## Transitioning to Independence: Late Adolescents Access to Food and Health Care and Self-Management of Food Allergies

by

### Zainab Laheri

A thesis submitted in partial fulfilment for the requirements for the degree of Doctor of Philosophy, at the University of Central Lancashire

November 2024

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- 1 Abstract
- 2

3 The period of transition from late adolescence to adulthood is a pivotal life stage characterised 4 by increasing autonomy, risk-taking and many developmental changes. This can lead to 5 poorer food choices, which will directly impact dietary intake. The presence of a food allergy 6 will significantly impact both food choice and dietary intake due to the implementation of 7 avoidance diets and the reduced access to safe, allergen-free food. The management of food 8 allergies during the life stage of late adolescence necessitates adequate support. Despite this, 9 access to sufficient support is a challenge for this group. At present, little research exists 10 exploring the food choice, food access, dietary intake and healthcare access of late 11 adolescents with food allergies. To understand the factors which influence food choice and 12 therefore dietary intake and to understand the challenges and opportunities faced by late 13 adolescents with food allergies when accessing food and healthcare is crucial. This can enable 14 the development of tailored interventions which contribute to a more robust support system, 15 consequently optimising the overall health and quality of life in this group. Therefore, the 16 overall aim of this research was to investigate the current food choice, food access, healthcare 17 access and dietary intake in late adolescents with food allergies in North West England.

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This research consisted of five stages - the first three addressing the current food choice, food access and healthcare access of late adolescents with food allergies; the fourth stage explored their dietary intake while in the fifth stage, possible interventions were discussed and suggested with a diverse group of participants (food-allergic patients, parents/carers and healthcare professionals) to improve the current food and healthcare access of late adolescents with food allergies.

25

26 A mixed methods approach was used for this research. Through quantitative questionnaires, 27 geographical mapping and qualitative focus groups, the current food choice, food access and 28 healthcare access of late adolescents with food allergies was explored. In each case, a 29 comparative analysis between late adolescents with and without food allergies was also 30 conducted. Main results highlighted no differences between groups in relation to food choice. 31 Challenges in accessing allergen-free foods were also identified. Similarly, late adolescents 32 with food allergies struggled in accessing sufficient healthcare, in particular nutritional and 33 psychological support were challenging. Through diet diaries the current dietary intake of late 34 adolescents with food allergies was also explored. Dietary intake was found to be broadly 35 similar in both late adolescents with and without food allergies. Diet quality was considered to 36 be poor in all participants, with increased intakes of saturated fat, refined carbohydrates, sugar 37 and salt and an inability to meet the recommended fibre intake. A novel approach of this

research was the collaboration between food-allergic patients, parents and healthcare
 professionals in recommending potential interventions based on the findings of each stage of
 this research.

41

42 The results of this PhD research have important implications for further research. Late 43 adolescents with food allergies desire to be like their peers and balancing this with the realities 44 of managing food allergies is a challenge. The need to create an environment that promotes inclusivity while at university and supports the needs of late adolescents with food allergies is 45 46 crucial. Additionally, access to quality health care that considers the unique needs during the 47 transition from adolescence to adulthood is an imperative aspect of management. 48 Collaboration is key - educational institutions, healthcare providers, policymakers and food-49 allergic patients themselves must work together to ensure a holistic and supportive approach 50 in the management of food allergies.

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#### **List of Abbreviations**

- AFF Allergen Free Foods
- BSACI British Society for Allergy and Clinical Immunology
- DRV Dietary Reference Value
- EAACI European Academy for Allergy and Clinical Immunology
- FA Food Access
- FAP Food Allergic Patients
- FC Food Choice
- GPsWER's GPs with Extended Roles
- HCA Healthcare Access
- HCP Healthcare Professional
- IMD Index of Multiple Deprivation
- LA Late Adolescents
- LSOA's Lower-Layer Super Output Areas
- NHS REC National Health Service, Research Ethics Service
- NICE National Institute for Health and Care Excellence
- NIHR National Institute of Health Research
- NW North West of England
- PAL Precautionary Allergen Labelling
- P/C Parent/Carers
- UCLan University of Central Lancashire

#### Acknowledgements

I would like to take this opportunity to thank all those who made this Doctoral thesis possible.

First and foremost, I would like to thank my supervisory team Dr Jan Mei Soon-Sinclair, Professor Mick McKeown and Dr Timothy Smith for their invaluable guidance, support and expertise throughout this journey. In particular, I wish to extend my sincerest thanks to my primary supervisor Dr Jan Mei Soon-Sinclair, for your dedication, expertise, and continued feedback during every phase of this research. Your tireless efforts in reviewing my work and your insightful comments and suggestions have been instrumental in shaping this thesis. I feel extremely fortunate for your guidance and am deeply thankful to have had you as my mentor.

I would also like to acknowledge Dr Komali Kantaman, Dr Upaka Rathnayake and Dr Randika Makumbura for their continued guidance and support in the geographical mapping chapter and also to Dr Shingai Nyarugwe for your assistance with focus groups and thematic analysis.

I am also very grateful to the National Institute of Health Research, ARC North West Coast, (NIHR ARC NWC) for their funding, which played a crucial role in the successful completion of my research project.

A huge thanks to all of my public advisors – your valuable insights, experiences and feedback have certainly enriched the depth and quality of this thesis.

A special mention to all of my family, I am extremely fortunate for your continued support.

And lastly to my husband - thank you for your encouragement and understanding during the challenging phases of my research journey. I am profoundly grateful for your continued patience, support and belief in me.

- 1 Chapter 1
- 2

3

#### 1.1. Introduction

4 5

6 The primary focus of this research was to explore the current food choice (FC), food access 7 (FA), dietary intake and healthcare access (HCA) of 18-25year olds with food allergies in the 8 North West of England. This research has been made possible through funding from the 9 National Institute of Health Research, Applied Research Collaboration, North West Coast 10 (NIHR ARC NWC). A Health Inequalities Assessment Toolkit (HIAT) was used to continuously 11 inform this research ensuring equity at every stage.

12

13 The World Allergy Organisation (2017), has defined food allergy as a 'hypersensitivity reaction 14 initiated by proven or strongly suspected immunologic mechanisms.' Food allergies are 15 typically mediated by IgE antibodies, which are characterised by the rapid onset of symptoms 16 following ingestion. This can include hives, swelling, vomiting, abdominal pain and in more 17 severe instances, anaphylaxis. In some cases non-igE mediated mechanisms can also be 18 involved. Effects of these types of reactions are generally delayed upon consumption of the 19 offending food, causing milder reactions, with gastrointestinal symptoms and inflammation the 20 most common of manifestations (Lopez et al., 2023). Over the last few decades, diagnostic 21 rates of food allergy in the UK are ever increasing (Daniels et al., 2021). While self-reported 22 food allergy in the UK has reached up to 20%, the number of clinically diagnosed food allergies 23 is much lower affecting between 1 and 2% of the UK population (FSA, 2017; Allergy UK, 2024). 24 Food allergy can develop at any age and are more common in children than adults. 25 Approximately 6% of the adult UK population are affected by food allergy (FSA, 2024), while 26 in children this is thought to be between 6 and 8% (BSACI, 2024). In individuals where 27 sensitisation has occurred from previous exposure, any food protein can cause allergy. In the 28 UK there are eight top allergens that trigger 90% of all food allergy reactions – milk, egg, soy, 29 wheat, fish, shellfish, peanut and tree nuts (Allergy UK, 2021). A recent study conducted by 30 the Foods Standards Agency (2024) highlighted how peanuts and tree nuts were most likely 31 cause allergic reactions in UK adults. Allergies to fresh fruits (related to birch pollen) were also 32 prevalent in this group, while milk, fish, shrimp and mussels were least likely to cause allergies. 33 In comparison, milk, egg and peanuts are the most common causes of food allergy in UK 34 children (BSACI, 2024).

35

36 From the age of 18, individuals will likely transition into further education or employment 37 naturally shifting from a phase of heavy reliance on parental influence, to one of greater 38 autonomy (Zarrett and Eccles, 2006; Curtis, 2015; Bonnie and Backes, 2019). Much literature 39 indicates that for this period of late adolescence to adulthood, 18-25 years is perhaps the most 40 inclusive range (Zarrett and Eccles, 2006; Beresford and Stuttard, 2014; Curtis, 2015; 41 Jaworska and Macqueen, 2015; Steinberg, 2015; Sawyer et al., 2018; Roberts et al., 2020). 42 Therefore, this piece of research will use the age range of 18-25 years to characterise 43 this period of 'late adolescence.' The life stage of late adolescence itself is both unique and 44 complex. It is characterised by varying stages of biological growth, social transitions and 45 psychological advances. These individuals will likely have an increased desire for 46 independence and a belief of invincibility. The need to explore and experiment is heightened 47 as social identity is pursued, often leading to much risk-taking in this group (Zarrett and Eccles, 48 2006; Curtis, 2015; Sawyer et al., 2018; Bonnie and Backes, 2019). Throughout this process 49 of human development, the additional burden of managing a food allergy will prove challenging 50 and thus, it is no surprise why LA with FA possess the highest risk of fatal reactions (Newman 51 and Knibb, 2020). Optimal access to quality food and healthcare is therefore demanded in this 52 group. Despite this, little support in this regard is currently available specifically for this group 53 of individuals.

#### 54

55 For LA with food allergies, the need for a quality diet encompassing all essential nutrients, 56 without compromising safety is crucial - not only as means of enhancing academic 57 performance, but also to maintain good overall health. The implementation of an avoidance 58 diet (as is one of the main forms of treatment for food allergy) will prove difficult in LA. These 59 individuals will be influenced by social pressures and peer pressures and the increased risk-60 taking can make it difficult to appropriately screen food products to ensure their suitability. 61 Consequently, this will restrict FC while also increasing the risk of accidental exposure (Dilley 62 et al., 2018; Tackett et al., 2019). Furthermore, while allergen-free foods offer a safe and 63 diverse means of improving FC and consequently dietary intake, they are considerably more 64 expensive, with their availability limited to large supermarkets. In addition to this, accessing 65 sufficient healthcare for LA with food allergies is a challenge (Royal College of Physicians, 66 2003; Barker et al., 2021). This stems from multiple reasons. For instance a limited number of 67 allergists, reduced confidence and training among health professionals and increased waiting 68 times for diagnosis and treatment (Diwakar et al., 2017; Khaleva et al., 2020). Delayed and/or 69 inadequate allergy care will lead to an increased risk of allergic reactions in patients, causing 70 a host of issues; for example, heightened anxiety, social isolation, reduced dietary quality, and 71 in more severe cases, hospitalisations and anaphylaxis. This in turn will dramatically reduce 72 overall health and well-being (Groetch and Venter, 2020; Knibb et al., 2023). Two additional 73 contributing factors to the reduced food and HCA in LA with FA, are geographical location and 74 socioeconomic status (Warner et al., 2006; Bilaver et al., 2016).

75 Clearly, the inabilities of for LA with food allergies to access appropriate food and healthcare 76 will not only prove detrimental to health, but will inevitably increase the existing burden on the 77 healthcare systems. In the field of allergy, research in specifically LA between the ages of 18 78 and 25 years is almost non-existent, with most studies focusing on either childhood or 79 adulthood. While some literature has looked at the current food and HCA of those with food 80 allergies, little research has explored this in the UK context. Similarly, few pieces of research 81 have investigated the impact of food allergies on the food and HCA of specifically LA, despite 82 this being a crucial life stage which will shape future behaviour. Hence, there is a need to 83 further investigate food and HCA in this group of LA to identify existing disparities and 84 challenges faced. This will lead to the development of effective interventions that will improve 85 the overall health and well-being of these individuals. Therefore, in this PhD research the 86 current food and HCA of LA with food allergies will be investigated.

87

#### 88 1.1. <u>Research Aims and Objectives</u>

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The overall aim of this research was to investigate the current FC, FA, HCA and dietary intake
in LA with food allergies in North West (NW) England. The aim is supported by 5 specific
objectives.

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94 FC is a multifactorial and complex process. Biological (taste, smell, hunger), social (family, 95 peers, culture), psychological (emotion, stress) and economic (cost, availability, income) 96 factors are considered to be major determinants of FC. The period of transition from late 97 adolescence to adulthood is a challenging developmental stage, due to factors such as 98 increased peer pressure, risk-taking and heightened emotions, which can lead to poor FC. 99 Additionally, the presence of a food allergy itself can further elicit negative FCs. Therefore, the 100 first objective was to understand these various factors impacting FC behaviour in LA 101 with and without food allergies. Additionally, physical access to food is an important factor 102 in predicting FC behaviour and thus, the second objective was to determine the access to 103 healthy, nutritious food and allergen-free food in those with and without food allergies. 104 In addition to this, FC behaviour has a direct impact on dietary guality and therefore, the third 105 objective involved determining the dietary intake of individuals with and without food allergies. To our knowledge, this is the first piece of research investigating FC, FA and dietary 106 107 intake specifically in LA with food allergies. Results obtained from these studies will further 108 our understanding of FC and FA during this critical period of transition and will help to identify 109 the most influential determinants of FC. This information can therefore be utilised to empower young people in adopting healthier behaviours, which will consequently allow for nutritional 110 111 needs to be met, inevitably improving future health status.

112 Throughout this period of transition, LA will have to assume personal responsibility while 113 managing their chronic food allergies. During this time, individuals will require healthcare 114 systems to provide the necessary support and guidance. Despite this, adequate support is 115 currently not available that targets the specific needs of LA with food allergies, undergoing this 116 critical period of transition. Individuals will have no choice but to continue to attend paediatric 117 allergy clinics before transferring to adult allergy clinics at approximately 18 years. With little 118 or no services to support this transition process, LA will often be left feeling lost in the system. 119 They will feel as though they have outgrown the support they once relied on during their 120 childhood years, while feeling too young to adopt the role of an adult. Therefore, the fourth 121 objective explored the current HCA for LA with food allergies from both the perspective 122 of the food allergic patient, the parent and the HCP. Additionally, the barriers and 123 facilitators experienced by HCP in providing care for this group were also determined. 124 Limited research is currently available investigating current healthcare for LA with food 125 allergies. It is hoped that the findings from this study will help to identify the healthcare needs 126 of food-allergic patients and any existing gaps in knowledge and training of HCP. This in turn 127 will allow for the recommendation of necessary interventions, with the intention of informing 128 and influencing services to maximise the quality of care distributed, ultimately allowing for the 129 successful management of food allergies.

