish that the situation had never started.
- 23. I criticised myself for what happened.
- 24. I avoided being with people.
- 25. I knew what had to be done, so I doubled my efforts and tried harder to make things work.
- 26. I convinced myself that things aren't quite as bad as they seem.
- 27. I got in touch with my feelings and just let them go.
- 28. I asked a friend or relative I respect for advice.
- 29. I avoided thinking or doing anything about the situation.
- 30. I hope that if I waited long enough, things would turn out OK.
- 31. Since what happened was my fault I really chewed myself out.
- 32. I spent some time by myself.

# Appendix Q

# Adherence to Food Allergy Specific Self-Care Behaviours

#### MANAGEMENT OF YOUR FOOD ALLERGIES AND ANAPHYLAXIS

We would now like to know a little bit about how you manage your food allergies. Please read the following sentences and put a  $\checkmark$  in the box which most accurately describes what you do.

I try to avoid fo	ods which I kno	w I am allergic	to		
Not applicable	Always true	Often true	Sometimes	Rarely true	Never true
When I eat out	(friends' house	s/restaurants/t	ake aways) I asl	k about the ingre	dients
Not applicable	Always true	Often true	Sometimes	Rarely true	Never true
l carry an auto-i	njector with m	e at all times			
Not applicable	Always true	Often true	Sometimes	Rarely true	Never true
			true		
I carry antihista	mines with me	at all times			
Not applicable	Always true	Often true	Sometimes	Rarely true	Never true
			true		
I carry my inhal	ers with me at a	all times			
Not applicable	Always true	Often true	Sometimes	Rarely true	Never true
			true		

# Appendix **R**

## **Goal-Based Outcomes**

# **GOAL-BASED OUTCOMES RECORD SHEET**

In attending this workshop, what are some of the problems you want help with or some of the skills you want to start using?

Goal Number	Goal Description
1	
2	
3	

On a scale from zero to ten, please circle the number below that best describes how close you are to reaching your goal today. Remember: zero is as far away from your goal as you have ever been, and ten is having reached your goal completely.

# **Goal Number 1**

					Halfwa	y to reac	hing goal				
Goal not at	0	1	2	3	4	5	6	7	8	9	Goal reached
all met											

#### Any additional comments on this goal?

# **Goal Number 2**

					Halfwa	y to reac	hing goal				
Goal											Goal
not at	0	1	2	3	4	5	6	7	8	9	reached
all met											-

# Any additional comments on this goal?

# **Goal Number 3**

	Halfway to reaching goal										
Goal not at all met	0	1	2	3	4	5	6	7	8	9	Goal reached

# Any additional comments on this goal?
#### Appendix S

### Workshop Feedback Form for Intervention Group

### **Participants Feedback on Group**

## 1. Please indicate how strongly you agree or disagree with each of the following statements. In general, I found taking part in the group workshop:

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
Beneficial					
Supportive					
Enjoyable					
Helped you to manage worry/anxiety in relation to your food allergy					

## 2. How much do you agree or disagree with the statement 'Support for managing anxiety for young people with food allergies is useful'?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree

#### 3. How did you find the length and timing of the group?

4. What aspect(s) of the group did you find most useful?

5. Are there any aspect(s) of the group you did not find useful?

6. Is there anything you think would be helpful to change about the group content or how it was presented?

- 7. How likely are you to continue to use information / skills that you gained from the workshop (e.g. worry management strategies) going forwards?
  - O Very Likely
  - O Likely
  - O Neither likely nor unlikely
  - O Not likely
  - O Very unlikely

If so, what from the group will you continue to use?

#### 8. Do you have any additional comments about the group?

## Part 2 – Second Empirical Paper

What Needs to Change to Improve the Psychological Wellbeing of Young People with Food

Allergy: A Qualitative Study

Word count: 9,175

## Abstract

Research has highlighted the psychosocial impact of living with food allergy on young people. However, there is a paucity of qualitative data from young people themselves in terms of how they would like support for their psychological wellbeing. The aim of the present study was to further understand the experiences of young people with food allergy in the UK, including the challenges they face, to inform structural changes in how they are supported. Ten young people were asked about their experiences of living with food allergy and the psychological impact, through semi-structured interviews. Using reflexive thematic analysis, three themes were generated which each addressed an aspect of change that could improve their psychological wellbeing: psychological impact should be talked about, improvements in safety and risk management, and interpersonal relationships and understanding. This study provided a helpful insight into what young people find beneficial for their wellbeing to guide implications across various systems. This included health professionals being more aware of the psychosocial impact from diagnosis, schools should be more open and consistent with food allergy management strategies, and friends should be educated on the management of food allergy. Reflections on the quality of the qualitative analytical process are discussed.

## Introduction

Food allergy is defined as an immune-mediated adverse reaction to exposure or ingestion of food, causing symptoms such as a rash, itching, swelling, vomiting and life-threatening anaphylaxis if not treated promptly (Sicherer, 2011). In the UK, food allergy affects approximately 2.3% of adolescents and the highest rates of fatal food anaphylaxis are observed during teenage years (Conrado et al., 2021; Pereira et al., 2005). Fatal anaphylaxis in adolescents is regularly documented in the media in the UK such as that of Shante Turay-Thomas in 2018 and Natasha Ednan-Laperouse in 2016 (BBC News, 2019; Russel, 2021). With the high-profile cases in the media, adolescents with food allergies are reminded of the high levels of risk they have to navigate in this already challenging developmental stage. DunnGalvin et al. (2009) proposed impacts on aspects of this developmental stage including identity, social embarrassment, and experiences of feeling safe. They described adolescence as the time to gain autonomy and control whilst negotiating the power balance between parent and child. However, food allergy also involves high levels of anxiety from both the parent and child.

Adolescents often report feeling misunderstood by others and speak about the psychological consequences of 'being different' (DunnGalvin et al., 2009; Mackenzie et al., 2010). Living with food allergy has unique challenges as ingredients can be hidden in food without awareness and so constant checking and vigilance is required. In addition, compared to other health conditions, food allergy is more invisible as symptoms only arise if the young person comes into contact with the allergen. Outwardly to the uninformed eye, this could result in views that the young person is otherwise fine and therefore does not need additional support. However, the constant need to be vigilant and adhere to strict routines can cause significant distress as uncertainty and lack of personal control have been found to be central to the experience of having food allergy in adolescence (DunnGalvin et al., 2009). A study

comparing young people with a peanut allergy and those with insulin-dependent diabetes mellitus found that those with a peanut allergy felt more threatened by adverse events, experienced higher levels of anxiety and had more restrictions on their activities (Avery et al., 2003). Food allergy has been found to impact quality of life by limiting family activities, restricting eating outside of the home, and reducing school attendance (Cummings et al., 2010).

A review of the research from the last two decades highlighted the psychological impact for young people with food allergies: they may experience heightened levels of anxiety, depression, social exclusion, lower self-esteem, and higher internalizing problems (Polloni & Muraro, 2020). Adolescents with comorbid physical health conditions and anxiety are at greater risk of developing mental health difficulties throughout adulthood which can impact health outcomes and functioning (Friedman & Morris, 2006). Other health conditions with known psychological impact, such as diabetes, have quality measures to improve the quality of care provided and commissioned. One of these measures is having systems in place to offer young people access to mental health professionals with an understanding of diabetes (NICE, 2016). More widely, it has been acknowledged that families benefit when psychologists are embedded within paediatric multidisciplinary teams as a more holistic approach to understanding, adjusting, and coping with the young persons' health condition can be taken (Mercer et al., 2015). However, despite this, psychological services for young people with food allergies are sparce and have been described as the 'unmet need' for families in the UK (Knibb et al., 2019). This paper called for psychological services to be provided whilst consideration of the psychological impact to be built into primary care.

A synthesis of qualitative data from teenagers with food allergy described the key challenge as trying to find a balance in coping with the burdens on quality of life whilst managing risk effectively in a world with many factors beyond their control (Johnson & Woodgate, 2017).

They described qualitative studies as limited to positivist analysis through relying on data counts and there being incongruencies with the stated aim and methodology. Other research has called for further understanding of the experiences and feelings of adolescents about their allergies to reduce the likelihood of anaphylaxis and identify areas of more support (Newman & Knibb, 2020).

In summary, there is a documented psychosocial impact on young people with food allergy and there are early qualitative explorations of their experiences, but this research has come with various methodological limitations. Given this contextual background, the aim of the present study was to further understand the experiences of young people with food allergy in the UK, including the challenges they face to inform structural changes in how they are supported.

## Method

#### **Ontological and Epistemological Approach**

A critically realist stance was adopted, which understands the experiences, meaning and reality participants report as valid whilst acknowledging that true reality is unknowable (Morris, 2003). This allowed for an analysis which recognised the individual's lived reality whilst also considering the construction of this in a context co-created by the interviewer, cultural expectations, beliefs, and societal influences (Maxwell, 2012). Critical realism is recognised as useful for analysing social problems and suggesting solutions given it can engage in explanation and causal analysis (Fletcher, 2017). Psychotherapies and thematic analysis can be located within this stance (Harper, 2011). Reflexive thematic analysis was chosen as it follows the critical realist co-created understanding of reality and provided a flexible way to approach this. It also can take into account wider social contexts and suits research with clear implications for practice (Braun & Clarke, 2020). The data was

conceptualised, analysed, and interpreted within a particular sociocultural context of the researcher and this is acknowledged and reflected on.