130

131 Socioeconomic status has a considerable influence on FA and HCA. Those with fewer 132 resources who are from socio-economically disadvantaged groups, are more likely to make 133 poorer choices in relation to food (Monterrosa et al., 2020). Likewise, the cost of medication 134 and continued support (e.g. travelling long distances for healthcare) will further burden these 135 individuals, limiting their access to appropriate food and healthcare (Minaker et al., 2014). The 136 presence of a food allergy itself will automatically place these individuals at a further 137 disadvantage, consequently increasing their risk of food and health insecurity. Therefore, data 138 collection for each of the above aims was concentrated in the NW Region of England, as this 139 area has a large number of neighbourhoods with high levels of socioeconomic deprivation. LA 140 are the most understudied age population with respect to FC, FA, HCA and dietary intake, 141 despite this being a crucial life stage where optimal dietary guality and healthcare is required. 142 Even less data are available for LA with food allergies and as such, the target population for 143 each of the above studies focused on those between the ages of 18 and 25 years. A 144 comparison for each of the above aims between those with and without food allergies was 145 also conducted, as means of exploring any potential differences between the two groups. 146 The overall results from each study will further our understanding into the current FC, FA, HCA

and dietary intake of LA with and without food allergies in the NW. This will ultimately lead
 to the final objective to suggest preventive interventions with FAPs, parents of

individuals with food allergies and healthcare practitioners who have had experience in providing care for LA with food allergy. Based on the findings of each phase, a collaborative effort in the form of potential interventions to improve the current FC and therefore dietary intake, FA and HCA in LA with food allergies will be suggested. Consequently, the proposed recommendations will provide an evidence based foundation that if implemented, will undoubtedly have potential to mitigate the negative impacts of food and health inequity in LA with food allergies.

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#### 157 1.2. Thesis Outline

- 158
- 159 An overview of the PhD study has been illustrated in Figure 1.1



176 **Figure 1.1.** An overview of the PhD study

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182 The current chapter (Chapter 1) provides a general overview of the research, research aims183 and thesis outline.

184

Chapter 2 reviews the existing literature in relation to FC, FA and HCA. It begins by reviewing the incidence and prevalence of allergy in a global context, later moving on to a more specific focus in the UK and the NW region. Health inequalities in allergy care are then mentioned, followed by a discussion of allergy at the primary care level and the importance of transition care. The beneficial role of a range of allied health professionals in allergy care are also discussed. This chapter then moves on to looking at FC behaviour in specifically LA before concluding with a section on food insecurity.

192

193 In Chapter 3, quantitative questionnaires were used to determine an initial insight into factors 194 influencing FC as well as food and HCA of LA with and without food allergy. The food and 195 HCA results from this chapter were then geographically represented using mapping software 196 (ArcGIS), to highlight which specific areas within the NW had reduced access to food and 197 healthcare. A comparison was also made between those with and without food allergies. This 198 is described in Chapter 4. Chapter 5 specifically focuses on the current HCA available for LA 199 with food allergies from the perspective of the HCPs themselves. This again was achieved 200 through quantitative questionnaires. In Chapter 6, an in-depth analysis of FC, FA and HCA is 201 determined through qualitative focus groups. Thematic analysis using NVivo was used to 202 analyse the data. In this study, the perspective of the food-allergic patient, the parent and the 203 HCP was considered. FC behaviour determines food consumption and Chapter 7 therefore, 204 provides a comparative analysis of dietary intake in LA with and without food allergies. Data 205 collection was achieved through 4-day diet diaries and analysed using the software Nutritics. 206 Based on the findings of each of the above studies, Chapter 8 discusses interventions to 207 improve the current FC and therefore dietary intake, FA and HCA of LA with food allergy in 208 NW England. This was achieved through one qualitative focus group, whereby through 209 collaborative effort, food-allergic patients, parents and HCP contributed to potential 210 interventions. The final Chapter (Chapter 9) readdresses the principal aim and objectives of 211 this research and provides an overview of the findings of the studies conducted throughout 212 this project. Limitations are mentioned and recommendations for further research are also 213 outlined in this chapter.

- 1 Chapter 2
- 2

#### 3 Literature Review

4

5

#### 2.1. Allergy – Incidence, Prevalence, Treatment and Direct Cost

6

7 The incidence and prevalence of allergy across the world has increased and is continuing to 8 do so (Daniels et al., 2021). Approximately 20% of the global population is affected by allergic 9 disease (Dierick et al., 2020). This is being seen in both developed and developing countries. 10 Developing countries are most at risk, where the paucity of allergy care services alongside the 11 sharp increase associated with urbanisation, will cause a significant burden (Asher, 2011; 12 Hossny et al., 2019; Daniels et al., 2021). The UK has one of the highest rates of allergy, with 13 approximately 18 million allergy sufferers (BSACI, 2023). It has been estimated that 44% of 14 all UK adults and 50% of all UK children are experiencing some allergy-related conditions 15 (Cruddas, 2023; Allergy UK, 2024). In particular, there has been an increased prevalence of 16 food allergies. (Rachid and Keet, 2018; De Martinis et al., 2020). Currently, 2.4 million people 17 in the UK are living with a food allergy (FSA, 2024). Therefore, this high prevalence of allergic 18 disease warrants sufficient management.

19

20 One primary treatment of food allergies is the avoidance of the offending allergen. This in itself 21 is a challenging task. One which requires knowledge of interpreting food labels, an increased 22 vigilance to minimise the risks of cross contamination and an adequate communication of the 23 food allergy to other's (Rachid and Keet, 2018). Recent developments in food allergy research 24 are also exploring additional options, including oral immunotherapy (the practice of gradually 25 increasing amounts of a food allergen to desensitise the immune system) and sublingual 26 immunotherapy (placing food allergens beneath the tongue to desensitise the immune 27 system). One example of oral immunotherapy for peanut allergy sufferers is the use of a drug 28 called Palforzia - the first licensed treatment for peanut desensitisation. These alternative 29 options offer potential treatments for those with food allergies and have shown great promise, 30 thus raising hope for the many suffers of food allergic disease (Sicherer et al., 2020; Muraro 31 et al., 2022; Pouessel and Lezmi, 2023).

32

The increased prevalence of allergy will place an increased burden on the health care systems
 (Tang and Mullins, 2017). Health care services will face considerable direct medical costs,
 owing to the diagnosis, management and prevention of allergic disease (Daniels et al., 2021).

36 In the UK, the cost to the National Health Service for all allergic diseases exceeds £1 Billion 37 per annum (Allergy UK, 2024). A UK study on peanut allergies estimated the annual cost per 38 patient to be between £253 and £333, with a national burden of £33 and £44 million in the 39 year 2015 alone (Scott et al., 2019). Additionally, this substantial cost associated with the 40 management of food allergies is further emphasised by Fong et al. (2022). They mention the 41 significant economic burden of food allergies in the UK, highlighting the direct medical costs 42 associated with hospital admissions and treatments and the indirect medical costs like lost 43 productivity due to time off work. They further mention the high cost of allergen free foods, 44 which further add to the financial strain of food allergic patients. A more recent study 45 conducted by Allergy UK in 2023, further highlights the ongoing financial strain associated with 46 managing food allergies. In this study, 63% of parents expressed their concerns about the 47 financial burden associated with managing their child's food allergy (Allergy UK, 2024).

48

Clearly, the cost of allergic disease is high. With allergies expected to rise, the cost required for management will only continue to increase, further straining the burden that already exists on the health care systems (Fong et al., 2022). Effective allergy services can and will reduce the overall burden on both the patient and the health care systems, thereby reducing overall costs.

54

#### 55 2.2. <u>Allergy Service Provision</u>

56

Allergy is a major public health problem. Despite a global increase in the incidence and prevalence of allergy, services remain inadequate and are struggling to meet current demands (Barker et al., 2021; Daniels et al., 2021). This challenge is not a new one with the Royal College of Physicians highlighting the insufficiency of allergy services as early as 2003 (Royal College of Physicians, 2003).

62

63 Access to and standards of allergists and allergy services greatly vary across countries. In 64 2006, Warner et al. conducted a study that showcased the global variation in allergy service 65 provision in a number of countries. Their results highlighted an enormous variation between 66 countries at this time (Table 2.1). For instance, Germany had approximately 5,000 certified 67 allergists, clearly offering a much better allergist to population ratio when compared to many 68 other countries. On the other hand, the UK had only 1 allergist per 1,083,333 people - one of 69 the lowest ratios globally. There were also some countries, for example Bangladesh, where 70 there were no certified allergists at all, illustrating the global inequity in allergy care (Warner et 71 al., 2006).

72 Fast forward to the year 2019 and the situation for allergy care had not improved in many 73 regions. Fyhrquist et al. (2019) conducted a study to update and expand on the findings from 74 Warner et al. (2006), specifically focusing on both specialists and subspecialists in allergy care 75 (Table 2.2). Their research indicated that countries such as the UK continued to remain 76 behind, having the lowest ratio of specialists and sub-specialists in allergy per 100,000 77 inhabitants. It was specified how the UK had only 0.05 specialists and 0.15 subspecialists per 78 100,000 inhabitants, reflecting minimal progress over the 13 years. Conversely, countries like 79 Germany had significantly higher numbers with 6.04 subspecialists per 100,000 inhabitants, 80 illustrating a better allocation of resources towards allergy care in this country.

81

Interestingly, even highly developed regions such as Hong Kong, were found to have limited allergy service provision. Chan et al. (2015), highlighted how the ratio of allergy specialists to patients can reach a shocking 1:2.8 million in Hong Kong (Chan et al., 2015). Additionally, only four Immunology and Allergy specialists were listed in the Hong Kong Medical Council Specialist Register, with only two of them practicing allergy (The Medical Council of Hong Kong, 2017; Lee et al., 2019), further emphasising the limited resources in this country.

88

89 By 2021, the gap in allergy service provision remained a pressing issue, despite the growing 90 recognition of the need for improved healthcare services to manage the increasing prevalence 91 of allergies (Barker et al., 2021; Daniels et al., 2021). Although improvements have been made 92 in addressing the shortage of allergy services globally, significant gaps remain. Chong et al. 93 (2023) further emphasise the ongoing challenges in accessing allergy care, particularly in the 94 context of the UK. Their research highlights the persistent shortage of allergists, the uneven 95 distribution of resources and the high financial burden on allergy patients and the healthcare 96 system. They argue that although some countries have made strides in improving the number 97 of allergy specialists and improving service provision, the UK continues to struggle with 98 inadequate resources and difficulties in accessibility. They conclude their research by 99 emphasising the need for continued investment in allergy services and more equitable 100 distribution of healthcare services to better manage the growing allergy epidemic. Despite the 101 UK being a highly developed country, they still face considerable challenges in allergy service 102 provision, as reflected in both historical and recent studies.

#### **Table 2.1.** Number of allergists per head of the population across different countries

Country	Allergists per head of	Country	Allergists per head of	Country	Allergists per head of
	the population		the population		the population
Argentina	1:46,353	Honduras	1:1,380,000	Romania	1:197,577
Belgium	1:900,000	Hungary	1:50,000	Serbia/Montenegro	1:500,000
Brazil	1:100,000	Israel	1:52,000	South Africa	1:1,666,666
Bulgaria	1:106,250	Italy	1:43,200	Spain	1:44,000
Chile	1:500,000	Japan	1:61,200	Sweden	1:42,857
Colombia	1:571,428	Lebanon	1:121,000	Switzerland	1:36,649
Czech Republic	1:17,543	Malaysia	1:25,000,000	Thailand	1:1,000,000
Denmark	1:135,000	Mexico	1:175,000	Turkey	1:1,076,923
Ecuador	1:2,400,000	Mongolia	1:2,250,001	United Kingdom	1:1,083,333
El Salvador	1:470,000	Paraguay	1:200,000	Ukraine	1:94,441
Finland	1:94,545	Peru	1:1,360,000	Uruguay	1:110,000
France	1:1,240,000	Philippines	1:66,115	USA	1:65,546
Germany	1:16,000	Portugal	1:63,334	Venezuela	1:109,090
Greece	1:183,333				

\*Source: Warner et al., 2006

104	Table 2.2. Number of allergy specialists and sub-specialists absolute and (per 100,000 inhabitants) across different countrie	s
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Country	Specialists	Sub-specialists	Country	Specialists	Sub-specialists
Albania	48 (1.64)	-	Kosovo	17 (0.95)	-
Austria	-	-	Latvia	-	25 (1.28)
Belgium	-	-	Lithuania	60 (2.08)	8 (0.28)
Bulgaria	74 (1.04)	-	Luxemburg	1 (0.17)	15 (2.57)
Croatia	29 (0.69)	60 (1.43)	Netherlands	4 (0.02)	37 (0.22)
Cyprus	2 (0.17)	-	Norway	-	-
Czech Republic	350 (3.30)	-	Poland	1200 (3.14)	-
Denmark	-	-	Portugal	250 (2.42)	-
Estonia	3 (0.23)	15 (1.15)	Romania	181 (0.81)	-
Finland	-	110 (1.99)	Russia	2000 (1.39)	-
France	520 (0.80)	1300 (2.00)	Serbia	-	31 (0.35)
Georgia	233 (5.96)	-	Slovakia	253 (4.65)	-
Germany		4962 (6.04)	Slovenia	-	-
Greece	148 (1.33)	-	Spain	1500 (3.24)	103 (1.04)
Hungary	-	500 (5.14)	Sweden	70 (0.71)	-
Iceland	-	12 (3.58)	Switzerland	150 (1.77)	-
Ireland	-	-	Turkey	-	316 (0.39)
Israel	-	90 (1.07)	UK	30 (0.05)	100 (0.15)
Italy	1630 (2.74)	-		1	

\*Source: Fyhrquist et al., 2019

- Indicates lack of specialist/sub-specialist

#### 105 2.2.1. UK Allergy Care

106

107 Even developed countries such as the UK are delivering suboptimal allergy care, greatly 108 reducing patient experience and health outcomes. The UK has an outstanding record of 109 scientific allergy research, yet historically clinical services for allergy sufferers have been 110 severely under resourced and under supplied, leading to poorer patient care (Warner et al., 111 2006; Finlay and Egner, 2010; Diwakar et al., 2017; Fyhrquist et al., 2019; Chong et al., 2023). 112 In 2010, Finlay and Egner described the UK allergy care as 'basic' – a valid statement given 113 that at that time, there were only six fully staffed major allergy clinics in the UK offering a full-114 time service and an additional nine allergy services offering a part-time service. Moreover, 115 these specialist services were also hindered with untrained personnel and the high numbers 116 of poor referral practices from primary care services led to long waiting times and so reduced 117 patient care. The lack of specialists also meant that clinical training opportunities were limited 118 (RCP, 2003; Finlay and Egner, 2010; RCP, 2010). 119

Since then however, the number of allergy clinics in the UK have considerably improved, with 115 allergy clinics now available according to the BSACI. While the North of the UK is home to 40 allergy clinics (17 adult allergy clinics and 23 pediatric allergy clinics), the South has a total of 75 allergy clinics (24 adult allergy clinics and 51 pediatric allergy clinics (BSACI, 2024). This stark contrast between the North and the South suggests that although access to allergy services have become more widespread, the distribution of services is uneven, indicating a continued struggle in in equitable access to allergy care.

127

#### 128 **2.2.1.1.** Call for Improved Allergy Services in the UK

129

A number of reports spanning from the early 1990s to 2010 have extensively detailed the
 paucity of allergy specialists, the inadequate training among HCPs and the poor
 communication between stakeholders and health services in the UK.

133

The Royal College of Physicians (RCP) (a professional membership body for physicians) released two reports in the 90's – 'Allergy: conventional and alternative concepts' and 'Good allergy practice: standards of care for providers and purchasers of allergy services within the NHS.' Both reports highlighted the need of delivering a competent allergy service to the public. They drew attention to the importance of good clinical practices in allergy and the standards of care required. Additionally, the dangers of relying on practitioners of complementary and alternative medicines were also mentioned. Although both reports were well received and

detailed the efficacies of certain interventions, they did not necessarily impact the 141 142 improvement of allergy services in the NHS (RCP 1992; RCP, 1994). The continued impact of 143 allergies and the continued shortage of allergy services consequently led to the third report in 144 2003. This report further outlines the inadequacies of allergy services, the unmet needs of 145 many patients suffering from allergy and as a result, the reduced quality of life they endure 146 (RCP, 2003). The contents of this report was extremely critical that the Department of Health 147 conducted a review in 2004, which led to a UK parliamentary report being issued and a 148 document titled 'The provision of allergy services' was created. The report highlighted the 149 serious problems that existed in the care of allergy patients, particularly in the primary care 150 setting. Recommendations for the inclusion of allergy training in the curriculum for trainee 151 doctors and specialist allergy clinics was made (House of Commons, 2004). In 2006, the 152 Department of Health published a further report 'A review of services for allergy.' The report 153 highlighted the 'serious problems' that existed in the quality of NHS allergy service provision. 154 The need for a greater capacity of services in allergy along with clinical specialists was outlined 155 (Department of Health, 2006). Similarly, the House of Lords Science and Technology 156 Committee led an inquiry into allergy in 2007. A number of practical steps were recommended, 157 including the development of expert centres, which would lead to an improvement in services 158 (House of Lords, 2007). Unfortunately however, these many reports by the House of 159 Commons, Department of Health and House of Commons did not lead to any change in health 160 care policy concerning allergies. In fact, seven years on from its last report, the RCP released 161 yet another titled, 'Allergy services: still not meeting the unmet need' which illustrated that 162 despite the development of multiple intervening parliamentary reports, issues relating to 163 allergy service provision had still not been adequately addressed, largely due to lack of funding 164 being provided (RCP, 2010). All these reports which were published in the UK, showcase that 165 even affluent developed areas can deliver sub-optimal care, leading to reduced patient 166 outcomes and experiences. Additionally, they consistently highlight the ongoing challenges in 167 allergy care, emphasising the persistent gaps in service provision over nearly two decades.

168

169 In recent times, there has been a greater focus on addressing these issues. Many national 170 and international organisations have developed various clinical guidelines which incorporate 171 published evidence to improve and standardise care in the UK. For example, the UK National 172 Institute for Health Care and Excellence (NICE) have produced guidance on multiple allergy 173 topics including eczema, anaphylaxis, food allergy and drug allergy (NICE, 2020). Equally, the 174 British Society for Allergy and Clinical Immunology (BSACI) and the BSACI Standards of Care 175 Committee (SOCC) have developed guidelines for conditions such as allergen 176 immunotherapy including allergic rhinitis, drug allergies, anaphylaxis, chronic urticaria/angio-177 oedema and additionally, specific guidance on food allergies such as milk, nut, peanut and

egg allergy (BSACI, 2006; BSACI SOCC 2021). More recently, the BSACI have released a new initiative to enhance UK allergy services by empowering GPs with specialised training in allergy care – GPs with Extended Roles (GPwER's). The work focuses on increasing the number of GPs who can effectively manage allergy cases within primary care, reducing the strin on specialist services and thus improving patient outcomes. This initiative represents a significant step towards addressing the gaps in allergy service provision in the UK (BSACI, 2023).

185

186 Similarly, the lack of allergy services in Europe were also recognised and advances in 187 research and care in this field were prompted. The European Academy of Allergy and Clinical 188 Immunology (EAACI) released multiple guidelines over time which detail evidence-based 189 recommendations for use in clinical practice (EACCI, 2023). From amongst these multiple 190 guidelines, majority address the clinical aspects of care with only few focusing on supporting 191 patient self-management and education and even fewer involving patients and caregivers. 192 who play a key role in the management of allergy itself. Most recently, EAACI have developed 193 a practical toolbox specifically for the effective transition of adolescents and young adults with 194 asthma and allergies. Their research considers a multidisciplinary approach and includes a 195 careful selection of valuable resources, tailored for HCPs, patients, parents, the workplace 196 and the wider community (Vazquez-Ortiz et al., 2023). Thus, to date this EACCI toolkit is the 197 most comprehensive guideline available for the management of allergies.

198

#### 199 **2.2.1.2**. Summary

200

201 There is a renewed momentum to improve allergy care and significant strides have been made 202 to address the shortcomings in UK allergy services. At present however, little real-life 203 application and implementation of these guidelines have been seen. The primary reason for 204 this would be the lack of priority and investment into allergy service provision, as well as the 205 lack of political will (Sinnott and Dudley-Southern., 2011; Jutel et al., 2013; Vance et al., 2021; 206 Chong et al., 2023). As more research is conducted, further advancements in allergy are 207 anticipated and this will likely lead to more effective and widespread implementation of 208 guidelines and strategies to better manage allergies, improve patient outcomes and reduce 209 the burden of allergies in the UK.

210

211

212

#### 214 2.2.2. Accessing Allergy Care in the North West

215

216 Access to quality allergy care is necessary for all those suffering from allergies. 217 Communication, understanding and trust are essential components that must be established 218 to provide effective care. This requires both the patient and the HCP to be both physically and 219 mentally present during a consultation (Angier and Jay, 2019). Services closer to the home of 220 patients will therefore support their ability to attend. However, there is a marked geographical 221 inequality in allergy service provision in the UK. Most specialists are based in London and the 222 South East. Specifically, those living in the NW face challenges in accessing health care for 223 their allergy, due to limited availability of allergy services in this region (BSACI, 2024). One 224 main reason for this, is due to the high levels of deprivation that exist in the North West (NW). 225

#### 226 **2.2.2.1.** Indices of Multiple Deprivation

227

Deprivation refers to the unmet needs caused by a lack of a broad range of resources and opportunities (Noble et al., 2019). Deprivation can lead to health inequalities which can lead to an increased incidence of disease, a greater number of mental health issues, reduced quality of life and high mortality rates. Therefore, increased deprivation levels will consequently lead to an increased burden on the health care systems (Charlton et al., 2013).

233 The English Indices of Deprivation is an important tool that attempts to measure this broad 234 concept of multiple deprivation across England. The Indices of Deprivation is based on a 235 weighted combination of seven distinct domains (1. Income Deprivation, 2. Employment 236 Deprivation, 3. Education, Skills and Training Deprivation, 4. Health Deprivation and Disability, 237 5. Crime, 6. Barriers to Housing and Services, 7. Living Environment Deprivation) (see Figure 238 2.1). This allows for an overall relative measure of deprivation to be produced, known as the 239 Index of Multiple Deprivation (IMD), which consequently highlights the most deprived areas in 240 England.

241 In 2019, the latest Indices of Deprivation report was released highlighting those areas within 242 England that are the most deprived (Noble et al., 2019). Noble et al. (2019), highlights how 243 45% of districts ranked in the most deprived areas of England, are in the NW region. The 244 report further emphasises these high levels of deprivation through highlighting patterns of 245 deprivation across large areas known as Local Authority Districts. Across England, 317 local 246 authority districts exist, with 1 being the most deprived and 317, the least deprived. 247 Additionally, the report highlights deprivation across smaller neighbourhoods of relatively even 248 size containing approximately 1,500 people known as Lower-layer Super Output Areas

249 (LSOA's). Overall, the NW contains high levels of deprivation, with 45% of local authority 250 districts ranked in the most deprived decile. This high deprivation is further emphasised in 251 Table 2.3, which shows the 20 Local Authority Districts within England ranked as the most 252 deprived, based on a series of different measures. This data further reinforces the increased 253 overall deprivation that exists in the NW region. Based on the average rank, there is a 254 concentration of Local Authorities in the most deprived decile in areas in London, the Midlands, 255 the North East and in particular the NW, of which 9 of the 20 Local Authorities from this region 256 were ranked as some of the most deprived. Areas in the most deprived decile based on the 257 average score measure included large cities in the Midlands and the North. Particularly 258 cities/towns within Merseyside, Greater Manchester and Lancashire were amongst the most 259 deprived. Amongst the Local Authority Districts that were considered the most deprived 10 per 260 cent nationally, a higher concentration existed in the NW, with 10 of the 20 districts from this 261 area. The local concentration of deprivation, which includes those LSOA's that are extremely 262 deprived, showed particularly high concentrations primarily in the NW. For both income and 263 employment measures, deprivation was greatly concentrated in London boroughs and the 264 Midlands. Certain areas in the NW did feature in the most deprived decile in the income and 265 employment measures. Specifically, Manchester and Liverpool were amongst two areas from 266 the NW that were most deprived in both measures (Table 2.3).

267 The pattern of deprivation across Local Authority Districts and LSOA's helps in identifying the

268 overall intensity of deprivation across England. Clearly, high levels of deprivation were evident

across the NW region in comparison to other areas in England, based on the 2019 indices.



- 270 Figure 2.1. A description of the seven domains and their weights, which are combined to form
- 271 the overall Index of Multiple Deprivation

Table 2.3. The top 20 Local Authority Districts ranked as most deprived, based on a series of
 summary measures of the Index of Multiple Deprivation, 2019

Rank	Average Rank <sup>1</sup>	Average Score <sup>2</sup>	Most deprived 10	Local	Income	Employment
			per cent <sup>3</sup>	Concentration <sup>4</sup>	Scale <sup>5</sup>	Scale <sup>6</sup>
1	Blackpool	Blackpool	Middlesbrough	Blackpool	Birmingham	Birmingham
2	Manchester	Knowsley	Liverpool	Knowsley	Manchester	Liverpool
3	Knowsley	Liverpool	Knowsley	Middlesbrough	Liverpool	Leeds
4	Liverpool	Hull	Hull	North East Lincolnshire	Leeds	Manchester
5	Barking and Dagenham	Middlesbrough	Manchester	Liverpool	Bradford	County Durham
6	Birmingham	Manchester	Blackpool	Burnley	Sheffield	Bradford
7	Hackney	Birmingham	Birmingham	Hull	County Durham	Sheffield
8	Sandwell	Burnley	Burnley	Wirral	Cornwall	Cornwall
9	Hull	Blackburn with Darwen	Blackburn with Darwen	Barrow in Furness	Sandwell	Bristol
10	Nottingham	Hartlepool	Hartlepool	Hartlepool	Leicester	Nottingham
11	Burnley	Nottingham	Bradford	Redcar and Cleveland	Nottingham	Kirklees
12	Newham	Sandwell	Stoke on Trent	Newcastle	Bristol	Sandwell
13	Hastings	Bradford	Halton	Manchester	Kirklees	Wirral
14	Blackburn with Darwen	Stoke on Trent	Pendle	Great Yarmouth	Hull	Hull
15	Stoke on Trent	Rochdale	Nottingham	Thanet	Newham	Sunderland
16	Middlesbrough	Hyndburn	Oldham	Hastings	Tower Hamlets	Leicester
17	Rochdale	Hastings	Hastings and North East Lincolnshire	Bradford	Enfield	Wakefield
18	Hyndbum	Salford	-	Blackburn with Darwen	Wirral	Wigan
19	Wolverhampton	Oldham	Salford	Sefton	Walsall	Newcastle
20	Salford	Great Yarmouth	Rochdale	Salford	Wolverhampton	Doncaster

\*Source: Indices of Deprivation, Department for Communities and Local Government, 2015 & 2019

\*Red Font indicates Local Authority Districts based in the NW

- <sup>1</sup> Average level of deprivation across the higher level area, based on the ranks of all Lower-layer Super Output Areas
- <sup>2</sup> Average level of deprivation across the higher level area, based on the scores of all Lower-layer Super Output Area
- <sup>3</sup> The proportion of the Lower-layer Super Output Areas in the higher level area that are classified as the most deprived 10 per cent in the country
- <sup>4</sup> Identifies the higher level areas with extreme levels of deprivation, by comparing the most deprived Lower-layer Super Output Areas in the higher level area, against those in other areas across the country
- <sup>5</sup> Volume of deprivation in the larger area according to the number of people who are income deprived
- <sup>6</sup>Volume of deprivation in the larger area according to the number of people who are employment deprived

#### 274 **2.2.2.2.** Allergy Services in the North West

275

276 In early 2003, concerns were raised regarding the limited allergy service provision in NW, 277 England. This was prior to the development of the RCP 2003 report (RCP, 2003). Owing to 278 the lack of full-time allergy specialists in the NW and the small number of clinicians working in 279 this field, a strategy to improve allergy services in this region was developed. This led to the 280 development of a document titled, 'A framework for an adult allergy network in the NW: the 281 NW integrated clinical allergy service.' Though the strategy outlined stimulated much 282 discussion nationally and was in principle agreed with NW primary care trusts, it was not 283 implemented in the NW. In 2006, more work into this area was carried out to emphasise the 284 need for allergy service provision in the NW to be addressed. In response to this, The House 285 of Lords 2007 report (House of Lords, 2007) recommended setting up allergy centres in each 286 Strategic Health Authority (SHA). The government came to the conclusion that any future 287 development and provision of services in allergy would require a much clearer understanding 288 of the skills and competencies needed within the health care setting, to ensure the delivery of 289 high quality, cost-effective care at each stage of the patients journey. However, they did 290 consider the possibility of establishing a lead SHA for allergy who would communicate with 291 interested parties and Specialised Commissioning Groups (SCG's). The Department of Health 292 therefore wrote to all SHA Chief Executives to determine expression of interest. Following this, 293 the NW SHA was appointed in August 2008 and a pilot allergy service in the NW to improve 294 services was commissioned. The project received non-recurrent funding from the Department 295 of Health and was undertaken by the NW Specialised commissioning Group (NWSCG) and 296 24 primary care trusts in the NW region. The duration of the project spanned from February 297 2009 until January 2011 (Sinnott and Dudley-Southern, 2011).