#### **Participants**

This study was part of a larger randomised control trial (RCT) of the feasibility of a Cognitive Behavioural Therapy (CBT) based workshop for managing anxiety in adolescents living with food allergy. All participants that were allocated to the intervention arm and had taken part in the CBT-based workshop were invited to take part in an interview once the 3-month follow-up measures were completed. Braun and Clarke's (2013) recommendation for sample size for the completion of a professional doctorate research project was followed and 10 participants were aimed to be interviewed for the current study. It was hoped that 10 would allow for new knowledge to be generated whilst facilitating a close association to the interviewees and the data (Crouch & McKenzie, 2006). When arranging the interview, all participants were given the option to have their parent present if it would help them feel more comfortable.

For the recruitment for the RCT, participants were recruited online via social media websites and recruitment was supported by the Anaphylaxis Campaign who allowed study advertisement on their social media channels. Participants who were interested in taking part in the workshop feasibility study were sent information sheets and invited to a telephone screening. During the screening, participants were informed there would be an optional interview once the follow-up data had been collected. Participants were then sent consent and assent forms depending on their age, where they were given the option to consent to the interviews, recording and subsequent analysis (Appendix G & H in study 1). The participants all had a diagnosed food allergy and self-reported anxiety in relation to the management of their food allergy. More detailed information about participant inclusion criteria and methodology of the workshop can be found in the first study in this thesis.

#### Design

Ethical approval was given by The University of Surrey Ethics Committee (EGA Ref No: FHMS 20-21 002, Appendix A in study 1).

A qualitative approach was chosen as it was deemed appropriate for uncovering the complexity of human difficulties and what lies behind them (Boswell & Cannon, 2022). Qualitative research can also provide thick descriptions of the real-world contexts in which they occur (Jhangiani et al., 2015). The semi-structured interview format was utilised as it allows for increased flexibility to follow up on important matters to the interviewee in order to have better knowledge-producing potential (Brinkmann, 2014).

Interviews ranged in duration from 34 minutes and 118 minutes with an average interview time of 66 minutes. The interviews took place over the video platform Zoom and were audio recorded. Using video platforms for qualitative research provides practical flexibility and allows the interviews to be in 'safe locations' of the participant's choosing, hopefully supporting their comfort (Hanna, 2012). At the beginning of each interview, participants were informed that the interview intended to explore their experiences of living with a food allergy and seeking psychological support. They were also reminded of their rights to confidentiality, anonymity, their right to withdraw from the research as well as confirming verbal consent for the recording (Oates, 2021). Given the interview could result in sensitive topics being discussed, this was monitored by the researcher, who is trained to manage such distress, and a protocol was created in line with what is described in Haigh and Witham (2015). This included assessing current mental status, reviewing if appropriate to continue and considering further referrals for additional support. However, this was not required, and so all participants were reminded that they could get in touch with the researcher to discuss further support if needed.

The interview schedule was developed based on previously summarised research that highlighted the psychosocial impact and supported through consultations with psychological experts in the area, young people with food allergy, and other researchers following similar interviews with adults and parents of those with food allergies. The schedule consisted of open-ended questions in relation to how food allergy impacts their wellbeing, what they want support with, what has helped or not helped previously and what they would want in relation to psychological support in the future (Appendix A). Elliot and Rodger's (2008) client change interview was included to explore changes following taking part in the CBT workshop, however, the workshop change data was deemed beyond the scope of the current study. Given the semi-structured nature, the interviewer followed the participants' lead and asked follow-up questions, so they had the opportunity to elaborate responses. These would vary between each interview depending on what was discussed. Every interview was then transcribed for analysis. The interviews, transcription and analysis were all completed by the same researcher.

#### Analysis

Reflexive thematic analysis was chosen to understand the data set as a whole and as it can be flexibly used across the epistemological and ontological spectrum for a wide range of research questions (Braun & Clarke, 2022). The approach was inductive so that theme development could be directed by the data, and the explicit content of the data was interpreted semantically.

Although an inductive approach was taken, it was acknowledged that the analysis was still taking place within the context of the researcher's prior knowledge and understanding of the current literature to produce interpretive stories about the data. In addition, given the context of this researcher as the facilitator of the workshop, the final interpretations fell more within 'constructed crafting' with both description and interpretation as described by Finlay (2021).

The analysis can best be described as 'reflexive thematic analysis' (Braun & Clarke, 2019) and the researcher's ongoing reflexivity in relation to the interview process and analysis will be discussed further.

Following the stages set out by Braun and Clarke (2019) for reflexive thematic analysis, the familiarisation began with transcribing and was then 'read and re-read' to allow for 'immersion' in the data (Moustaka, 1994). Preliminary coding was then conducted systematically across the data set which involved searching for keywords, phrases and experiences that were then given initial shorthand labels. This was initially done using printed out copies of the data, allowing codes to be noted in the margin and the relevant data highlighted and thereafter further developed and evolved in an online version on Microsoft Word. This then led to the grouping of categories of meaning together (see Appendix B for examples of coding). These initial themes were then reviewed in supervision to ensure that they were fitting at both the level of individual extracts and across the data set with a thematic map being developed (Appendix C). It was felt that given the large data set, being able to characterise the subtleties of these would have been unmanageable in one paper and so three different potential narratives were considered: the psychological impact, mechanisms of change following the workshop and what needs to change to support psychological wellbeing (Appendix D). The researcher felt that the most clinically meaningful narrative would be answering what needs to change to support the psychological wellbeing of young people with food allergies, this decision is reflected on further in the reflexive essay (Appendix E). Themes were then refined to a coherent narrative which provided a rich and detailed story, using extracts from across the data. For the data extracts presented with '...' this indicates omitted data and some brief verbal fillers have been removed to aid the readability of the data. The analytic narrative was then written up according to the considerations highlighted by Morrow (2005) such as owning one's perspective, grounding in

examples and resonating with readers. A reflection on the quality of the qualitative study based on criteria suggested by Yardley (2000) can be found in Appendix F.

## Results

Table 1 shows the demographic information for the 10 young people interviewed in the current study. Demographic data was aggregated, and they were all given pseudonyms for the current paper to maintain anonymity. In choosing pseudonyms, the researcher tried to select names that resonated with the young person's actual name (Saunders et al., 2015). The participants ages ranged from 11 to 17 years (mean 14.3 years) and included 7 females and 3 males.

A thematic map with the final themes and subthemes was created, using extracts from quotes to label subthemes (Figure 1).

## Table 1

Variable		n
Gender	Female Male	7 3
Age (years)	Range Mean	11-17 14.3 years
Ethnicity	White British White Irish Fijian	8 1 1
Type of food allergic to	Nut Egg Milk Peanut Fish Shellfish Fruits	10 6 3 2 1 1 1
Approximate age diagnosis	Range Median	5 months – 13 years 54 months (4.5 years)
Experienced Anaphylaxis?	Yes No Unsure	6 2 2
Parent present in interview	Present Not present	4 6

Summary of Participant Demographic Data

#### Figure 1

#### Final Thematic Map of Themes and Subthemes



#### **Reflexive Thematic Analysis**

Three themes were generated from the reflexive thematic analysis, which were labelled as 'psychological impact should be talked about', 'improvements in safety and risk management', and 'interpersonal relationships and understanding'. Within these themes, there are three, three and two subthemes respectively, which reflect areas of change to improve their psychological wellbeing. Quotes have been provided to illustrate each theme.

#### Theme 1: Psychological impact should be talked about

This study stemmed from there being little research from the perspective of young people with food allergy themselves, despite the literature highlighting the psychosocial impact. Therefore, it is unsurprising that they expressed that in real-world situations the psychological burden also isn't spoken about. Young people expressed the benefits of being given spaces to open up about their experiences and also highlighted new challenges that have arisen from the COVID-19 pandemic.

## Subtheme 1.1: There's never a mention of anything to do with the psychological, emotional or anything impact of living with allergies. Ever.