298

299 It was realised that large tertiary centres would not be practical and cost-effective in large 300 cities in close proximity to one another. Rather, having access to specialist centres in 301 secondary care centres would be better received. Therefore, the primary aim was to add new 302 services to already existing ones. Specialist-led services existed in the cities of Liverpool, 303 Manchester and Preston and thus, these served as 'hubs' to create a network of inner-city 304 allergy centres. Specifically, specialist allergists, immunologists and clinicians with a particular 305 expertise in allergies were linked to the networked centre. Additionally, a multi-disciplinary 306 approach was taken and thus, specially trained nurses and GPwER's also formed part of the 307 service. Figure 2.2 outlines the development of the allergy service across the NW (Sinnott and 308 Dudley-Southern, 2011).


\*Source: Sinnott and Dudley-Southern., 2011

# 309 **Figure 2.2.** Development of allergy services for children and adults in North West, England

A number of lessons emerged during the course of the project. With improved diagnosis and treatment at the primary and secondary level, majority of patients can be treated at earlier stages. This will lead to the rapid identification of allergies and allow them to be treated appropriately, while also limiting unnecessary referrals to tertiary centres. Additionally, it was found that primary care physicians lacked confidence in diagnosing and treating more complex allergies and an increased level of training and education in this group will prove beneficial. The pilot study further demonstrated that there is a need for allergy specialists to dedicate 317 time into the training and mentoring of primary and secondary care practitioners. Moreover, 318 a costing exercise revealed that there is a significant variation in the provision of resources 319 across clinical practice and allergy service providers. To combat this, the authors suggested 320 introducing a mandatory national tariff to cover the costs of the services including training and 321 education provisions. Furthermore, the project demonstrated that there is a substantial need 322 for the delivery of competent, adequately resourced, integrated patient pathways, which 323 currently does not exist in many parts of the UK including the NW. However, this will require 324 different commissioners to work closely together, which itself is not simple to accomplish 325 (Sinnott and Dudley-Southern, 2011).

326

327 There is no doubt that the NW Allergy project raised awareness for the need of better allergy 328 service provision in this region. Despite this, many commissioners failed to appreciate the 329 burden of allergic disease and were reluctant to engage in initiatives to address these issues. 330 In their report, Sinnott and Dudley-Southern. (2011), point out that the NHS financial 331 constraints meant that current allergy services are unlikely to be prioritised leaving services 332 vulnerable and thus, inequity of care for many patients with allergies will continue to persist. 333 At present, in the NW of England 40 allergy clinics exist, of which 17 provide adult allergy 334 services and 23 focus on pediatric allergy. While this shows an improvement in the number of 335 available services, this region still falls behind. In comparison the South of England, which 336 currently is home to 75 allergy clinics, offers an increased number of allergy services (BSACI, 337 2024). This gap emphasises that despite years of effort, the same challenges continue to 338 persist - that is the ongoing difficulties of ensuring equitable access to allergy care across 339 different regions.

340

#### 341 2.2.3. Inequity in Care

342

343 Equal access to sufficient health care services is a basic requirement for all individuals. 344 Despite this, much inequity is present. Health inequalities exist in those suffering from allergies 345 and differences in healthcare access (HCA) are frequently seen in this group, leading to 346 adverse patient outcomes. These disparities are inherently linked to socioeconomic 347 disadvantages (Tepler et al., 2022).

348

349 Those from low income families experiencing deprivation struggle in accessing health care for

their allergy. It has been well established that allergy service provision across the UK is poor.

There are a limited number of specialist centres and few allergy specialists available. As such,

352 patients will have no choice but to travel long distances to obtain necessary support and/or

353 treatment. Many individuals with allergies experiencing socioeconomic deprivation will also 354 have little or no means to attend clinics and will often rely on public transport, which itself can 355 prove costly. Additionally, the increased travel will incur further costs in terms of money and 356 time. There will be added expenses of food and parking and travelling long distances will 357 repeatedly disrupt education and/or work (Minaker et al., 2014; Angier and Jay, 2021; Daniels 358 et al., 2021). This will often lead to irregular attendance by those in low-income families 359 causing patients to be discharged, inevitably losing their support. This lack of engagement 360 with medical services will firstly impact the quality of care and reduce patients' compliance of 361 medication, increasing the risk of accidental ingestions and anaphylaxis. (Filippidou et al., 362 2014). Secondly, patients will be forced to seek alternative forms of care. For instance, many 363 individuals will practice self-care and particularly, there has been a predominant increase in 364 the use of the internet to diagnose and treat allergic conditions. Though this may be more 365 easily accessible, it is often unregulated and inaccurate. Consequently, this will prove more 366 detrimental to health and thus, increase the already high burden on primary care and specialist 367 allergy services (Halls et al., 2018; Morris, 2019; King et al., 2020). Moreover, the cost of 368 specific medication (adrenaline auto-injectors) in those with allergies will present a financial 369 burden. Prescription rates of adrenaline auto-injectors have significantly increased in the UK 370 and with it the cost (Minaker et al., 2014; Diwakar, 2017). On average, the cost of an 371 adrenaline auto-injector in the UK via prescription is £9.65 (NHS, 2021) and this is 372 considerably more when bought at a pharmacy or online (Diwakar, 2017). This necessary 373 medication which is life-saving also has a limited shelf-life and thus, will need to be renewed 374 regularly further increasing costs (Minaker et al., 2014; Diwakar, 2017; Fong et al., 2022).

375

376 Particularly for those with food allergies, there are additional financial burdens. At the core of 377 management is the avoidance of offending allergenic foods and the inclusion of safe, 378 nutritionally sound alternatives. However, while allergen free foods (AFF) are tailored to suit 379 the needs of those with food allergies, they are more expensive with availability limited to large 380 supermarkets and health shops (North and Brown, 2017; Polk and Diwakar, 2017; Tepler et 381 al., 2022). AFF are between 2 to 4 times more expensive than non-AFF and hence, those 382 from lower socioeconomic backgrounds greatly struggle to access them (Polk and Dinakar, 383 2017; Coleman-Jensen et al., 2022; Tepler et al., 2022). Racial disparities were also seen in 384 accessing AFF, with Johns and Savage (2014), highlighting how Black caregivers reported a 385 lower likelihood of accessing such foods in comparison to White caregivers (Coleman-Jensen 386 et al., 2022). Moreover, research conducted by Bilaver et al. (2016), found that in those with 387 food allergies whereby individuals were facing a high economic burden, it was especially 388 challenging to access specialised care, due to the added costs of increased hospital visits, 389 emergency care visits, the costliness of avoidance diets and the inclusion of AFF.

390 Furthermore, research also indicates that there is a lack of culturally sensitive health education 391 among HCP, which can lead to the delivery of unequal care in patients. (Ryan et al., 2005). 392 Studies have shown that there is a high burden of food allergy in ethnic minority groups, yet 393 these individuals struggle to access guality health care (Krishna et al., 2020; Davis et al., 2021; 394 Jones et al., 2022). Mahdavinia et al. (2017), further emphasises this showing how inequity in 395 food allergy care exists between children of different racial backgrounds. The results of their 396 research highlighted how Black and Hispanic children were found to have shorter follow up 397 appointments with an allergy specialist, when compared with White children with the same 398 food allergy. Similarly, Kanaley et al. (2020) also highlighted how Asian, Black and Hispanic 399 children were less likely to receive food allergy diagnostic testing and be seen by an allergist 400 than White children with allergies.

401

402 Health inequalities are clearly apparent in those seeking health care for their allergy. This 403 inequity can impact all stages of an individual's care from diagnosis, prevention and 404 management. Firstly, reduced access to specialist care and poor delivery of allergy care by 405 HCP will lead to suboptimal management in patients. Secondly, those from a lower 406 socioeconomic background and those from a Black and Minority Ethnic group will face 407 additional barriers in accessing care for their allergy. As such, these individuals will have an 408 increased risk of adverse reactions, inadequate nutrition and poorer health outcomes. HCP, 409 allergy charity bodies and food companies must therefore recognise these additional burdens 410 presented to those with allergies and provide necessary support where possible. These 411 disparities in HCA further emphasise the need for more focused research on how these factors 412 affect LA with food allergies. Without proactive measures to address equity in food access 413 and healthcare services, health outcomes will continue to decline further, leading to an 414 increased burden on the healthcare systems. Specifically, this thesis will explore food access 415 and HCA in LA with food allergies in the NW region, with an aim of suggesting evidence-based 416 interventions to address these critical issues.

417

# 418 2.2.4. Allergy at the Primary Care Level

419

In the UK, a considerable amount of pressure is placed on the primary care physician or GP who provide the first point of medical contact for patients, as well as the gatekeeper to higher levels of care (Finlay and Egner, 2010; Agache et al., 2013; Diwakar et al., 2017; Chong et al., 2023). Allergy accounts for approximately 8% of GP consultations in the UK (Diwakar et al., 2017). As a basic obligation, GPs should know what their patients require and when needed they should be able to direct patients to timely appropriate care (Finlay and Egner,

426 2010). Despite this significant responsibility placed upon primary care physicians, GPs 427 possess little specialised training in allergy and are not equipped to competently deal with 428 patients (RCP, 2003; Levy et al., 2004; Daniels et al., 2021). In fact, in 2002 one survey 429 completed by 500 GPs in the UK showcased how allergy care was considered to be poor, with 430 many GPs treating patients without any basic training (Levy et al., 2004). A follow-up study in 431 2009 was conducted by Hazeldine et al. (2010), to determine if GP perceptions on allergy care 432 throughout the UK had changed. Their results revealed no notable improvements in GP 433 perceptions of UK allergy services between the period of 2002 and 2009 and further 434 highlighted that problems still persisted in allergy care throughout the NHS. These findings 435 were further mirrored by a similar survey conducted between 2010 and 2011, which looked 436 into the allergy training provision of GPs in the UK (Ellis et al., 2013). The persistence of these 437 issues can potentially explain why morbidity rates remain unacceptably high and additionally 438 why the costs associated with allergic diseases at the primary care level are substantial.

439

440 Much research indicates how GPs struggle in providing care for allergic patients as there are 441 few services and facilities in place to assist them. Specifically in the primary care setting, there 442 is a lack of availability of diagnostic testing and there is an increased difficulty in accessing 443 specialists. As such, the ability to adequately attend to the needs of those with potentially life-444 threatening allergic diseases becomes a struggle (Levy et al., 2004; Levy et al., 2009; 445 Hazeldine et al., 2010; Lowe et al., 2010; Diwakar et al., 2017). Many studies further 446 emphasise this, showing how the current allergy knowledge and training available to GPs was 447 inadequate, how only few GPs were familiar with guidelines to managing allergic disease and 448 how the continuing medical education programs for GPs were unsatisfactory (RCP, 2003; Hazeldine et al., 2010; Agache et al., 2013; Diwakar et al., 2017; Ryan et al., 2017). In 449 450 particular, GPs lacked knowledge and education in recognising allergic disease and had 451 difficulty in conducting diagnostic work-ups and referrals (Ryan et al., 2005; Agache et al., 452 2013; Diwakar et al., 2017; Ryan et al., 2017). Managing areas such as food allergy proved 453 more difficult for GPs, with previous research highlighting how only less than 30% of primary 454 care practitioners were able to comfortably interpret food allergy tests (Gupta et al., 2010).

455

Furthermore, GPs in primary care should be capable of recognising and treating milder cases of allergy, with only more severe and complex cases referred to consultants. This approach could prove more effective and reduce the overall burden on secondary and tertiary health care services, through reducing hospital admissions and treatment costs. However, the lack of support, knowledge and training provided for primary care physicians, will dramatically reduce their confidence and ability in diagnosing and managing allergic disease. As such, GPs will also commonly refer patients with mild to moderate allergies, resulting in delays in patient

463 management and therefore poor patient outcomes. This will additionally lead to a waste of 464 health care resources (Levy et al., 2004; Agache et al., 2013; Diwakar et al., 2017). Research 465 from both the UK and Ireland further emphasises how lack of knowledge and training amongst 466 GPs will lead to incorrect referrals, which are often counterproductive. Their research revealed 467 how only between 9% and 23% of referrals to allergy clinics made by primary care physicians, 468 were in fact diagnosed as patients with allergy (Jones et al., 2010; Conlon et al., 2015). 469 Additional research reinforces this, mentioning how allergies are under-diagnosed and 470 incorrectly treated at the primary care level (Jutel et al., 2013). Similarly, research by Ryan et 471 al. (2017) further supports this, showing how greater than 75% of GPs had inadequate 472 knowledge of allergen immunotherapy and felt they had little confidence in referring patients 473 to specialist care. Much research has also highlighted how GPs lack the knowledge to 474 appropriately prescribe and administer adrenaline auto-injectors, which is the only effective 475 treatment for anaphylaxis (Clark et al., 2004; Russell et al., 2010; Saleh-Langenberg et al., 476 2015; Chooniedass et al., 2017; Robinson et al., 2017; Cimen and Sayili, 2022). In fact, 477 approximately half of patients presenting to the emergency department, report having never 478 received adrenaline (Russell et al., 2010; Gelincik et al., 2013; Banerji et al., 2014; Alvarez-479 Perea et al., 2015; Sidhu et al., 2016). This can prove quite costly, with many studies reporting 480 how delayed and under-prescribed adrenaline are significant risk factors for the cause of fatal 481 anaphylaxis (Pumphrey 2000; Lieberman, 2005; Chooniedass et al., 2017; Turner et al., 482 2017).

483

484 Therefore, it is clear that this inappropriate management of allergies across primary care is 485 prevalent. First, it places an increased burden on secondary and tertiary health services, 486 causing a considerable financial burden (Jones et al., 2010; de Magalhaes et al., 2017; 487 Sullivan et al., 2017). Secondly, a negative impact on the quality of life of many allergy patients 488 will likely be seen (Diwakar et al., 2017). Lack of knowledge and training and confusion among 489 GPs can dramatically reduce the quality of care for patients with allergies and is one of the 490 primary causes of distress among patients (House of Commons, 2004). Barker et al. (2021) 491 suggest that one way of combating the knowledge and training of primary care providers, is 492 to include allergy content in the undergraduate curriculum for medical students and to 493 additionally provide ongoing postgraduate training courses. The World Allergy Organisation 494 (WAO) have previously outlined a comprehensive list of components to be included in the 495 undergraduate curricula (Potter et al., 2009). Despite this, in the UK implementation of these 496 recommendations have not been uniformly incorporated for medical undergraduates. This gap 497 in medical education contributes to the ongoing challenges in providing effective allergy care 498 by primary care physicians (Shehata et al., 2006; Shehata et al., 2007; Busse et al., 2012; 499 Reid et al., 2019).

### 500 501

#### 2.2.4.1. GPs with Extended Roles

502 In 2010, the RCP reported a greater need of improved allergy services and the need for more 503 allergy specialists, supported by an increasing training of GPs (RCP, 2010). One outcome 504 suggested by the RCP and the House of Commons was the use of GP's with special interests 505 in allergy (GPwSIs) – now referred to as GPwERs. GPwERs are GPs with special experience 506 or training which allows them to take referrals and provide care for patients normally seen by 507 specialists (Roland, 2005). This concept of extended roles for GPs within the community who 508 have additional knowledge and expertise pertaining to the field of allergy, has been suggested 509 before (Ryan et al., 2005). In fact, in the year 2000 the NHS introduced their 10 year plan of 510 reform, in which a key part included the idea of specialist GPs taking referrals from fellow GPs 511 in certain specific areas of disease. This concept aimed to improve patients access to 512 specialist care. As a result it was hoped that waiting list times and referral costs would be 513 reduced (NHS, 2000). A similar concept to this was implemented in the late 90's, whereby 514 specialists would travel to specialist outreach clinics established in primary care settings, in 515 order to provide specific care for patients. This provided a positive impact and led to reduced 516 waiting times and high patient satisfaction. However, the cost to the NHS of implementing 517 such a strategy was high (Roland et al., 1998). These findings mirror that of further studies, 518 who also detail the impact of utilising GPwERs. For instance, a randomised controlled trial 519 and an economic evaluation were undertaken by Salisbury et al. (2005) and Coast et al. (2005) 520 respectively. Their results did highlight that in the field of dermatology, GPwERs were 521 effective. Not only was the service more accessible, patients were seen more quickly, they 522 were more satisfied with the care received and were also found to have similar outcomes 523 when compared with patients seen in a specialist clinic. Despite this positive outcome, the 524 NHS cost of referring patients to GPwERs was 75% more than sending patients directly to 525 specialist clinics. This was primarily due to the fact that patients receiving care in specialist 526 clinics, alongside being seen by specialist consultants, would also be seen by junior hospital 527 staff who received lower salaries. It therefore seems that the idea of specialist GPs incurs a 528 greater cost to health services. What is clear however, is that the role of GPwERs is effective 529 for the patient and does seem to work and if this is underpinned with funding and investment, 530 then it will undoubtedly prove an efficient way of increasing specialist capacity.

531

532 Though much literature has vouched for the inclusion of GPwERs, this concept has seldom 533 been adopted in the field of allergy itself. In fact, to our knowledge there have only been two 534 reports in the UK of the use of GPwERs in allergy, both based in London (Levy et al., 2009; 535 El-Shanaway et al., 2019). The aims of these locally enhanced allergy led clinics, were to 536 ultimately bridge the gap between primary care and secondary and tertiary care. It was hoped 537 that through establishing an integrated multidisciplinary pediatric allergy service, the 538 availability of allergy care would be more accessible and there would exist a greater 539 consistency in the allergy care being provided, thus improving overall patient satisfaction. The 540 inclusion of GPweERs, alongside nurses and dietitians who were able to provide specific 541 tailored care for patients with allergy, provided a unique and beneficial addition. The outcomes 542 of both clinics were positive. Overall, a significant reduction was seen in the number of allergy 543 related attendances at the hospital. Patients were seen much quicker with one clinic reporting 544 a reduction in waiting times of at least three weeks, while the second clinic reported an 545 average wait time of only 18 days. In both clinics, fewer referrals were made to secondary and 546 tertiary care, which consequently resulted in overall financial savings and overall patient 547 satisfaction. Therefore, both Levy et al. (2009) and El-Shanaway et al. (2019) clearly 548 demonstrated that it is possible to deliver a primary care-based specialist service for those 549 with allergies, while maintaining patient satisfaction and ensuring a beneficial economic 550 outcome.

551

552 Despite the promising results of both these studies, it is important to note the limitations. Both 553 clinics were based in London where healthcare resources are perhaps better than other parts 554 of the UK, e.g. the NW of England. Therefore, this limits the generalisability of these findings 555 to more deprived areas where healthcare services may be more constrained. Additionally both 556 clinics focused on pediatric patients, with little emphasis on LA or young adults. LA is a 557 demographic facing considerable unique challenges in the management of their food allergies. 558 LA often have greater autonomy over their food choices and may encounter different barriers 559 in accessing healthcare such as financial constraints, lack of knowledge about allergen 560 labelling and dietary needs and inadequate healthcare support to meet their individual needs. 561 Thus, it is unclear whether the successes observed by Levy et al. (2009) and El-Shanaway et 562 al. (2019) can be replicated in older populations where circumstances may differ. Moreover, 563 one of the two clinics (Levy et al., 2009) was terminated due to competing financial priorities 564 and constraints, suggesting the importance of financial support in sustaining such clinics, 565 which unfortunately may not be feasible in all healthcare settings. This further highlights the 566 need to consider financial barriers that may impact the implementation of similar models in 567 regions such as the NW, where resources are likely constrained.

568

Quite recently, the continued poor care of allergic disease in the UK has led to the development of a GPwER framework, to create a network of specialist GPs who are trained in the field of allergy. This framework has been facilitated by the BSACI and endorsed by the Royal College of General Practitioners and is based on prior and current frameworks in the fields of respiratory and dermatology respectively. The framework itself has been reviewed by 574 primary care professionals and specialist BSACI members and includes essential components 575 to assist GPs working in allergy. Currently, many GPs will practice and provide advice and 576 treatment to allergy patients without any national guidance for allergy extended roles. 577 Therefore, this new framework will aim to standardise the training for GPs to support the 578 delivery of allergy care and improve the quality of services at the primary care level. This will 579 be achieved through ensuring GPs have better access to training and allowing them to 580 understand and develop the required knowledge and skills beyond their role as a generalist. 581 Consequently, this will enable them to become more suitably qualified in demonstrating 582 competence when delivering allergy care. This scheme is set to be trialled and piloted in 583 December 2023 by two GP members. Following the pilot phase of this framework, it is hoped 584 that a UK map of GPwERs in the field of allergy will be created and linked to existing pediatric 585 and adult allergy networks (BSACI, 2023).

586

#### 587 **2.2.4.2.** Improving the Knowledge and Training of GPs

588

589 GP's are central to care and will continue to shoulder one of the greatest burdens of allergy, 590 if the current care is not improved. The standard of allergy care delivered in the primary care 591 setting can significantly influence the management and prevention of allergies and hence, 592 patient satisfaction and patient quality of life (Agache et al., 2013). The patient need is clear – 593 accurate diagnosis, state of the art management, continuity of care and expert clinicians who 594 can clearly distinguish between what is and what is not allergy. Quite simply, patients should 595 be seen at the right time, in the right place by individuals with the right expertise.

596

597 Integrated care is one of the best ways of achieving this and thus, will allow individuals to be 598 empowered and take effective control of their allergic disease (Finlay and Egner, 2010). Levy 599 et al. (2009) not only suggest the importance of improving training for GPs at both the 600 undergraduate and postgraduate level, but also the importance of increasing the number of 601 specialised primary care health providers. They further suggest structured allergy training 602 whereby GPs receive standardised allergy education, which has previously been proven to 603 improve the health outcomes of patients while also improving the confidence and competency 604 of HCPs in managing allergic disease (Sheikh et al., 2007). Finlay and Egner (2010), suggest 605 appointing a lead consultant allergist within each NHS trust to oversee the delivery of allergy 606 care. Strong leadership from allergy clinicians is essential to develop education and training. 607 This will help to improve cost-effective service provision and enhance quality of care. It is also 608 imperative that models of care which prove successful should be shared and emulated across 609 NHS trusts and nationally. Additionally, in order to improve clinical effectiveness, Roland

610 (2005), highlight the need of GPs having ongoing training and education, through close 611 relationships with local specialists. Similarly, El-Shanaway et al. (2019) also point out the need 612 for ongoing educational support for GPs and suggest that going forward this is of vital 613 importance to improve and maintain allergy care, as currently there is a lack of allergy training 614 available. Likewise, Demoly et al. (2019) illustrate the importance of adequate training for GPs 615 along with improved access to quality medical advice from specialists. They suggest the use 616 of online tools such as, webinars, on-demand videos and decision making tools. Such tools 617 will prove particularly valuable for GPs, taking into account their restricted time due to high 618 workload. Additionally, the online resources proposed by Demoly et al (2019) encompass key 619 information which are easily accessible to GPs and are especially designed with clear 620 guidance and signposting. This will allow GPs to reduce unnecessary referrals and ensure 621 where possible, that patients are seen sooner and closer to home. Moreover, Daniels et al. 622 (2021), suggest providing postgraduate training opportunities to GP's, which will boost their 623 confidence in diagnosing, managing and referring patients appropriately. They also propose 624 a 'level of competence approach' which considers the core, additional and specialist 625 competences, needed to equip physicians with the necessary skills to deliver a high standard 626 of care for patients with allergies (Figure 2.3). Furthermore, an allergy management support 627 system to empower GPs to better manage allergy patients, has also been developed for use 628 in the primary care setting in Netherlands (Flokstra-de Blok et al., 2017). Such a strategy has 629 proven successful and similar initiatives could therefore prove valuable if adopted in the UK 630 (de Blok et al., 2018). Consequently, each of these strategies could potentially improve the 631 delivery of high quality healthcare in the primary setting, improving patient experience while 632 simultaneously reducing unnecessary costs.



Figure 2.3. Proposed recommendations for the competency of primary care physicians in
 allergy, organised into 'core', 'additional' and 'specialist' competences (Daniels et al., 2021)

656

#### 657 2.2.4.3. Summary

658

659 While efforts have clearly been made to improve allergy services, still, there is an unmet need. 660 It seems as though the allergy epidemic has taken the health care systems by surprise and currently, there is a failure on the part of government and funders to acknowledge this rapid 661 increase. The ever-increasing prevalence and complexity of allergies will continue to strain 662 663 the health care systems and unless further improvements are made to provide adequate allergy services, patients will continue to suffer. Effective management of allergies will save 664 665 both time and money and allergy care delivered by GPs who possess sufficient training and 666 knowledge will be instrumental in achieving this. In fact, research by Conlon et al. (2015) and

567 Smith et al. (2015) highlighted how up to half of allergy referrals in the UK can easily be 568 managed in the primary care setting, if GPs were appropriately trained. If steps are not taken 569 and good quality care cannot be facilitated, then the lives of patients will continue to be at risk 570 from fatal anaphylaxis, from malnutrition due to the implementation of inappropriate diets and 571 from a range of mental health issues stemming from inappropriate and unnecessary anxiety 572 (Finlay and Egner, 2010).

673

#### 674 2.2.5. <u>Transition Care</u>

675

676 Allergic disease can manifest at any age and hence, the standard and quality of allergy care 677 must be sufficient in every life stage (Daniels et al., 2021). Particularly, during the critical period 678 of late adolescence individuals with allergies require greater support. Late adolescents (LA) 679 between 18-25 years, with their innate qualities of risk-taking and perception of invincibility, are 680 perhaps the most vulnerable group (Warren et al., 2017). These individuals between 18-681 25 years will be in a state of transition from late adolescence to adulthood (Jaworska and 682 Macqueen, 2015; Sawyer et al., 2018; Roberts et al., 2020). This period is a time of physical, 683 cognitive, psychological and social development (Monks et al., 2010; Roberts et al., 2020). 684 This coupled with responsibility of self-management of their allergy, makes it an extremely 685 stressful and significant period in their lives (Warren et al., 2017).

686

687 To enhance management, access to adequate healthcare is a basic requirement that must be 688 available to all those suffering from food allergies (Stallings and Oria, 2016). It is imperative 689 that LA with food allergies who will be undergoing a crucial developmental period, have the 690 means to obtain sufficient knowledge, skills and confidence, allowing them to gain 691 independence and enhance individual self-management abilities. This will prove beneficial in 692 supporting them throughout their adult life, consequently leading to improved health (Roberts 693 et al, 2020). Despite this, allergy service provision across the UK is severely lacking, with a 694 shortage of allergy clinics and specialists available, who can provide the necessary advice 695 and treatment relating to this period of transition. This will prove problematic given that in the 696 UK the incidence of allergies, in particular food allergies, will firstly continue to rise (Cruddas, 697 2023), secondly, this increasing number of allergic disease is associated with higher health 698 care usage and an increased burden on the NHS (Cruddas, 2023) and finally, LA with food 699 allergies possess the highest risk of fatal reactions (Newman and Knibb, 2020). Therefore, 700 sufficient transition support and provision of health services is a necessity in this group - to 701 ensure good mental and physical health and to allow for successful transition care, therefore optimising overall health (Kalinyak et al., 2016; Knibb and Gore, 2020; Vazquez-Ortiz et al.,2023).

704

705 Research has defined transition care as 'an active and evolving process that addresses the 706 medical, psychosocial and educational needs of young people as they prepare to move from 707 child to adult centred health care (Blum et al., 1993; Sawyer et al., 1997; Rosen et al., 2003; 708 Ladores, 2015). A key focus of the transition process is preparation. However, to this day 709 transition is not given much priority with adolescents receiving limited or in some cases no 710 education and preparation relating to key aspects of health care transition (Lotstein et al., 711 2005; 2009). For instance, previous research has highlighted how only 42% of LA with special 712 health care needs, had an opportunity to discuss transition care with their HCP (Lotstein et 713 al., 2009). Similarly, research has shown that amongst those services who possessed 714 transition resources, approximately only 50% performed an assessment of 'readiness' to 715 determine the suitability of the patient in transferring to adult services. This was primarily due 716 to the lack of a validated patient-centred tool/guideline, that could assist in the evaluation of 717 such a process (McLaughlin et al., 2008; Schwartz et al., 2011). Likewise, in a study by 718 Lotstein et al. (2005) of children with special health care needs, only 50% of parents reported 719 discussing transition care with the paediatrician. The UK primarily sees paediatric care 720 providers transfer patients to adult services at the age of 16. In some cases patients will be 721 incorrectly discharged altogether. This will come at an extremely inopportune time with 722 individuals undergoing major physical and developmental changes. Consequently, this along 723 with educational/workplace pressures, will result in severe consequences (Knibb and Gore, 724 2020).