Young people expressed that this research was the first time that they had heard others talk about the psychological impact of living with food allergy, or indeed had the space to consider it themselves:

Yeah, there hasn't been much out there in terms of who you can talk to about how you're feeling because not many people know about it much and this is the first thing that's actually happened where people talk about the anxiety bit towards allergy. They just say 'oh yeah, you can die from this blah blah blah' but they don't talk about how people feel when they have allergies and like what they are feeling when other people are eating stuff they are allergic to. Like the anxiety part of it, for some people that bit doesn't exist for allergies. (Sarah)

It was highlighted that there is an understandable focus on the medical management and avoidance of the allergen as *'they just hand you a list of things you should avoid. That's it.' (Daniel).* However, focusing on avoidance without acknowledging the balance of impact on quality of life and experiences they may have, could result in significant restrictions being placed on the young person's life. This can lead to unnecessary avoidance and prevent young people from taking part in important daily developmental activities (Manassis, 2012). In addition, having an awareness of how food allergy is related to anxiety could support them in understanding how to approach situations and make sense of their responses when related to an understandable emotional response:

Because you can like cope with allergies and you can stay safe, and you can check everything. But actually, if the way in which you're doing that is impacting your mental health and quality of life whatever, then it's probably not, you know, that should be like looked into as well. (Charlotte)

It was thought that if practices could be changed where the emotional experience was asked about or acknowledged that this could have made living with food allergy easier for them. Previous research has recommended that clinicians are aware of the association between allergy and anxiety and can recognise maladaptive anxiety to refer for support (Polloni & Muraro, 2020). In addition, young people who had previously attended support groups valued the information provided and would have benefited from being given it earlier in their allergy journey (Jones et al., 2018). This suggests that beyond direct psychological interventions, psychologists have a role to play in providing consultations and resources to primary care physicians who see young people early on in their allergy journey. Young people in the

current study recommended that at the time of diagnosis, resources could be signposted to in order to allow them to explore the impact and increase their awareness of how to manage food allergy related anxiety:

I think that process it could be a lot easier if you were given these strategies to kind of think through things, or if like people more generally, like when they were given an allergy diagnosis, were kind of signposted to resources. (Charlotte)

It would just be so nice to have that kind of like hospitals saying 'here's ways you can manage it because you're going to have a daily anxiety over whatever you eat. So here are some ways that you can help break that down and help manage that anxiety and stress'. Um it would just be nice that instead of having to seek that out from your own, it's there and ready for you the second that they say 'you're now allergic to this and you cannot eat it. You need to carry this so that if you eat it, you don't die'. You know it would be nice to have kind of support systems in place from the get go. (Jenny)

The psychological impact was also reported to not be spoken about across other services that support young people with food allergies. Those that had received psychological support in the past didn't feel like the unique challenges and experiences of anxiety linked to food allergy were appreciated or understood. Young people were aware that their anxiety was different to more general anxiety and this wasn't accounted for in practitioners' approaches to support:

In general, I think that there isn't enough specific specialised support for people with food allergies and the anxiety around it. Like there is definitely support for people with anxiety but not specific to this kind of like almost strand of anxiety that stems from food allergies. (Jenny) It appeared that their anxiety was treated as more general trait anxiety when in fact what they wanted support with was the specific state anxiety linked to their allergy (Spielberger, 1972). The specific influence that food allergy has on anxiety has led to measures being created for adult populations to address this gap in clinical practice and it is hoped that similar will be considered for young people (de Holanda et al., 2021). In addition, websites that are dedicated to supporting families with allergies and anaphylaxis were viewed as being parent focused. A recent review of freely available online support found all were aimed at either parents or adults (Vreeken-Ross et al., 2021). Young people felt like their experiences and voices were not considered and would benefit from more collaborative information being available:

On websites that are specifically dedicated to talking about allergies or anaphylaxis, a lot of the resources are aimed at either parents looking after kids with allergies and what they can do to keep their kids safe. Rather than if their child or whoever wants to know more about how they can feel better themselves or think about things in a more positive way generally. (Charlotte)

#### Subtheme 1.2: It was very helpful to get me to open up about it.

Young people acknowledged the value of them being able to be open about their feelings in relation to managing their food allergies. They found it beneficial to talk through different ways of managing situations and how to rationalise heightened levels of anxiety with other people:

I guess just talking to my parents about how I was feeling, how they could help me get through it and like help me get like gradually getting up to like being myself again. (Sarah) I suppose it would help like talking to someone about about what's going on in your head about it, and like anything that you're worried about because then they could offer a different perspective on it as well. (Abi)

As well as generally being more open about their experiences, it was also helpful for young people to be able to speak to others with food allergies. As living with a food allergy can be quite isolating, speaking to others and normalising their experiences allowed them to feel more empowered to stand up for themselves:

Whereas when you talk to other people and you realise there's so many people living with allergies, it's not like you have access to those statistics really when you're younger but knowing that there are a lot of other people in the same situation as you, that you do have the power to like say no and to be in control of situations. (Charlotte)

Yeah, I think it would be good just for people who do have allergies just to speak to each other about their experiences and what, how they've dealt with it. And I think it would just benefit both of them because it's someone talking about, and it's also someone, it could just like calm a worry for someone. (Katie)

Jones et al. (2018) found that when young people attended support groups for food allergies this improved self-esteem, both when managing their allergy and generally. It also provided opportunities for them to feel included as they valued having the space to share experiences with others with food allergies. For other health conditions, such as cancer, peer support has proven effective in promoting full psychosocial development and can sometimes be the only opportunity to openly and freely express burdens (Treadgold & Kuperberg, 2010).

Subtheme 1.3: Being at home during over lockdown actually made things a lot easier in terms of allergies.

The psychological impact of living with food allergy, including the impact of constant vigilance, isolation from social events, and managing uncertainty has been documented (Johnson & Woodgate, 2017). However, the impact of COVID-19 and subsequent lockdowns on young people with food allergies has yet to be explored and was highlighted by those interviewed. During the initial stages of lockdown, when schools and restaurants were closed, some young people spoke about how this helped them as they weren't exposed to these anxiety provoking situations:

I think I did good in lockdown because I wasn't worrying about going to school. And I did a lot better in my schoolwork as well, because I wasn't distracted of what's gonna happen if I have a reaction. I could concentrate because I was comfortable at home. (Katie)

However, after experiencing months in the safety of their own home, returning to school and other social activities proved to be a significant challenge for some young people as they no longer felt they could manage the risk that these activities involved. This could be understood through CBT maintenance cycles of anxiety as avoidance of feared situations may ease discomfort in the short term, but in the long term can result in increased anxiety (Clark & Salkovskis, 2009). Some had still not been able to return to school full time given the anxiety they felt around it:

I never used to think I had anxiety attacks before, but I think being locked up in the house for a while kinda changed my view on things. And then when lockdown came out, I felt so anxious going around places, friend's houses, eating food that they've made because I've been so used to, in my own house eating my food and my parents have made. (Sarah) We understand that the COVID-19 pandemic had an impact on the wellbeing of young people (Corr et al., 2021). However, this has highlighted the unique impact it had on those with food allergy and warrants further exploration.

#### **Theme 2: Improvements in safety and risk management**

Risk management in adolescents with food allergy is regularly spoken about, with them being labelled as the 'risk-taking' age group (Newman & Knibb, 2020). However, the researcher noted how risk conscious the young people that took part in the interviews were, and the knowledge and capability they described appeared well beyond their developmental stage. Rather than reflecting on times when they took unnecessary risks, instead, they highlighted when systems outside of their control get in the way of their ability to manage the risk themselves.

# Subtheme 2.1: It's just been like a constant 'oh I'm at school now, something could happen'.

Schools' approach to risk management appeared to be a mediating factor of the level of anxiety that young people interviewed experienced:

They've tended to happen, like they've all happened at school... I just wake up on a morning and I think about it and I think about 'okay what's the day going to be like?' and it crosses my mind every morning. (Abi)

For some, their experiences highlighted that there was no clear school procedure for managing food allergy and the school had communicated that it was not their responsibility. This is particularly worrying considering the Prevention of Future Deaths report for Karanbir Cheema, a 13-year-old boy who had a fatal allergic reaction after having cheese thrown at him in school. The report highlighted how important it is to have allergy action plans in place and instructions communicated effectively as part of the school's first aid training (Hassell, 2019):

*Um, they won't tell me who's EpiPen trained, they won't tell me if they've had training, they won't tell me who can help me. They said if I have allergic reaction at school, the teachers are there to teach, not to help me. (Katie)* 

For this same young person, she described having a reaction as '*chaos*' due to the first aider not being aware of how to manage it as well as being unsure if the relevant people had been contacted to escalate the risk management:

There was a lot more chaos...rather than just me, it was like worrying about the first aider, because she didn't know where my EpiPens were and then worrying about her trying to give it to me and then worrying about, because there's so much going on, is someone ringing the ambulance? or someone ringing my mum? (Katie)

A survey sent to schools in Cumbria, UK highlighted that only 47% felt confident to manage anaphylaxis and 81% felt they needed further training (Raptis et al., 2020). It is hoped that more schools will take advantage of the free training provided by the Anaphylaxis Campaign to improve the understanding and management in schools (Anaphylaxis Campaign, 2022). More commonly, young people reported that policies had been put in place by their school, but the adherence to these policies varied. They described that despite schools being 'nut free' there were still occasions where staff and students brought in nuts or other food they were allergic to, either on purpose or accidentally:

However, I live in a house with 50 girls and there have been incidents where people have brought nuts into school like into house and that's very very nerve wracking. Especially when they go behind my back and say like 'oh, don't tell Jenny'. Yeah, it

happened twice with this one girl, so that wasn't very fun. But we have a no nut policy in our house, but people still bring it in. (Jenny)

There was a teacher at my secondary school who would bring in chocolate all the time and sweets and just completely forgot about me in a way. So, I was always having to remind them: Don't bring this into the lesson I've got allergies, and this is what you have to do. (Lucy)

As these policies were not widely implemented or monitored, it resulted in a lot of this responsibility being placed on the young person themselves to inform others of why it is important and asking them to not bring in certain foods. As Polloni et al. (2015) found that living with food allergy can result in feelings of social isolation and low self-esteem, it is understandable that these conversations can be very difficult:

It's more like I'm telling the teacher what would happen if I had a reaction. I'm more clued up than them... So, it's more me telling the teacher, they're listening to me, it's a bit like that. (Raeesa)

It's just like I wish that they had, like more enforcement of it, but it's very difficult with 50 girls to check everyone else's food and being like 'Oh well this has nuts in, sorry you can't have it'. Like I have to go to my house mistress and say 'this person isn't getting rid of the nuts or locking them away so could you please just take it?' Which is very like stressful... (Jenny)

It was thought to help others understand why such policies were in place and the experience of those with allergies, that initiatives such as education in assemblies would be beneficial. This too was highlighted in Karinbar's report, that targeted education to improve pupils 'patchy understanding' would improve safety (Hassell, 2019). In addition, Abi has been working with her school to start initiatives such as allergy awareness week to recognise the importance of allergies and being valued like other important topics covered. Education in schools could also possibly help reduce social anxiety and allow young people to feel more comfortable about sharing their diagnosis (Goodwin et al., 2017):

I think we need to have more allergy awareness in school like I feel like there should be like assemblies and like things to do in form, in form time. People just don't understand it, and I'm definitely going to push for the allergy Awareness Week next year. Because we do other things like Anti Bullying Week, Autism Awareness Week like we do like we do plenty of other things like that. So, you know, I feel like they they need to do that as well because they have people like, it's not just me, like there's a lot of people that carry Epipens in the school. And some teachers have allergies as well, so it's really important for us. (Abi)

So, in school having little or like assemblies and having more awareness about anxiety towards...allergies. Because I mean, I know many people don't have allergies but for the people that do, they don't feel well heard enough about the anxiety they have towards with their certain allergy and like they need someone to talk to about it, but they feel like they can't because no one understands it very well. (Sarah)

In some instances, schools had taken an overly cautious approach which resulted in young people being isolated or missing out on experiences that their peers had:

It wasn't too great then, they kind of separated when I was like eating yeah, at school, when I was eating in lunch and stuff they... I couldn't eat with anyone else, I had to eat by myself and in my classroom and stuff. (Lewis)

We also have a snack straight after school where they put it out, so it might be doughnuts or cookies or sausage roll or something. And sometimes they will put a label on it like 'Jenny, do not eat' and then I'll get like the worst little granola bar you *can ever imagine and everyone else is just having doughnuts, it's just like....sigh.* (*Jenny*)

Policies that are most effective are those which take a 'whole school' approach and are developed in partnership with parents, pupils, and healthcare providers to ensure that there is a focus on training, risk assessment, and communication (Higgs et al., 2021; Turner et al., 2020). There were instances which described teachers taking an active role in understanding the management of the young person's allergy and this positively impacted their wellbeing and sense of safety within school:

Well, I think I think that teacher also has like researched um like the signs of a reaction because, especially the anaphylaxis one, he knew before I did... So I'm quite, it makes me feel safer, definitely. (Abi)

It definitely makes me feel more confident like in secondary school I was absolutely fine going on a trip without my mum or parent, just knowing that teachers could handle anything should they have a need to. Knowing they were prepared, yeah it definitely eases some of responsibility I felt, like of being extra extra careful which isn't always fun when you're 16 and you want to be going out with your friends or you just want to enjoy the trip or something like that. (Lucy)

When risk management was actively managed by the school it was described as 'the sense of burden that you carry with it is slightly less.' (Lewis' mother) and resulting feeling of 'we are not spending our life apologising for having allergy' (Lewis' mother). Beyond having allergy management plans consistently implemented, some schools also proactively arranged meetings between pupils who had allergies which allowed for young people to meet others with allergies, something they rarely have the opportunity to do:

The school nurse set up a meeting between me and I think two other girls with allergies... So, I think generally like my school, because there were quite a few people with allergies was very aware of that. (Charlotte)

Some young people also took part in extracurricular activities, and this highlighted the difference in support when education on symptoms, knowledge of how to manage, and consistent allergy free zones were implemented:

Dancing's good with supporting and my friends at dancing and my dance teachers, they put up signs saying this is nut free zone, no peanuts, no nuts. And then in the studios they have like what to do mild symptoms and then not mild symptoms and then what number to call. (Katie)

Like I also, I'm also at the local hockey club. They're supportive as well because all my team know like that my EpiPens are in a certain pocket in my hockey kit bag and you know, this is what to do. They know what to do and they know not to eat anything on days that we're training or playing matches. (Abi)

# Subtheme 2.2: How many people are walking around with first aid training actually have got first aid training or actually understand what an EpiPen is.

It was highlighted that both in schools and other locations (e.g., restaurants and museums) that there was either no first aid training or that it was inadequate:

They don't understand like what would happen if I was to have an allergic reaction. And when I did, a caretaker looked after me, no teachers, the first aider injected herself. (Katie)

Not only would that EpiPen then be not usable and EpiPens obviously do have like a big cost... But it did just kind of, like I remember getting like really angry about the

fact that you know there's been a lot of high highly publicised allergy deaths in recent years or hospitalisations, and the fact that he was like a security guard, who you'd assume had first aid training. (Charlotte)

Correct EpiPen administration technique has been found to vary in patients (37%), caregivers (32%) and healthcare staff (21%) however, it was also shown to improve with brief training and demonstrations (El Turki et al., 2017). Charlotte spoke about a security guard inappropriately handling her EpiPen and risking it being unusable. She was later informed that he had in fact been first aid trained and so this understandably resulted in frustrations about how he was so unaware of the danger he was causing. It highlighted that simply stating someone is first aid trained is not enough to understand how to manage an allergic reaction and this should be something more closely regulated:

It does make you kind of question things about like, well, how many people are walking around with first aid training actually have got first aid training or actually understand what an EpiPen is, how many people would recognise that. (Charlotte)

It was proposed that more in-depth first aid training should be mandatory in schools and can give more people confidence in knowing how to use an EpiPen and respond to someone experiencing an allergic reaction:

Everyone should know how to use an EpiPen. I think that should be basic, like in schools people should get CPR training when they are like in year seven. They should get EpiPen training because the likelihood that someone will have an allergic reaction is high. (Jenny)

#### Subtheme 2.3: Like 'No, I'll stick to my safe restaurant, thank you'.

Restaurants are understandably highlighted as a location where risk management needs to be proactively monitored. Previous research has highlighted that despite reported confidence, there are gaps in restaurant staff knowledge of allergy and so families need to adapt their behaviour accordingly (Bailey et al., 2011). Young people spoke of experiences where they were brought incorrect items or getting a message from the chef saying, '*there's nothing they could do for us because it was just very inconvenient having allergies.*' (*Lewis' mother*). They explained the challenges in having to explain the importance of their allergen and the emotional impact when they aren't listened to:

It's more like I think when you're out for a meal or something and so, especially when you're with family and or if like they get the order wrong or something and you don't want to make a fuss, but equally you kind of know that you've got to make fuss because it could have really seriously injured you. And it's also completely wrong if you explained that you've got an allergy to something, and they then serve you something that you can obviously see they haven't got the order right or something. (Charlotte)

Um, maybe um people. Do you know like when they have allergy books and tick what allergy they've got in the food when you go out? They keep that at the front, so maybe not so people with allergies have to ask for it they could just take it up and put it back. Because that for some people might be a bit overwhelming, asking for it. That might make them feel a bit more anxiety, if that makes sense? (Raeesa)

Most young people had regular places where they felt safe as they had clearer policies about the management of food allergies. It appeared that what helped to facilitate a more enjoyable experience was when places serving food would be transparent about allergens as well as either proactively asking or being involved in campaigns such as the 'just ask' to normalise talking about allergies: But the stalls are really good with allergies, so you can ring them... and you can add it to your notes and you can go up and visit them and all the allergy sheets are online. And say it says may contain it will have a little MC or it will have a tick... I didn't have like that much anxiety. I'd been before, I felt a lot more safer. (Katie) Certain restaurants that we've been to, there's been like certain council programmes where it's called 'just ask' and it's up to the members of staff to say. Because for young people it's hard to say, 'I've got a nut allergy'. (Katie's mother)

As well as having clear information available and proactive staff, Begen et al. (2018) highlighted that clinicians also have a role in empowering people to pursue their legal rights to ask about allergens when eating out.

#### **Theme 3: Interpersonal relationships and understanding**

Other people play an important role in managing allergies considering how leading up to teenage years, parents are responsible for the management and act as a safety mechanism (DunnGalvin et al., 2009). When gaining autonomy, the importance of others not only extends to those previously discussed such as schools and restaurant workers but the views of peers and how they view and respond to the young person's allergy.