725

726 Limited research exists looking at the current transition care of LA with allergies. Khaleva et 727 al. (2020) conducted a Europe-wide study assessing the challenges of HCPs in working with 728 adolescents and young adults and their current transition processes. The study involved 41 729 countries and registered over 1000 responses. Their research further outlines key limitations 730 experienced by HCPs, with regard to their current transition services. It was found that 77% 731 of HCPs had no specific resources to strengthen care for adolescents with allergies; 76% of 732 HCPs, although recognising the significance of the transition process, had received no specific 733 training in the care of late adolescence. These statistics are somewhat worrying, given that 734 the role of HCPs is key, in allowing for successful self-management and smooth transition into 735 adulthood (Protudjer et al., 2019). The study carried out by Khaleva et al. (2020) prompted the 736 development of guidelines by EAACI for the effective transition of adolescents and young 737 adults with allergic conditions, with a multidisciplinary approach at its core. Following this 738 research study, an EAACI taskforce developed a toolkit to provide a range of practical

resources to assist in the development of transition services for LA (Vazquez-Ortiz et al., 2023). It is hoped that the resources outlined in the toolkit will serve as a guideline for HCPs globally to improve and support current transition practices across allergy services. There is of course a need to monitor the effectiveness of these guidelines through regular monitoring and audits, to ensure evidence-based standards are met.

744

745 While the study by Khaleva et al. (2020) did include UK participants, no other UK research 746 has explored challenges experienced by HCPs when providing care for LA with food allergies. 747 Their study also relies on an online cross-sectional survey which could present methodological 748 limitations. This approach may not capture the full complexity of issues in relation to HCA and 749 practices of HCPs, as it lacks the depth that qualitative research could provide. Therefore, the 750 results from this study may not fully address the nuanced challenges which LA face, 751 particularly in the UK context. This highlights a crucial gap in the literature and consequently 752 emphasises the need for more detailed qualitative research to provide a richer understanding 753 of HCA and transition care in this group.

754

755 It is often assumed that when reaching a certain age, individuals should, without adequate 756 support, automatically demonstrate the necessary skills and know-how to navigate the world, 757 whilst assuming responsibility for a chronic health condition (Kalinyak et al., 2016). In fact, 758 research dictates that this period of transition from adolescence to adulthood is complex and 759 achieving successful transition is challenging (Protudjer et al, 2019). A successful transition 760 process should provide adolescents with education, guidance, preparation and skills to 761 empower them into becoming independent young adults, who have the ability to effectively 762 and competently manage their chronic condition and make good informed decisions about 763 their future health (Vajro et al., 2018; Knibb and Gore, 2020). Therefore, understanding the 764 many challenges that LA face, providing optimal health care and ensuring that a strong support 765 system is in place, is vital. Without this, how can it truly be possible to nurture these individuals 766 and allow them to thrive and be successful - not only in the self-management of their food 767 allergy, but in all aspects of their lives (Kalinyak et al., 2016; Roberts et al., 2020).

768

# 769 2.2.6. Multidisciplinary Care

770

The growing severity and complexity of allergic disease means that allergy specialists and trained GPs alone will not be sufficient to deliver quality care (Flokstra-de Blok et al., 2017; Skypala et al., 2018). In fact, previous research illustrates how allied health professionals themselves feel that they are only moderately proficient to treat patients with allergies and that they are in need of increased training (Groetch et al., 2010; Maslin et al., 2014). The burden of allergic disease for the patient is extensive. Hence, a multidisciplinary approach with trained practitioners (i.e. nurses, dietitians, psychologists, pharmacists etc.) offers a means to ensure the delivery of high quality holistic care for patients with allergies. There is much evidence which indicates the beneficial and effective role of various HCP in the care of allergy.

780

#### 781 **2.2.6.1.** *Nurses*

782

783 Nurses can be of particular benefit to patients with allergy. If appropriately trained, they can 784 teach patients how to competently use adrenaline auto-injectors and administer diagnostic 785 tests and treatments to patients (Wooler, 2001; Saleh-Langenberg et al., 2017; Skypala et al., 786 2018; Daniels et al., 2021). Nurses will also have the unique opportunity to enhance their 787 individual learning and skills through working closely with GPs and allergy specialists (Skypala 788 et al., 2018; Kelman et al., 2019; Daniels et al., 2021). Moreover, they often have more time 789 with the patient than the physician and thus, are likely to establish a relationship. As such, 790 they will become more approachable and can provide relevant advice, resources and 791 education to both patients and parents (Ibrahim et al., 2022; Muraro et al., 2022). This is 792 especially important when patients receive large amounts of information following a session 793 with the GP or allergy specialist, which may prove difficult to understand and retain (van Os-794 Medendorp, et al. 2020). Providing reassurance, emotional support and counselling to patients 795 with allergy, is also a key role that nurses can partake in (van Os-Medendorp, et al. 2020; 796 Muraro et al., 2022).

797

798 Recent research from the UK has proven how the role of qualified nurses can prove 799 instrumental in the quality of care received by FAP. Hammersley et al. (2022) demonstrated 800 how a nurse led allergy clinic in primary care was extremely effective for patients with food 801 allergy. Nurses who possessed postgraduate allergy qualifications and extensive secondary 802 care experience were able to effectively diagnose, manage and provide relevant education to 803 patients with allergies through face-to-face and remote consultations. Thus lessening the 804 burden on the primary care physicians. Despite these findings, research by Hammersley et al. 805 (2022) did have limitations. This included low sample size and additionally, there was 806 incomplete follow up data for some participants resulting in bias, as those who did not 807 complete the post-assessment intervention assessments may have benefited less from the 808 intervention. Further UK studies are needed to evaluate the effectiveness of nurse-led 809 interventions and to additionally explore strategies for standardising training across different 810 healthcare settings. Despite the beneficial role of nurses, in the UK there are insufficient

811 numbers of trained nurses working in the field of allergy (RCP, 2003; National Allergy Strategy 812 Group and All Party Parliamentary Group, 2021).

813

#### 814 2.2.6.2. Dietitians

815

816 In patients suffering from food allergies, avoidance of the offending allergen is the cornerstone 817 of management. If guidance by a trained professional is not available, patients will be at risk 818 of an imbalanced diet as well as chronic and acute reactions. Challenges created by the 819 ubiquitous nature of food along with the changes in nutritional requirements with age, make it 820 especially important for those with food allergies to receive sufficient quality of care (Daniels 821 et al., 2021; Muraro et al., 2022). The period of late adolescence is an important life stage 822 whereby many developmental changes will take place. These individuals will have an 823 increased need of nutrients including calcium, phosphorus, magnesium, protein, zinc and iron 824 in females. Muscle mass and bone mass must be maintained and so, healthy eating becomes 825 paramount (Das et al., 2017). Often, unmonitored diets of those suffering from food allergies 826 will lead to the implementation of unnecessary restrictive diets which will pose nutritional 827 consequences and will negatively impact health (Steinman et al., 2010; Groetch and Venter, 828 2020). For instance, Meyer et al. (2014), highlight how exclusion diets which were of poor 829 nutritional quality resulted in obesity in those with food allergies. Dietitians therefore play a 830 crucial role for patients with food allergies.

831

832 Research has highlighted how dietary counselling has a significant impact on the nutritional 833 status of those with food allergies (Canani et al., 2014). Dietitians themselves have the ability 834 to provide personalised diet plans that suit the needs of the patient and reflect an adequate 835 and balanced diet (Groetch and Venter, 2020; Leone et al., 2023). Additionally, they can 836 monitor the health effects of food elimination diets and can advise appropriate food 837 alternatives, while maintaining diet diversity (Hubbard, 2003; Groetch et al and Venter, 2020; 838 Mazzocchi et al., 2017; Daniels et al., 2021). Moreover, they can advise patients and families 839 on how to read and interpret labels and can recommend the use of appropriate supplements 840 where needed (Leone et al., 2023). Research further indicates that based on their knowledge 841 and expertise, dietitians will have the ability to conduct allergy focused diet histories and food 842 challenges and can therefore aid diagnosis and treatment (Skypala et al., 2015; Bird et al., 843 2020). Parents have also reported that dietitians have proven extremely useful in providing 844 emotional support to patients and families (MacKenzie et al., 2015). A recent study conducted 845 by Collinson et al. (2023), further highlighted the beneficial role of dietitians in pediatric food 846 allergy. Their research illustrated how dietetic-led clinics reduced primary and secondary care appointments, diagnosed FAP quicker, therefore resolving symptoms more rapidly andreduced the time taken to access dietetic care.

849

850 It is clear that proper dietary intervention is necessary for patients with food allergies and to 851 ensure nutritional adequacy, supervision from a trained dietitian and/or nutritionist should be 852 an integral part of allergy consultation. This becomes even more essential for those with 853 multiple and complex food allergies (Venter et al., 2012). In the UK, many community dietitians 854 who are experts in their field do exist, however they have not been specifically trained in allergy 855 and thus, may not be able to provide competent care for patients suffering from allergic 856 disease (National Allergy Strategy Group and All Party Parliamentary Group, 2021). More 857 research in this regard is therefore needed to explore the practical challenges dietitians face 858 and how their training can be improved to provide effective allergy care. This can help to 859 develop strategies to ensure dietitians are better equipped in providing effective, 860 comprehensive care for patients with food allergy.

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#### 862 **2.2.6.3**. **Psychologists**

863

864 The entire process of having, managing and treating allergies can cause significant long term 865 psychological issues and severely impact quality of life. There is a constant fear of 866 experiencing an allergic reaction by sufferers and this will make living a normal life extremely 867 challenging. A survey of 6000 allergy sufferers by Allergy UK revealed how over 62% of 868 patients felt that their allergy 'significantly affected all aspects of their lives.' (Allergy UK, 2015). 869 A further report in 2015 revealed how 44% of allergy sufferers are living in fear of potentially 870 fatal reactions, which has led to high levels of anxiety over the most basic everyday activities, 871 including eating and leaving the home (National Allergy Strategy Group and All Party 872 Parliamentary Group, 2021).

873

874 Many studies have highlighted this significant impact of allergies on the mental health and 875 quality of life of patients. A study conducted by Stadler et al. (2022) showed how allergies 876 (insect venom, food/food additives, drug) and urticaria led to increased rates of depression 877 and thus, reduced quality of life amongst patients in a tertiary allergy centre. Research has also suggested that an episode of anaphylaxis, is considered a traumatic event which may 878 879 lead to Post Traumatic Stress Disorder (PTSD) in patients with severe allergies (Avery et al., 880 2003; Weiss and Marsac, 2016). Knibb et al. (2023) further reinforces this, highlighting how in 881 adults the impact of anaphylaxis is greatly related to stress, anxiety and depression, which will 882 significantly impact quality of life. Likewise, Budu-Aggrey (2021) found strong evidence to

indicate that allergies are associated with depression, anxiety, bipolar disorder and
neuroticism. Furthermore, the diagnosis and treatment of allergy itself can cause considerable
psychological impacts on the patient (Daniels et al., 2021; BSACI, 2023). For example, the
application of adrenaline is a known cause of anxiety amongst patients with allergies (Daniels
et al., 2021).

888

889 Food is ubiquitous and for those suffering from food allergies there is a greater risk of an 890 allergic reaction which will constantly be present (Daniels et al., 2021; Fiocchi et al., 2021). 891 Avoidance of the allergenic food is challenging and requires constant vigilance, which places 892 an increased stress on patients (Knibb et al., 2023). In extreme cases, the avoidance of foods 893 will lead to social isolation and continuous anxiety (Feng and Kim, 2019). Also, the constant 894 effort in needing to regularly read and interpret food labels can be laboursome and time-895 consuming for most. A report conducted by the Foods Standards Agency (2001) revealed how 896 the simple act of shopping will take 39% longer for FAP, which will negatively impact their 897 quality of life. Additionally, the widespread use of Precautionary Allergen Labelling (PAL) 898 which encompasses an increasingly high number of unregulated statements, will further leave 899 sufferers in a state of constant uncertainty, fear and therefore, anxiety (Fiocchi et al., 2021). 900

901 Furthermore, the transition from adolescence to adulthood is a challenging developmental 902 stage. This group of individuals will often engage in risky behaviour as they attempt to 903 establish their identity. Research from the United States shows how only 40% of food-allergic 904 college students were found to adhere to their dietary restrictions (Greenhawt et al., 2009) 905 and how many adolescents will knowingly ingest 'may contain' foods placing them at an 906 increased risk of anaphylaxis (Sampson et al., 2006; Monks et al., 2010; Greenhawt et al., 907 2016). When in a social situation adolescents will often fail to inform peers about their allergy 908 and will often refuse to carry their adrenaline auto-injector, further emphasising this risk taking 909 behaviour in LA (Warren et al., 2017; Sicherer et al., 2020). One study revealed how only 910 6.6% of US students with food allergies carried their adrenaline auto-injector (Greenhawt et 911 al., 2009). Likewise, Robinson et al. (2019) found that carriage of the adrenaline auto-injector 912 was suboptimal in US adolescent students, especially where these individuals were 913 independent of parental supervision. In comparison, little UK research details risk taking 914 behaviour in LA. One UK study however did reveal similar concerns, mentioning low rates of 915 carrying adrenaline auto-injectors in adolescents. They further mentioned barriers of this, 916 including failure to recognise anaphylaxis, lack of knowledge regarding technique and when 917 to administer the adrenaline auto-injector and fear of using the adrenaline auto-injector 918 (Gallagher et al., 2012). In LA, the pressure to conform to certain situations dominates self-919 preservation and as such, leads to increased risk taking behaviours which is one of the leading causes of food induced anaphylaxis in this group (Monks et al., 2010; Warren et al., 2017;Sicherer et al., 2020).

922

923 Additionally, mental health and quality of life is dramatically reduced in LA. Increased levels 924 of anxiety, including general anxiety and separation anxiety are particularly seen, alongside 925 anorexia and bulimia nervosa (Shanahan et al., 2014). In a study among UK adolescents, lack 926 of knowledge and fear of using an adrenaline auto-injector contributed greatly to high levels 927 of anxiety (Gallagher et al., 2012). One US study highlighted social isolation, depression and 928 performance anxiety in food allergic adolescents (Antolin-Amerigo et al., 2016), while another 929 US study revealed how a staggering 43% of food allergic individuals in early and late 930 adolescence were subject to some form of bullying (Warren et al., 2017). Furthermore, eating 931 out and socialising is made more difficult - particularly in those with food allergies. LA often 932 avoid social venues due to fear of being exposed to a food allergen, consequently leading to 933 social vulnerabilities (Stjerna, 2015; Newman and Knibb, 2020; Herbert and DunnGalvin, 934 2021). The myriad of mental illnesses that adolescents are likely to be burdened with, coupled 935 with the management of allergies and the challenging developmental period they will 936 undertake, can have devastating effects.