#### Subtheme 3.1: I just hate it when people think 'oh it's just an allergy'.

When it comes to the role of other people in the lives of young people with food allergy, one of the biggest challenges is the misunderstanding of the severity of an allergy:

And like I just hate it when people think 'oh it's just an allergy'. And it is an allergy, but it's different from like dying and having like a little sneeze like hayfever or something. (Sarah) All young people interviewed called for increased awareness of what allergies and anaphylaxis are, including the symptoms and how these are managed. Those that had been diagnosed later in life acknowledged their understanding was limited until they experienced it themselves. In addition, those that had allergies from infancy explained that, due to other people being unaware of how allergies work, they questioned their own understanding:

Probably awareness, I guess, because I don't think it's like a very known thing, unless it impacts your life, cause I didn't know anything about it till I was, you know, knew I had an allergy. (Seb)

I remember a teacher once saying, 'oh have you not outgrown them yet?' and I was kind of like, well I felt like, was I supposed to have outgrown them? (Charlotte)

With the current lack of public awareness of allergies, Abi shared how it took her friends witnessing her go into anaphylaxis before they understood the severity of her allergy:

Because, like sometimes they'd still eat, before the nut and peanut ban, they would they would still eat nuts at lunch and I'd have to like leave the table. Like I'd have to leave and I had to like go outside instead, I just couldn't be there. And, I just felt a bit like: Why? Why would you do that if it meant I had to leave the table? And then like since coz a few of them have seen actually seen me go into anaphylaxis before, so I think they understand. I think that kind of helped them understand like it's a bit more serious. (Abi)

A few young people shared times when their friends or friends' parents had tried to include them but had only considered one allergen or thought that making something gluten-free would be enough. They described how disheartening this could be as they had to manage these difficult and awkward conversations whilst also considering how 'you don't want to hurt other people's feelings and then them to stop trying to include you' (Charlotte). The role that media has to play in the public perception of food allergy was also acknowledged as harmful. Charlotte described the 2018 children's film 'Peter Rabbit' as a character was pelted with their allergen. In addition, a book 'One of Us Is Lying' was given out in a school which features a young person giving themselves fatal anaphylaxis due to being bullied. The school described it as an *'educational aid'*, but it resulted in Katie coming home from school *'very distressed'*. Katie's mother described the graphic detail of the anaphylaxis *'like a Netflix film'* which it has since been produced as and therefore worrying about the impact it may have on other young people with allergies. The reactions to allergies in media are generally caricatured and can leave young people feeling frustrated about how they see themselves portrayed:

And that does probably come from public misconceptions, and kind of I guess like stereotypes of allergies, especially in the media, like portrayed as people like blowing up after eating something like you know, their face swelling up suddenly or someone being kind of weak because they've got like tonnes of allergies. (Charlotte)

#### Subtheme 3.2: It was very heart-warming to know that other people take it seriously.

Even though every young person shared experiences of others not taking their allergies seriously or not understanding their severity, they also talked about individuals or examples of when people did. They explained *'having people surrounding you that understand it makes it better about the whole situation about having allergies and not feeling as panicky and like stressed out about it' (Sarah)*. In addition, after numerous incidents where they were left out or not considered, it was highlighted the difference made when they are thought about as *'It makes me feel a bit better that someone actually cares to get something that I could have'* (*Daniel*). Friends appeared to make the biggest difference to a young person's wellbeing

when they were proactive in learning more about their allergy and took opportunities to understand how to administer an EpiPen and follow their allergy management plan:

Secondary school and college was amazing. Like all my friends would come round and the first time we ever met up I think they were all asking: 'Okay, how do I use the EpiPen? What do I need to look out for? What should I do?' And they refreshed that every year. Like if we went out for a meal or something, they were always checking: 'oh, have you talked with the waiter, have you gone to the manager? Is everything safe for you' and like checking up on me if we're going out somewhere. (Lucy)

Beyond showing an understanding of the severity of food allergy, some described how their friends spoke up on their behalf to ensure that the correct questions are asked when food is served or that policies in school were being enforced:

If I have anxiety, they'll help, they'll say not to worry or they'll say, if I'm having one of those days where I don't feel confident or I don't wanna ask about it, they'll do it. They'll say 'my friends got a nut allergy' and they'll ask everything. (Katie)

*Um just like if they if they see anybody with any nuts or anything they they go and tell them like you can't have those. And then if they like refuse to put them away like they go and find teacher and say like oh, someone has nuts. (Abi)* 

## Discussion

This analysis explored the experiences of young people with food allergy to further understand what could be done to improve their psychological wellbeing. In doing so, insight was gained into what matters to young people and what could be changed to support them: 1) psychological impact should be talked about; 2) improvements in safety and risk management; 3) interpersonal relationships and understanding. Those interviewed highlighted that young people with allergies do not exist within a vacuum and instead their experiences can be heavily influenced by the various systems and structures around them. Bronfenbrenner's Ecological Systems Theory views development as impacted by relationships characterised by multiple levels of context, from the more immediate environment to wider political influence (Bronfenbrenner, 1989). These systems and how they relate to the experiences highlighted by young people with food allergy has been summarised in Figure 2. The *microsystem* is the immediate and direct social and physical influences including family, peers, school, and medical appointments. It is these interactions that are personal and crucial in supporting development. In medical appointments, there are opportunities to consider more holistic needs and make reference to the psychosocial impact. It has previously been recommended for food allergy to be viewed as a long-term condition managed in primary care with the support of specialist allergy services (Akeson et al., 2007). The risk management approach that schools take is also crucial as they communicate their plans and policies with families. Urgent action for schools has been called for by experts in the field as they highlighted the need for statutory guidance and provision of high-quality training and resources (Turner et al., 2020). It was also acknowledged the role that peers play, both how friends can take an active role in the management of their allergy and having the opportunity to meet others with food allergy. The *mesosystem* is the interaction between the microsystems, such as how schools engage with parents to improve their understandings and co-ordinate support. They are also influenced by additional exosystems beyond their direct interactions, such as provisions for food allergy psychology services or how first aid training is delivered and monitored. The macrosystem is the established culture and society they are developing in, involving legislation and societal misunderstandings of the severity of food allergy. The charity, Allergy UK, has recently launched a patient charter at a parliamentary reception with a vision of quality standard of care for everyone, empowerment of patients

with support of informed healthcare professionals and promotion of better awareness of

allergy (Allergy UK, 2022).

#### Figure 2

Adaption of Bronfenbrenner's Ecological Systems Theory Following the Experiences of Those Interviewed in This Study.



The clinical implications within and across these systems that were generated by the experiences of those interviewed is summarised in Table 2. It has highlighted the changes that all systems around a young person with food allergy need to be taken into consideration. Some changes may take more long-term political and environmental changes, but others can be more easily implemented to make a significant difference in the lives of young people.

The NHS long term plan highlighted the importance of clinical networks for children with long-term conditions, which involved sharing best clinical practice, integration of skills and quality improvement including psychological consultations (NHS, 2019). For food allergy, this may include sharing information about allergy anxiety from diagnosis and psychological training offered to multi-disciplinary teams. A 'whole school approach' policy is most effective and should be developed in collaboration with family's and healthcare providers to focus on training, risk assessment, communication of management as well as peer education (Higgs et al., 2021).

#### Table 2

Summary of the Possible Clinical Implications

What	needs to change?
Psych	ological impact should be talked about
•	Health professionals should have more awareness of the psychosocial impact of living with food allergy and be more prepared to signpost or share resources on this from diagnosis.
•	There should be more specialised psychological support available to this population.
•	Young people with allergies should be given more opportunities to meet others with food allergies to share their experiences.
•	The impact of COVID-19 has a unique impact on this population, this is not something
	that can be ignored.
Impro	vements in safety and risk management
•	Schools need to be clear and open in their communication about how food allergies are managed.
•	When specific policies are put in place, the school should be responsible for monitoring and enforcing this.
•	There should be more awareness and education of the severity of food allergies within schools.
•	Schools should work jointly with families to ensure there is a balance of risk and quality of life considered.
•	First aiders should be aware of how to treat Anaphylaxis, and this should be more widely known throughout the population.
Interp	ersonal relationships and understanding
•	The general public needs to have a better understanding of the severity of food allergy.
•	The media needs to take more responsibility for how food allergies and the treatment are misrepresented.
•	Friends can play a large role in the management of food allergy and should be educated on allergy action plans and how to speak up when it comes to food allergy.

The young people in this study also highlighted the varied impact COVID-19 had on their wellbeing and general ability to manage their allergy, a topic for which there is currently little understanding. Tamara Hubbard, a counsellor who specialised in food allergy based in the USA, recently tweeted her observations of there being less social media engagement and a decrease in food allergy anxiety in the early stages of the pandemic whilst having fewer opportunities to practice safety skills and therefore delays in building allergy confidence (Hubbard, 2021). In Australia, parents reported negative impacts of COVID-19 being difficulties accessing safe foods and health services (Chen et al., 2021). Parents in the USA reported decreases in food allergy anxiety in May-June 2020 which was attributed to reductions in worries about unfamiliar places and management of allergic reactions by others (Westwell-Roper et al., 2022). This follows similar experiences of the young people interviewed as they reflected a sense of safety being in their home and not having to go to places that can usually involve managing a lot of uncertainty, such as school or places to eat. When the world started to open up again, this provided unique challenges after a period of feeling safe at home and as such appeared to be much harder for young people to approach situations as they once could. This warrants further investigation and has highlighted an important area for raising awareness in families and healthcare professionals.

The analysis was completed solely by the researcher in line with the subjectivity and epistemological position taken in reflexive thematic analysis. Therefore, the conclusions that have been formulated are based on the researcher's assumptions and position in relation to the psychological needs of young people with allergies. This includes being passionate about there being more psychological support available to young people with food allergy and engagement with other health professionals who may understand the psychological impact but ask 'what next?'. It is understandable that another researcher analysing the same data may have generated different themes and so this has been reflected on and explored further to be
transparent about the role previous assumptions and experiences played in analysis (Appendix E).

Although attempts to ensure quality in the analytical process have been presented through reflexive essays and reflecting on Yardley's (2000) principles, additional searches for disconfirming cases within the data was not completed. This is viewed as a valuable strategy to assess the credibility and validity of qualitative research as it can check for conflicting discourses within participants' narratives (Antin et al., 2015). However, it was felt that those that didn't need things to change to improve their psychological wellbeing had provisions in place to support them, which were highlighted in the analysis (e.g. having teachers that actively engage with the family). Nevertheless, disconfirming case analysis may still have provided further insight into the complexity of young people's experiences.

The themes were generated by the researcher, who identifies as white British, interpreting the data from the sample of participants that took part in the interviews, who largely identified as white British. Previous research has identified the relatively high prevalence and burden of paediatric food allergy in the non-white population with clinical outcomes related to access and engagement with healthcare services affected by factors such as cultural norms and health beliefs (Jones et al., 2022). In addition, all that took part had self-reported anxiety in relation to their food allergy and saw value in taking part in research in relation to this. It could be possible that different messages may have been communicated by those who do not want to engage with psychological support in relation to their food allergy. Future research would benefit from considering participants' demographics to explore a breadth of voices.

Food allergy research generally takes a positivist stance to attract more biomedical populations whilst qualitative work represents a traditionally low proportion of research (Johnson &Woodgate, 2017). In addition, most psychological intervention research has been

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aimed at parents of those with food allergy (Boyle et al., 2017; Knibb, 2015; Sugunasingha et al., 2020; Vreeken-Ross et al., 2021). This study has provided a first-hand description of the experiences of young people themselves and it is their voices that should be championed in future recommendations for practice. It is important for policymakers to be aware it is not the sole responsibility of the young person with the allergy but the systems around them to ensure the psychological impact is spoken about, their safety is taken seriously and there is increased awareness of the severity of anaphylaxis.

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# Appendices

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# Appendix A

# Semi-Structured Interview Schedule

# **Interview Schedule**

### Part A: Living with a food allergy and seeking psychological support

## 1. Tell me about your experience of living with food allergy?

Do you feel living with a food allergy impacts on your quality of life/enjoyment? Does it affect worry / your mood?

2. What made you interested in attending the workshop and seeking support for anxiety in relation to food allergy? What did you want support with?

What problems do you face? What problems would you like help with? What areas do you feel you need support with?

**3.** Are there any times or significant events when this was particularly bad? Any times when you felt more able to manage?

When it is worse, what is the difference? What is it that you worry about (i.e. a reaction, friends, something else?) What would you have wanted to be different?

# 4. In your opinion, what keeps these problems going?

Why have they not gotten better on their own? Are there any other factors which you think may influence your ability to manage your food allergy?

# 5. What do you do at the moment to manage the problem?

What strategies do you use to help you cope? What things help you to cope? How effective are these things? Is there any that you would want to tell other young people? What would you like to be different?

6. What support (e.g. doctor/ support group/self-help/teacher/friends/parents) have you sought/been given in order to help with these problems?

What has been helpful about this support? What has been unhelpful? What is the role of your friends and family in managing your food allergy? Do you feel like people with food allergy get enough support? What is already done or what more could be done?

7. What are your experiences of accessing psychological support in particular, in relation to your food allergy?

What do you think psychological support could offer you to help with these things? What is needed from a psychological intervention in order for it to be useful to you?

8. Taking into consideration everything we have discussed, what do you think are the main reasons why a child with a food allergy may require psychological intervention?

What might be unique to food allergy compared to other health conditions?

9. Do you think similar workshops are needed for those with food allergy and worry? If not, is there anything else you would recommend?

*Final:* Is there anything you want to tell me that we have missed so far?

# Part B: Client Change Interview Schedule (Elliott and Rodgers, 2008)

**1.** What has taking part in the workshop been like for you? How has it felt to participate?

How did you find the group format?

- 2. <u>Changes:</u>
  - a. What changes, if any, have you noticed in yourself since attending the workshop?

(Interviewer: Reflect back change to client and write down brief versions of the changes for later. If it is helpful, you can use some of these follow-up questions: For example, Are you doing, feeling, or thinking differently from the way you did before? What specific ideas, if any, have you gotten from the workshop so far, including ideas about yourself or other people? Have any changes been brought to your attention by other people?)

- b. Has anything changed for the worse for you since starting?
- c. Is there anything that you wanted to change that hasn't changed since starting?

# 3. <u>Change Ratings:</u> Go through each change and rate it on the following three scales:

- a. For each change, please rate how much you expected it vs. were surprised by it? (Use this rating scale:)
  - (1) Very much expected it
  - (2) Somewhat expected it
  - (3) Neither expected nor surprised by the change
  - (4) Somewhat surprised by it
  - (5) Very much surprised by it
- b. For each change, please rate how likely you think it would have been if you hadn't engaged with the workshop? (Use this rating scale:)
  - (1) Very unlikely without the workshop (clearly would not have happened)
  - (2) Somewhat unlikely without the workshop (probably would not have happened)
  - (3) Neither likely nor unlikely (no way of telling)
  - (4) Somewhat likely without the workshop (probably would have happened)
  - (5) Very likely without the workshop (clearly would have happened anyway)

- c. How important or significant to you personally do you consider this change to be? (Use this rating scale:)
  - (1) Not at all important
  - (2) Slightly important
  - (3) Moderately important
  - (4) Very important
  - (5) Extremely important
- 4. <u>Attributions:</u>
  - a. In general, what do you think has caused the various changes you described? In other words, what do you think might have brought them about? (Including things both inside and outside of the research)
- 5. <u>Resources & Limitations</u>
  - a. What personal strengths/aspects of your life do you think have helped you engage with the tools from the workshop?
  - b. What things about you/life situation do you think have made it harder for you to engage with the workshop?
- 6. <u>Helpful Aspects:</u>
  - a. Can you sum up what has been helpful about the workshop? Please give examples. (For example, general aspects, specific events)
- 7. Problematic Aspects:
  - a. What kinds of things about the workshop and CBT skills have been hindering, unhelpful, negative or disappointing for you? (For example, general aspects. specific events)
  - b. Were there things that came up which were difficult or painful but still OK or perhaps helpful? What were they?
  - c. **Has anything been missing from the workshop?** (What would make/have made your experience more effective or helpful?)
- 8. <u>The Research:</u>
  - a. What has it been like to be involved in this research? (Initial screening, research interviews, completing questionnaires etc.)
  - b. Can you sum up what has been helpful about the research so far? Please give examples.
  - c. What kinds of things about the research have been hindering, unhelpful, negative or have got in the way of the workshop? Please give examples.
- 9. <u>Suggestions:</u>
  - a. Do you have any suggestions for us, regarding the research or the workshop? Do you have anything else that you want to tell me?

# **Appendix B**

## **Examples of Coding Process**

Jenny: Yeah, I feel very like annoying and petulant, where I have to ask like does this have nuts in?' to lets say a server at a restaurant. Then if they said 'I don't know' it's kind of like you have to keep asking to get an answer like, 'Can I have food tonight? Could I eat here? Do I have to go back home and make myself something instead? Do I have what....' It's very like hard because very few people actually understand the severity. Like I understand that you do not know, however, you not knowing could leave me in hospital this evening. So it's very, I feel very annoying when I have to ask. And it's just quite almost disruptive, like having to ask people or having to double check beforehand. like oh, does this and that. Or going over to friend's house and asking parents 'Could you make sure that the food is nut free and that there's no cross contamination and if possible, could you know, put the Nutella on the top shelves?' That kind of thing 'and not have your 3 year old child with Nutella all over their hands trying to hug me'. You know? It's just a lot.

**HT:** Yeah okay, and I guess do you feel like similar workshops are needed for those with food allergy and worry?

Jenny: I think so. Like it was very useful to do the workshops, so I think that's definitely something that could be good. Say if the hospital like recommended 'here are some workshops you can go to, they are literally just online, like this will help you with tips to manage your food allergy and manage anxieties around it'. It would just be so nice to have that kind of like hospitals saying 'here's ways you can manage it because you're going to have a daily anxiety over whatever you eat. So here are some ways that you can help break that down and help manage that anxiety and stress'. Um it would just be nice that instead of having to seek that out from your own, it's there and ready for you the second that they say 'you're now allergic to this and you cannot eat it. You need to carry this so that if you eat it, you don't die'. You know it would be nice to have kind of support systems in place from the get go.