937

938 Furthermore, the management of food allergies will additionally lead to psychological distress 939 and poor quality of life in parents and carers. Much research has demonstrated how the 940 unpredictable and potentially life-threatening nature of food allergies has resulted in poorer 941 mental health and reduced quality of life in parents and caregivers of young children (Avery et 942 al., 2003; King et al., 2009; Lau et al., 2014; Morou et al., 2014; Birdi et al., 2016). The 943 psychological impact of allergy is commonly known to compromise school attendance, family 944 relationships and social life (Daniels et al., 2021; Herbert and DunnGalvin, 2021). In most 945 cases, family members will be significantly impacted by restrictions put in place due to their 946 child's food allergy (Mandell et al., 2005). For instance, family members would also adhere to 947 the allergy restricted diet of their children placing unnecessary restrictions on their own diet, 948 resulting in nutritional imbalance (Munoz-Furlong, 2003). Also, family activities and social 949 events will be restricted with many families avoiding such activities altogether, in order to 950 minimise risk and anxiety (Bollinger et al., 2006; Stjerna et al., 2014). Particularly, parents of 951 adolescents with allergies reported increased levels of anxiety when handing over the primary 952 responsibility of management to their children (Akeson et al., 2007; Lange, 2014). Therefore, 953 it is necessary that parents and families of patients suffering from allergies also receive 954 psychological support from trained professionals.

956 Clearly the role of the psychologist deserves an essential place within the field of allergy. At 957 present, the UK has established successful psychological services for many chronic 958 conditions e.g. diabetes, cystic fibrosis and oncology. Yet this provision is rarely offered to 959 patients with allergies (Mercer et al., 2015). A survey conducted by Young and Minshall (2016) 960 in the UK, revealed that although health professionals in pediatric allergy recognised the need 961 for psychological support, access to this support for patients and families was limited. 962 Currently, the UK has two allergy clinics who receive dedicated funding for psychological 963 services - Southampton General Hospital and Evelina London Children's Hospital, which were 964 established in 2014 and 2016 respectively. Both services offer a range of psychological 965 services, including interventions and parent workshops and additionally offer consultations to 966 support the multi-disciplinary team. Since their inception, a high number of patients have been 967 seen and treated in both clinics demonstrating the necessity of such a service. While some 968 psychological support is offered in tertiary centres in the UK, not much exists in the NW region. 969 This means patients would often have to travel long distances to receive support, which due 970 to financial status may not always be possible. Thus, resulting in many patients and many 971 families having no services at all (Minaker et al., 2014; Knibb et al., 2015). Research indicates 972 that the current limited access and inadequacy of psychological support is primarily due to 973 lack of funding (Knibb et al., 2019; Daniels et al., 2021). However, if psychological needs are 974 not met, greater costs on the health care system will be incurred.

975

976 In a typical consultation, there is often little time to adequately address the psychological 977 needs of patients and their families (Feng and Kim, 2018; Knibb et al., 2019). In instances 978 where patients were fortunate enough to receive some psychological care from their GP or 979 allergy specialist, the support was found to be inadequate (Akeson et al., 2007). Broome-980 Stone (2012) reinforce this, indicating that due to a lack of knowledge, HCP and services are 981 not fully equipped to address the needs of parents who have children with severe food 982 allergies and this in turn can lead to a reduced quality of life. Similarly, through their study 983 Mandell et al. (2005) found that lack of knowledge given to parents of children with peanut 984 allergy at the time of diagnosis, increased uncertainty and anxiety in management of the 985 allergy. Knibb and Semper (2013) further emphasise the inadequacies in allergy services. 986 Their research highlights how no significant differences existed in levels of anxiety and 987 depression before and after visiting an allergy clinic in parents of children with suspected food 988 allergy.

989

To ensure effective long-term management of allergies, access to specialist psychological
support alongside medical care is necessary (Birdi et al., 2016; Daniels et al., 2021; Muraro
et al., 2022). Increasing the number of dedicated psychological services across the UK will

993 have a positive impact. This could lead to a decrease in anxiety and depression in patients 994 and their families, which in turn could improve their quality of life. Additionally, ensuring 995 psychological support is more accessible may also improve patient adherence to medical 996 advice, which can assist in reducing the frequency of allergic reactions and hospital 997 admissions. In particular, increasing this accessibility in areas such as the NW region, which 998 currently has few hospitals with dedicated psychological support (Knibb et al., 2019) can also 999 help to mitigate the existing disparities in healthcare provision. Consequently, this can lead to 1000 fewer emergency visits by patients resulting in long-term cost savings for the NHS.

1001

1002 Psychologists have the ability to provide in depth psychological care. They can implement 1003 coping strategies and targeted interventions which can support patients with allergies and their 1004 families (Daniels et al., 2021). Skypala et al. (2018), mention that psychologists have a unique 1005 ability in providing individuals with a sense of empowerment and that this is achieved through 1006 the delivery of coping strategies that support their day-to-day management of allergies. 1007 Consequently, this improves the overall emotional wellbeing of patients. While little published 1008 research exists on interventions to improve the quality of life in those with food allergies, there 1009 is evidence to show the positive impact of cognitive behavioural therapy (CBT). CBT is a 1010 proven psychological intervention and has been shown to reduce food allergy related anxiety 1011 in parents. One UK study showcased how in mothers of children with food allergy, CBT was 1012 effective in reducing the psychological impact of food allergy. Namely there was a significant 1013 reduction in anxiety, depression and worry and an overall improvement in mental health status 1014 and therefore, quality of life (Knibb, 2015). Similarly, Boyle et al. (2017) conducted a 1015 randomised controlled trial where UK mothers of children with food allergy were provided with 1016 a brief intervention of CBT. While there was no significant changes in anxiety level at 6 weeks, 1017 there was a reduction in a group of mothers who had moderate to high levels of anxiety at one 1018 year, suggesting positive long-term effects on maternal psychological well-being. However, 1019 the short term impact remains unclear and further research is warranted to assess the clinical 1020 significance of such interventions. CBT has demonstrated positive effects, although the 1021 existing research, particularly in the context of food allergies, remains limited. Further research 1022 is needed to fully establish its clinical significance and long-term benefits. Expanding 1023 psychological services within allergy clinics could improve patient care by addressing the 1024 emotional and psychological needs of patients and their families. More research needs to be 1025 undertaken, particularly in regions such as the NW of England, where there exists little 1026 specialised psychological support for patients with food allergy. This can consequently lead to 1027 the implementation of comprehensive psychological support programs across undeserved 1028 regions, addressing gaps in care and improving the mental well-being and management of 1029 food allergies.

1030 All health care staff, including nurses, dietitians, GPs and social workers have a role to play in 1031 delivering psychological support to patients with allergy (Mandell et al., 2005; Mercer et al., 1032 2015). Mercer et al. (2015) further suggest that in order for psychological provision to be 1033 effective, good regular communication between professionals is paramount. Knibb et al. 1034 (2019) additionally recommend the need for health care providers, family members and the 1035 wider public to learn necessary skills from psychologists. This in turn can prompt the 1036 recognition of psychological behaviours and therefore, can lead to the implantation of early 1037 interventions which will prove beneficial. Furthermore, Barker et al. (2021) recommend 1038 including psychosocial aspects of allergy in the undergraduate medical curriculum, in the 1039 hopes of facilitating psychosocial care as a core competency in allergy practice at the primary 1040 care level. This will ensure more accessible psychological care for allergic patients.

1041

#### 1042 **2.2.6.4**. *Pharmacists*

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Alongside nurses, dietitians and psychologists, the important role of pharmacists in allergy care have also been emphasised in research. Pharmacists can provide medication advice and ensure appropriate medication is being used by patients for effective management (Skypala et al., 2018). They can also educate patients on the correct technique of administering adrenaline auto-injectors (Saleh-Langenberg et al., 2017; Daniels et al., 2021). Research also indicates that pharmacists can recognise the signs of an allergic reaction and will be able to support the diagnosis of new patients with food allergy (Barnett, 2003).

1051

## 1052 **2.2.6.5**. Summary

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1065

1054 Research clearly illustrates how the roles of different HCP in the care of patients with allergy 1055 is valued and of vital importance. The GP or physician will rarely have time to devote 1056 themselves to the additional aspects of care needed to successfully manage allergies. A multi-1057 disciplinary team of allied health professionals will certainly benefit. It will ensure timely, 1058 accessible, holistic care, which is of high quality and thus, allow for optimal allergy 1059 management in the patient. Consequently, reducing the overall burden on the primary care 1060 physicians and existing allergy specialists (Mercer et al., 2015; Skypala et al., 2018, Knibb et 1061 al, 2019; Barker et al., 2021; Daniels et al., 2021; Muraro et al., 2022; Knibb et al., 2023). 1062 Without such tailored support from trained professionals, food allergic patients and their 1063 families may face challenges in the management of their food allergies, increasing the risk of 1064 poor health outcomes and reducing their quality of life (Daniels et al., 2021).

1066 1067

#### 2.3. Food Choice in Late Adolescents

1068 Food Choice is a dynamic and complex phenomenon that is constantly evolving. Many factors 1069 influence the foods we choose to eat; biological, psychological, economic, social, cultural, 1070 physical and political factors are all significant predictors of FC (Monterrosa et al., 2020). 1071 During the challenging period of late adolescence, individuals will attempt to establish their 1072 identity. This profoundly impacts eating behaviours in this group. The transition to university 1073 life is associated with an increased autonomy over FCs and smaller food budgets. This 1074 coupled with the increased exposure to new social groups and food cultures will further define 1075 food intake (Sprake et al., 2018). Research indicates that while majority of LA contemplate 1076 healthy eating, they often struggle to make this a priority. Although some LA are able to lead 1077 a healthy lifestyle, many have no interest or motivation in altering their current eating habits 1078 (Brennan et al., 2020). In fact, LA between the ages of 18-25years are amongst the largest 1079 consumers of fast food and sugar sweetened beverages and have predominantly lower fruit 1080 and vegetable intake and thus, have an extremely poor diet (Pelletier et al., 2014; Rounsefall, 1081 et al., 2020).

1082

# 1083 2.3.1. The Social Aspect

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1085 The social context is a powerful influencer of food intake. Though eating is largely regulated 1086 by hunger and satiety, the presence of other people has a significant impact on eating 1087 behaviour (Robinson and Higgs, 2013; Pelletier et al., 2014; Robinson et al., 2014; Cruwys et 1088 al., 2015; Higgs, 2015; Higgs and Thomas, 2016; Herman, 2017; Suwalska and Bogdanski, 1089 2021). The social model of eating involves adjusting the amount of food eaten to the intake of 1090 the accompanying person (Liu and Higgs, 2019). This model includes two theories and can 1091 further explain eating behaviour. Situations where people are in a group or in the presence of 1092 acquaintances will lead them to eating more, as described by the social facilitation theory. 1093 In contrast, the theory of *self-presentation* suggests that when people believe others are 1094 watching them eat or judging their intake, food consumption will decrease (Higgs and Thomas, 1095 2016; Suwalska and Bogdanski, 2021).

1096

For individuals with food allergies, these social dynamics can negatively impact eating behaviour and dietary adherence. The desire to fit in can lead food allergic individuals to make risky FCs to avoid feeling excluded or judged, such as consuming allergenic foods (Greenhawt et al., 2016). The social facilitation theory indicates that in social settings there will be an increased food intake, which for those with food allergies can prove dangerous if safe food options are limited or allergies are not clearly communicated. On the other hand, the social presentation theory may cause food allergic individuals to restrict their food intake or avoid
eating in social situations, to prevent potential exposure to allergens or draw attention to their
food allergy (Graham and Ciciurkaite, 2023; Hanna et al., 2023).

1106

1107 Social cues can determine what is deemed appropriate with regard to food intake (Nisbett and 1108 Storms, 1974; Roth et al., 2001; Herman, 2017; Dix et al., 2022). In particular, peer influence 1109 is crucial in shaping the eating behaviours of LA. Food preferences are especially informed by 1110 peers as it is often seen as a positive emotional experience (Higgs and Thomas, 2016). 1111 Additionally, eating in groups is indicative of improved health and wellbeing (Dunbar, 2017). 1112 What was initially construed as a special occasion, has now increasingly become a common 1113 occurrence. In fact, eating with peers is especially prevalent amongst LA, as they embark on 1114 a journey of self-discovery and identity formation. This can be challenging for those with food 1115 allergies, as it often creates social pressures to conform to group norms and could lead to 1116 unsafe food practices (Jeong and Khandokar, 2024). When eating together, overindulgence 1117 of energy dense foods is accepted and even encouraged (Herman, 2017). Hence, it is no 1118 surprise why a substantial increase in weight gain has notably been documented in first year 1119 university students (Cockman et al., 2013; Deliens et al., 2014; Hebden et al., 2015; Sprake 1120 et al., 2018).

1121

1122 Stok et al. (2016), conducted a systematic review to assess the role of peer social norms on 1123 adolescents (10-25 years) food intake. Of the 33 studies included in their review, 32 revealed 1124 a significant association between peer social norms and food intake. A common finding among 1125 all studies, was the increased consumption of unhealthy snacks, fast foods and sugar 1126 sweetened beverages, but also the increased consumption of fruits and vegetables. The 1127 eating practices did not differ between those in early adolescence (10-17years) and late 1128 adolescence (18-25years), suggesting the significant nature of social norms throughout this 1129 entire period of adolescence. Similar effects of social norms were also observed irrespective 1130 if the norm referent group consisted of socially close or socially distant peers. Thus indicating 1131 that so long as individuals can identify with their peers in any way, they will mimic behaviour. 1132 It is important to note here that the studies included in this review focused on the general 1133 population and not specifically in those with food allergies. This group face unique challenges 1134 and social norms and peer influences could potentially exacerbate risky eating behaviour as 1135 they attempt to navigate group dynamics while manging their food allergy (Jeong and 1136 Khandokar, 2024). Future studies should therefore investigate FCs in those with food allergies 1137 and how peer social norms may influence FC and dietary intake.