Feeling annoying asking about allergy (restaurant)

Others not understanding severity

Positive workshop feedback

Hospitals giving information on food allergy and anxiety

Reaction happening in school

Allergy Awareness needed in schools

Abi: Um, well the last one was because a year 11 who had been in the classroom before I was had eaten a snickers bar in the classroom. And then, I just wish that more people... I think we need to have more allergy awareness in school like I feel like there should be like assemblies and like things to do in form, in form time. (HT: Yeah) People just don't understand it, and I'm definitely going to push for the allergy Awareness Week next year. (HT: Oh that will be amazing). Because we do other things like Anti Bullying Week, Autism Awareness Week like we do like we do plenty of other things like that. So you know, I feel like they they need to do that as well because they have people like, it's not just me, like there's a lot of people that carry Epipens in the school. And some teachers have allergies as well, so it's really important for us.

**HT:** Yeah definitely get those teachers kind of on side, and I think that would be amazing. If you start that in your school, that's really cool. And so I guess from that, do you feel like what would be nice to be different is, as you said, if

people actually just understood it a bit more and weren't so kind of dismissive of it, I guess.

Abi: Yeah, yeah, definitely. Because like some people are just like, like some people have said to me before 'oh it's not like you're going to die' and I'm just like uum OK?

**HT:** Yeah, so that real understanding, lack of understanding even of actually the severity of it. (Abi:Yeah). Yeah ok, that makes sense. And then the next questions thinking about, so in terms of the kind of food allergy related worries and anxiety. What do you feel like kept those worries going and kind of why they didn't, I don't know, just get better on their own overtime?

Abi: Um, I think it's just because I go to school like everyday, like everyday of the week apart from weekends obviously. And because like they've tended to happen like they've all happened at school like I've had most of my mild reactions at school as well. Because it's like I go school most days I just wake up on a morning and I think about it and I think about 'okay what's the day going to be like?' and it crosses my mind every morning. And then I go to school and I'm thinking like I always whenever I'm going anywhere in school, I always look around me at like what other people have with them. Or like what they're doing. And then, so I always look out for anything to stay away from if you know what I mean. And so it's never, it never really went away after cause I had my first anaphylactic reaction about two years ago and since then, it's just been like a constant 'oh I'm at school now, something could happen'. Others not understanding severity

Reaction happening in school

Increased anxiety /high alert in school

**Sarah:** I think it's a bit of both. Because I feel like, yeah I'm going to have a reaction but I feel like these people don't understand because they will think I'm weird and thinking 'oh yeah but you're not eating it so it doesn't really effect you in that way'. And like I just hate it when people think 'oh it's just an allergy'. And it is an allergy, but it's different from like dying and having like a little sneeze like hayfever or something.

**HT:** Mhm, yeah. So what sort of things would you want to be different in that situation?

Sarah: For people to like maybe see the difference between anaphylaxis and a small allergy and not make it, think it and not...make it as big of a deal as it actually is, and maybe a bit more understanding about how I'm feeling towards what they're eating. And like yeah.

**HT:** Yeah yeah, that makes complete sense. Um and what about times where you feel like you've been a bit more able to manage, maybe noticed the situations that sometimes you have found tricky or bit worried but you are able to cope? What...

**Sarah:** Um, like I don't know really, but like maybe like not feeling as cornered and like stressed out. I think like 'It's fine, they are over there with that and I'm over here doing my own thing so I'm gonna be alright' and not panicking as much, I think about what is going on.

Others not understanding severity

Others to understand differences of allergy and anaphylaxis Others to know how impac feelings **Sarah's mum:** I think it's the new group of friends, going back to your new group of friends as well.

Having friends that understand

**Sarah:** Like having people surrounding you that understand it makes it better about the whole situation about having allergies and not feeling as panicky and like stressed out about it.

Sarah's mum: Or different...

Sarah: Or different, yeah.

*Note: HT* = *Researcher* 

# Appendix C

# Code Groupings Across Whole Data Set to Start to Identify Initial Themes



# Appendix D

# Separating Groups of Codes into Three Separate Ideas: Psychological Impact, What Needs to Change to Improve Psychological Wellbeing, and Mechanisms of Change from Workshop







#### Appendix E

#### **Reflexive Essay**

Given I took on multiple roles throughout this research of recruiter, facilitator of the workshop, interviewer, and researcher, I was conscious about how this would be impacting myself as well as the young people and their parents that I was communicating with. Holding multiple roles of a clinical psychologist trainee and researcher can provide benefits due to competencies in addressing distress and understanding the clinical context. However, it is also important to consider how this could influence the research process and therefore recommendations highlighted in Thompson & Russo (2012) were considered. As I had met all the young people interviewed previously from when they had taken part in the workshop, I was aware they would already see me as someone that understands the importance of the psychological impact of living with food allergy. In addition, I hoped that this would also help them to feel more comfortable and speak openly about their experiences. In order to be person-centred, I made the choice to allow the young people to have their parent present if they wanted to. Having parents present is debated whether it allows for richer data through prompts and scaffolding or if it prevents children from being able to speak openly (Gardner & Randall, 2010). To mitigate this, I reminded those who had parents present that I really wanted to hear from the young person's perspective and when the parent explained something, I ensured that the young person's experience was heard also. This flexibility allowed for participants to feel more comfortable, and I believe allowed for richer data to be collected. After each interview, I kept notes of how I experienced the interview and considered how it impacted subsequent interviews. For example, I noted that I could have been quite leading in my questions so ensured I asked, 'does it impact...' rather than 'how does it impact...'. This also allowed me to be more guided by the young person and their experiences rather than my own questions.

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I decided to use reflexive thematic analysis to analyse the interview data, this is partly due to my familiarity with the process and that I find it an accessible way to interpret qualitative data. In addition to this, I was also aware that it can be used widely across different research questions and the development of analysis occurs across the whole dataset, which seemed appropriate for this study (Braun & Clarke, 2022).

The impact of COVID-19 was mentioned by almost all participants, and although there were some shared sentiments, I also realised how differently we experienced lockdowns and the sense of safety in this time. Whilst most young people expressed the sense of ease they felt in lockdowns due to not having to go to places where they needed to navigate risk, I noted I felt quite different. Having a close family member being diagnosed with cancer during the pandemic, I noticed my anxieties around contamination increasing and became increasingly risk averse when it came to anything to do with my mother's health. I suppose this had given me a small understanding of the daily experience of living with a food allergy that doesn't go away.

After some interviews, I did also notice that I got quite emotional, particularly those who expressed that following the workshop they had grown in confidence to speak up for their allergies and had been more assertive. They described the realisation that their needs matter and feeling more capable to manage in various situations. My response came from my understanding of the difficulties they face daily on top of the usual teenage struggles. I considered how when I was a teenager, it would have been amazing to have had something that influenced my confidence and self-esteem, even without a context of food allergies. Therefore, it made me more motivated to ensure that young people's voices could be heard to build on these changes. This also highlighted the importance of considering what was attributed to the workshop and what is separate from that in the analysis, which I was conscious of going forwards.

At the halfway stage of interviewing, I had started to consider themes across the conversations that were held and noted the role of others as the good, the bad and the ugly. I also reflected on the challenges of listening to stories where young people have been mistreated by others (e.g. teachers, peers, security guard) and responding with empathy whilst not letting the clinician side of me take over and start considering formulation and intervention with them. Instead, I tried to stay focused on understanding more about how they experienced this. During the analysis I also noted I responded how I would clinically working in paediatric psychology as I considered how it felt like young people and their families were going 'into the unknown'. This naturally led me to think about the Frozen 2 song and led me to consider how other codes related to other songs (Figure 3). In paediatric psychology, it is beneficial to engage with young people's interests to improve engagement and so this is something I would regularly do clinically (Zandt, 2020). Although I can appreciate that incorporating Disney into this analysis isn't appropriate, it did help me engage with my more creative side and helped to pull codes together to generate themes. Having now pulled together the final themes, I think it was a beneficial practice to be able to not create codes, subthemes, and themes in a linear fashion but through different lenses. Leaning into my creative nature allowed for a new perspective and for me to explore and open new avenues of interpretation.

## Figure 3





I also note that it has become one of my greatest frustrations with the literature or medical allergy community that all teenagers can be dismissed as 'risk takers'. Although it may be true of some, all that I spoke to were incredibly risk aware and had knowledge far beyond what I may have expected. This may have also been one of the reasons why I was more drawn to the change in the systems that are needed, rather than it being more of an individualised focus. I do feel that young people with food allergies deserve to be given more credit for all that they do, and the systemic changes need to be addressed to empower them to use their knowledge.

Something else that drew me to consider the systemic changes to support young people followed presenting the research from the first paper in this thesis at the British Society for Allergy & Clinical Immunology (BSACI) and World Allergy Organization conference. It was great to see the interest in psychology from professionals in this community and how they engaged with the ideas presented. However, it was also acknowledged that 'psychologists are like gold dust, no, diamond dust' as access to a psychologist is limited for these health professionals. I was also approached by a doctor that asked me to give them some tips on how to respond when patients present with anxiety. Acknowledging there was no one size fits all, I tried to emphasise the importance of just asking about how they are doing and validating these feelings. The doctor responded by saying they wanted something exact they can give each patient. I thought about how medical professionals can see psychology as a quick fix to minimise anxiety without acknowledging the role that is played by a more systemic formulation. Therefore, although I remain passionate about psychological interventions such as that highlighted in the first paper of this thesis, I felt it important that to improve psychological wellbeing it is not just down to a referral to psychology, more systemic changes need to occur.

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#### Appendix F

#### **Evaluation of Quality**

The researcher reflected on Yardley's (2000) suggested principles to evaluate the quality of this qualitative study.

### Sensitivity to Context

Prior to the development of the interviews, the researcher engaged with the relevant literature to explore factors influencing the psychological wellbeing of young people with food allergy. This allowed the researcher to understand gaps in the literature including a lack of evaluation of psychological interventions for young people and understanding what services can do to support their wellbeing. To remain sensitive to participants' perspectives, the researcher engaged with the Anaphylaxis Campaign by attending their support group leaders conference and had the opportunity to talk to families that were in attendance. In addition, in the development of the protocol, discussions with young people and their families were had to maintain their priorities at the centre of the research. Other forms of engagement included speaking during the Anaphylaxis Campaign 'Allergy Awareness Week' and presenting at the BSACI & World Allergy Organisation conference. There were many sociocultural influences on the research, which is why reflexivity was key throughout considering it was one of the first opportunities participants had to talk about the psychological impact as well as the complexity of their experiences of COVID-19. The researcher also provided additional support and was sensitive to the potential emotional impact of taking part in the study. Although there will always inevitably be a power imbalance with a researcher seen as an 'expert', this study had a somewhat unique experience in that all participants were familiar with the researcher prior to the interviews after attending the workshop. This hopefully allowed for bridging in the power differentials as the young people interviewed had more of an understanding of the researcher and their background. In addition, to promote comfort

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within the interview, young people were given the option to have cameras off or have their parents present.

#### **Commitment and Rigour**

Prior to starting the interviews, commitment to reflexive thematic analysis involved engagement with key resources. This included The University of Auckland's Thematic Analysis website (Braun & Clarke, n.d.), online webinars and papers demonstrating worked examples of reflexive thematic analysis (Trainor & Bundon, 2021). This learning was reflected on and developed through discussions in supervision. Once the interviews were completed, it was felt that the content was rich qualitative data and appropriate to continue with analysis. Immersion in the data was achieved through listening back to the interviews, personally transcribing, and re-reading the transcriptions alongside the audios to confirm accuracy. Following this, the remainder of the steps in reflexive thematic analysis were completed.

#### **Transparency and Coherence**

The researcher has attempted to be transparent with the analysis process taken and demonstrate this narrative through a reflexive essay, various stages of thematic maps and openness of the subjectivity in the interpretation. Numerous participant quotes have been used within the results with extracts of the coding process in the appendix to help readers understand how this process occurred. Transparency was also given to the young people that were interviewed as they were reminded of the aims of the interviews and allowed to ask any questions in relation to this. The research question aimed to understand, from the perspective of young people themselves, what they need to support their psychological wellbeing. The final analysis remains coherent in prioritising the perspective and voices of young people with food allergy.

### **Impact and Importance**

This study enriches understandings of what can be done to improve the psychological wellbeing of young people with food allergy from their own perspective. The findings are important on various levels, firstly giving the space for these young people to talk openly about these experiences and to know they are being listened to. More widely, it provides further directions of support that is provided by services that young people with food allergy access and how policies can support these changes. Further exploration of these recommendations can be found in the discussion.

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# **Clinical Experience and Assessment**

### Year 1: 12-month adult placement

### 1) September 2019 – February 2020: Community Mental Health Team (CMHT)

#### 2) February 2020 – September 2020: Early Intervention in Psychosis Team

Whilst in the CMHT, my work was predominantly focused on providing individualised cognitive behavioural therapy (CBT) for adults with clinical presentations of anxiety and low mood. Alongside a fellow trainee and two clinical psychologists I facilitated the Systems Training for Emotional Predictability and Problem Solving (STEPPS) group for those with a diagnosis of borderline personality disorder.

My move to the early intervention team also coincided with the pandemic & lockdown so I was involved with supporting the team to transition online. Later in my placement, I lead on a service evaluation to understand the experiences of clinicians and service users as mental health care transferred online in this period. I led a team of assistant psychologists and jr. doctors who interviewed both staff and service users across CAMHS and adult services. Using Thematic Analysis, the results were then presented to the trust to inform future online working. Individual work consisted of using various models such as CBT, Compassion Focused Therapy (CFT) and Acceptance and Commitment Therapy (ACT). Along with another trainee, we led a day long training on low intensity CBT interventions for low mood to support workers. In addition, I also created and led a training on trauma informed care in psychosis to the MDT.

#### Year 2: 6-month split CAMHS placement

**September 2020 – March 2021:** 

- 1) Targeted Mental Health in Schools (TaMHS) in a primary school
- 2) School for young people with severe and complex learning difficulties

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Halfway through this placement, all schools were closed again due to COVID-19 restrictions, so my role involved supporting family's and staff with re-adjusting to this.

In the primary school, I worked with young people drawing on narrative and strength-based models. I also created and facilitated a training for teachers on ASD/ADHD and what this looks like in the classroom. Once the school had re-opened, I was able to go back to completed a WISC.

In the school for those with severe and complex learning difficulties I worked both individually with the young person themselves or through consultations with their teachers and parents. This involved various observations and working with positive behavioural support (PBS) plans. I would have monthly PBS peer supervision to support this way of working. I also led on organising a pilot Tree of Life group for both parents and staff at the school.

### Year 2: 6-month split Older Adults placement

#### March 2021 – September 2021

1) General Neurology outpatient assessment service

### 2) Inpatient Acute Stroke Unit

I was supported throughout the placement to eventually lead a weekly neuropsychological assessment clinic. This involved triangulating data from background information, clinical interview and neurocognitive tests. Neurocognitive tests included: TOMM, WAIS, CVLT-II, D-KEFS, WMS, RBANS, Rey complex figure and others. Presentations were typically multiple sclerosis, but I also had assessments for dementia, chronic traumatic encephalopathy and epilepsy. The acute stroke ward involved joint sessions with various members of the MDT in the acute stage of recover from stroke. Individual work focused on psychoeducation

and behavioural activation. Measures used in this context were the ACE III and I was part of trialling the new Oxford Cognitive Screen.

### Year 3: 12-month specialist placement

#### September 2021 – September 2022

### 1) Paediatric Oncology Psychology Team

Within this placement, I have worked with young people diagnosed with cancer and their families providing individual and group support. This has been in both inpatient and outpatient settings, and I have drawn on CBT, ACT, CFT, Narrative and systemic family therapy models. Presenting problems have typically been around adjustment to diagnosis, managing side effects of treatment, procedural anxiety and work has been direct, through carers and liaison and consultations with other agencies. I led on recruiting and advertising for a parent support group which was co-facilitated with a clinical psychologist and later I supported a fellow trainee to facilitate it. I also set up the 'bubble' group on the ward which is a weekly group for young people aged 7+ on the inpatient ward to take part in low intensity activities where they have a space to discuss their feelings and experiences of diagnosis and treatment. Within this group I supervise a team of assistant psychologists. I have also been able to give various presentations, two within the team on 'the use of outcome measures' and 'managing food allergy within a hospital setting'. In addition, as part of the foundation in nursing training I did a presentation on the psychosocial impact of cancer. I have also had extensive experience on conducting neurocognitive assessments for young people diagnosed with brain tumours and developed my understanding of the impact of treatment, such as radiotherapy, on cognitive functioning.

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# PSYCHD CLINICAL PROGAMME

# TABLE OF ASSESSMENTS COMPLETED DURING TRAINING

### Year I Assessments

ASSESSMENT	TITLE
WAIS	WAIS Interpretation and Administration
Practice Report of Clinical Activity	A practice report of Clinical Assessment and Formulation using CBT with a white-British male in his mid-thirties presenting with anxiety.
Report of Clinical Activity N=1	A report of clinical assessment and intervention with Lizi: A woman in her late teens, presenting with low mood and low self-esteem in an early intervention service.
Major Research Project Proposal	Feasibility of a group intervention using Cognitive Behavioural Therapy (CBT) to reduce anxiety for children aged 11-17 with food allergy.
Service-Related Project	An evaluation of the adjusted Systems Training for Emotional Predictability and Problem Solving (STEPPS) group data.

### Year II Assessments

ASSESSMENT	TITLE
Report of Clinical Activity/Report of Clinical Activity – Formal Assessment	A cognitive assessment of a woman in her sixties with a reported decline in cognitive functioning and increased anxiety.
Presentation of Clinical Activity	A systemically-informed case presentation of Janet, a woman in her 70s whilst she was in acute stroke rehab

## Year III Assessments

ASSESSMENT	TITLE
Major Research Project Paper 1	A Feasibility Randomised Control Trial of a Cognitive Behavioural Therapy Online Group Intervention to Improve the Psychological Wellbeing of Young People Aged 11-17 with Food Allergy.
Major Research Project Paper 2	What Needs to Change to Improve the Psychological Wellbeing of Young People with Food Allergy: A Qualitative Study

Application of Systemic Ideas to a Clinical Scenario	Application of systemic hypothesising and practice following a referral of Joel and his family.
Report of Clinical Activity/Report of Clinical Activity – Formal Assessment	A report of clinical assessment and CFT intervention with Chloe: A young person in her teens, following her referral to the paediatric oncology psychology service.