1139 LA have a greater connection to social media and thus, this can further influence and establish 1140 eating behaviours in this group (Brennan et al., 2020). A Sensis social media report revealed 1141 how social media platforms were used by 89% of LA at least once per day (Sensis, 2017). 1142 This connection with a global audience will consequently lead to an increase in the exposure 1143 of advertising, which also plays a major role in eating habits of this group (Buchanan et al., 1144 2017; Klassen et al., 2018; Friedman et al., 2022). However, research indicates that health 1145 promotion organisations have a lesser presence and following on social media and often miss 1146 the mark when it comes to specific sub-groups (Klassen et al., 2018; Barklamb et al., 2020; 1147 Dix et al., 2022). Therefore, they are not as successful in delivering their message, which 1148 further explains the poor eating habits of LA. Often, individuals identify with the eating 1149 behaviour of an important or popular social group and eating behaviours are further 1150 established when individuals receive positive social feedback from their peers regarding that 1151 food (Robinson and Higgs, 2012; Stok et al., 2014). Social media provides a constant stream 1152 of social input to LA whereby they are able to engage with idealised versions of both their 1153 peers and strangers (Friedman et al., 2022). A common occurrence amongst LA is to post 1154 their eating habits across social media platforms, which often consists of unhealthy foods 1155 (Filippone et al., 2022). Additionally, the food industry have commercialised social media, 1156 inundating individuals with advertisements of unhealthy foods high in energy and low in 1157 nutrients (Qutteina et al., 2019; Friedman et al., 2022). Equally, social media influencers who 1158 share their lives on social media and develop emotional connections with their audiences, 1159 have emerged as popular and persuasive individuals that can negatively impact eating 1160 behaviour (Freburg et al., 2011; Uzunoglu et al., 2014). However, many health focused 1161 influencers don't possess professional accreditation and often provide misleading information 1162 which lacks evidence, particularly with regard to diet and nutrition (Easton et al., 2018). 1163 Similarly, social media is commonly used for support and information following a food allergy 1164 diagnosis. However, those with food allergies often encounter challenges in sourcing reliable 1165 and accurate content. This can negatively impact their ability to manage their allergies 1166 effectively and make informed decisions about FCs and diet (Hamshaw et al., 2019).

1167

# 1168 2.3.2. The University Environment

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During the years of late adolescence eating behaviour is largely influenced by unhealthy foods (Pelletier et al., 2014; Stok et al., 2014; Sprake et al., 2018). Students will often be living away from home and will no longer be under strict food supervision. Possibly for the first time in their lives, LA will choose where, when and what to eat (Li et al., 2022; Racine et al., 2022; Hafiz et al., 2023). This is quite different in comparison to childhood where parents select the foods 1175 of the family diet and children often model parents eating behaviours. Thus, food intake is 1176 somewhat better at home (Poobalan et al., 2014; Scaglioni et al., 2018). As these individuals 1177 enter into university, the food environment they are exposed to offers a large proportion of 1178 unhealthy foods (Sprake et al., 2018). There is much existing literature which illustrates that 1179 the university food environment is poor. Table 2.4 provides a collection of previous studies 1180 from various countries, including the UK, US Australia, Brazil, Netherlands, New Zealand, 1181 Norway and Ghana. The studies included in the review focus on FCs of university students, 1182 while some also measure the food environment and dietary quality of participants. Overall, the 1183 studies consistently demonstrate that the university food environment is poor, mainly offering 1184 unhealthy food options and negatively impacting food FC and dietary intake among students. 1185 Additionally, factors such as taste and cost significantly predicted FC and this led to the 1186 consumption of foods lower in nutritional quality. To our knowledge, limited studies have 1187 explored the FCs of LA with food allergies in the university environment. In fact, only one 1188 previous research has investigated FC in specifically LA with food allergies (Laheri et al., 1189 2022). The details of this study are additionally included in the subsequent review.

# **Table 2.4.** Previous literature highlighting the impact of the university environment on FC and dietary intake.

Reference	Year of Study	Country	Aim	Methodology	Findings
Kremmyda	2008	UK	To identify the eating habits of	A self-administered	Those students who lived at home whilst at university
et al			Greek students living in Glasgow	questionnaire was used to	were able to maintain dietary patterns. However,
			and to see if these habits were the	assess the diets before and	significant changes were observed in students who
			result of living away from home for	after commencing university in	were living away from home, with these individuals
			the first time.	Greek students living in the	consuming fewer fresh fruits, meats and cheeses and
				family home (n=43) or away	increasing their intake of snack foods, which were
				from home either in Greece	readily available on campus.
				(n=37) or Glasgow (n=55).	
Pelletier and	2013	US	To firstly quantify the prevalence of	An online survey was	Approximately 45% of students purchased foods and/or
Laska			purchasing campus foods, fast	completed by students from	beverages from at least one campus area venue greater
			foods and bringing food from home.	one community college and	than 3 times per week. Foods purchased in and around
			Secondly, they examined the dietary	one university.	campus was associated with higher fat and sugar
			intake and meal patterns of these		intake, while food prepared at home was healthier.
			students.		
Roy et al	2016	Australia	The availability, accessibility and	A scoring instrument called the	Two thirds of foods were sugar-sweetened beverages,
			promotion of foods and beverages	food environment-quality index	chocolates, high energy foods, chips or confectionary.
			was assessed across seven	was developed and used to	Healthy foods were less available and promoted less in
			institutions (three universities and	conduct a food environmental	comparison to unhealthy foods.
			four technical and further education	audit survey of 252 food and	
			campuses).	beverage outlets.	

# **Table 2.4.** Continued

Reference	Year of Study	Country	Aim	Methodology	Findings
Kourouniotis	2016	Australia	To assess the importance of taste	A questionnaire was	Taste was an extremely important factor of FC and
et al			on dietary choice and to determine	completed by 1306 Australian	those who rated taste highly, had a poorer diet.
			the dietary behaviour and dietary	students.	Participants were consuming fruits and vegetables but
			quality of university students.		were significantly more likely to consume foods high in
					fat, sugar and salt including cakes and puddings,
					biscuits, pizza, potato chips, takeaway meals and
					confectionary, as these were more readily available on
					campus and were cheaper to purchase.
Pulz et al	2016	Brazil	To evaluate the food environment at	The Nutrition Environment	Most food and beverages purchased from snack bars
			one Brazilian university including 6	Measures Survey-Restaurants	were made with processed ingredients and possessed a
			restaurants and 13 snack bars.	(NEMS-R) was adapted for	lower nutritional quality than similar products made on
				Brazil to evaluate and	campus. Only 16% of the food outlets provided food
				qualitatively classify the	ingredients or nutritional information of products.
				nutritional quality and	
				characteristics of the food.	
Roy et al	2017	Australia	To assess the association between	A purposely designed	A statistically significant difference was observed
			foods and beverages consumed	validated smartphone	between the number of university foods and beverages
			from the university environment and	application was used to collect	consumed in 5 days and the HEIFA-2013. Frequent on
			diet quality in young adults.	5 day dietary data from 103	campus food purchasing resulted in poor diet quality.
				university students. Diet	
				quality was assessed using	
				the 2013 dietary guidelines for	
				food groups and nutrients and	
				the validated Healthy Eating	
				Index for Australians (HEIFA-	
				2013.	

# **Table 2.4.** Continued

Reference	Year of Study	Country	Aim	Methodology	Findings
Van den	2019	Netherlands	Firstly, to investigate the fruit and	Cross-sectional questionnaire	Fruit and vegetable intake was found to be lower in
Bogerd et al			vegetable intake of university	data was collected using a	male students living independently. Students indicated
			students and associated	food frequency tool to	that the university environment provided sufficient fruits
			demographics and lifestyle	investigate the fruit and	and vegetables, however, they would be more willing to
			characteristics. Secondly, to	vegetable intake of Dutch	purchase them if they were more affordable.
			investigate students perceptions of	university students.	
			fruit and vegetable availability and		
			fruit and vegetable intervention		
			strategies in the university		
			environment.		
Roy et al	2019	New Zealand	To investigate the purchasing	A quantitative survey was	79% of participants were found to consume on campus
			preferences, behaviours and	used. The study audited 57	foods. Healthier food and beverage items were less
			opinions of the food environment	food outlets and 29 vending	available and accessible across campus, in comparison
			amongst students and staff at one	machines across 6 campuses	to their non-healthy counterparts. Additionally,
			large university.	at one large university.	unhealthy foods were promoted more and cost less than
					healthier items. Students were found to consume a
					greater quantity of unhealthy foods than staff.
Martinoz-	2021	Norway	To access the nutritional profile of		Most students were found to consume on compute
Marunez-	2021	norway	Products offered at one Nerwagien	An anonymous online survey	foods, particularly for lunch and as a speak. Results
Perez el ar			university on means of determining	was completed by 1069	revealed 20.9% of products were 'unbeeltby' and 25.0%
			the quality of the university feed	students	were fultre presented? Tests was also found to be the
			the quality of the university food		were unra-processed. Laste was also round to be the
			environment.		most important determinant of FC followed by price.

# **Table 2.4** Continued.

Reference	Year of Study	Country	Aim	Methodology	Findings
Mensah et al	2022	Ghana	To map and characterise the food	A Geographical Information	138 food outlets were identified, most of which were
			outlets within a Ghanaian university	System (GIS) was used to	situated near student residences.
			campus and to assess the	characterise the food	Food outlets were categorised as either NCD-healthy,
			healthiness of the food outlets.	environment at the University	NCD-intermediate or NCD-unhealthy. More than half of
				of Ghana campus. A	the food outlets qualified as NCD-unhealthy food
				classification system was	outlets, highlighting the poor food environment. (NCD =
				developed to assess the	Non-Communicable Disease).
				healthiness of food outlets	
				within the university	
				foodscape.	
Hutchesson	2022	Australia	To describe on-campus food	An online cross-sectional survey	Majority of students (94%) purchased foods and beverages
et al			purchasing behaviours; satisfaction	of 409 students between 2017	on campus. Students were not satisfied with the availability
			with the cost and availability of foods	and 2018 took place.	of healthy food options and thought prices of existing
			and beverages on-campus; and		healthy foods were high, which discouraged purchase of
		preferences for the on-campus food		these foods.	
			environment in Australian university		
			students.		
Coyle et al	2023	Australia	To assess the food environment at	Data was collected between	Majority of products were found to be unhealthy. A large
			one large university in Sydney,	March and July 2022 across 27	number of food and beverages exceeded portion
			Australia.	food outlets and 24 vending	recommendations, in particular sugary drinks. Packaged
				machines. The healthiness of	foods which were readily available on campus were
				the food environment was	unhealthy. Both students and staff struggled to identify
				evaluated by comparing items	healthier options due to many products failing to include the
				against the Healthy Food and	health star rating (a voluntary front of pack labelling system
				Drink in New South Wales	used in Australia, that provides an overall nutritional profile
				Health Facilities for Staff and	of packaged food).
				Visitors Framework.	

# **Table 2.4.** Continued.

Reference	Year of Study	Country	Aim	Methodology	Findings
Laheri et al	2022	UK	To explore factors influencing food	A food selection survey was	Taste and cost were the most influential determinants of
			selection behaviour in LA with food	distributed to participants with	food selection in both groups of participants. Labelling
			allergies and celiac disease.	food allergies and celiac	was found to be the least influential factor, despite this
				disease in order to determine	ensuring safety in this group of participants.
				the influence of five factor -	
				cost, taste, convenience,	
				health and labelling.	

- 1197 2.3.3. Additional Factors Impacting Food Choice
- 1198

1199 Multiple factors in addition to social aspects and the poor university food environment can 1200 negatively impact FC and dietary intake in university students. For food allergic individuals, 1201 these factors are exacerbated by the need to independently manage their condition for the 1202 first time. To the best of our knowledge, only two pieces of research have investigated the FC 1203 of food allergic participants – one in early adolescence (Sommer et al., 2014) and one in late 1204 adolescence (Laheri et al., 2022). Both studies were conducted in the UK and determined that 1205 those with and without food allergies are influenced by similar determinants of FC and the 1206 primary reason for this, is that those with food allergies strive to live a similar life to that of their 1207 peers. Beyond this, very little UK research has explored the food access, eating behaviours 1208 and dietary intake of this group. Given this gap in the literature, it can only be assumed that 1209 the various factors which influence FC in the general LA population will also impact those with 1210 food allergies. However, without sufficient research, it is difficult to draw definitive conclusions 1211 about the unique experiences and challenges faced by this group. This lack of evidence 1212 warrants further investigation into the food access, FCs, eating behaviours and dietary intake 1213 of LA with food allergies.

1214

1215 During the period of transition from late adolescence to adulthood, there is an increased level 1216 of stress. The need to build new social relationships, achieve high results, peer competition 1217 and lack of time management are all difficulties encountered by LA, which contribute to this 1218 increased stress. Consequently, this will lead to negative changes in food preferences and 1219 consumption (Hafiz et al., 2023). In general, it has been found that during times of stress 1220 individuals were more likely to consume high fat foods and snack foods e.g. sweets which 1221 required little preparation (Grunberg and Straub., 1992; Oliver and Wardle, 1999; Wansink et 1222 al., 2003; Zellner et al., 2006). Individuals with food allergies are likely to experience 1223 heightened stress levels owing to the difficulty in carefully navigating their dietary restrictions 1224 in unfamiliar environments where the availability of safe food options is limited (Larson et al., 1225 2020) potentially leading to an even greater reliance on unhealthy foods. Also, the need for 1226 social acceptance and autonomy from parents is one of the driving forces behind unhealthy 1227 eating behaviour (Poobalan et al, 2014; Stok et al., 2014). For those with food allergies, there 1228 may be a reluctance to stand out by adhering to dietary restrictions and this could lead to 1229 riskier FCs. Previous research from the US has noted the increased consumption of 'may 1230 contain' foods in LA (Sampson et al., 2006; Monks et al., 2010; Greenhawt et al., 2016), which 1231 raises serious concerns about their willingness to compromise safety for social conformity, 1232 regardless of the consequences.

1233 Moreover, reduced time to prepare food due to university related stress and low cooking 1234 confidence, will inevitably lead to an increased reliance and preference for packaged and 1235 convenience foods, which are of a poorer dietary quality (Stok et al., 2016). This challenge is 1236 particularly pronounced for food allergic students, who may find it difficult to identify and source 1237 safe food options while at university. Further studies from Australia have also shown that 18-1238 25 year olds perceive healthy eating as both time consuming and expensive and hence, value 1239 social, financial and spiritual ideals a great deal more (Dix et al., 2022; Friedman et al., 2022). 1240 The added burden of allergen avoidance in those with food allergies may impact their 1241 perception of healthy eating, making it seem more difficult and less appealing. In addition to 1242 this, lack of nutrition knowledge and a lack of awareness of the importance of a balanced diet, 1243 is a common obstacle leading to poor dietary choices in this group (Husain et al., 2021). 1244 Belogianni et al. (2022) further reinforces this. They investigated nutrition knowledge among 1245 UK university students using the general nutrition knowledge questionnaire. Although 1246 participants had good knowledge of which meals, desserts and drinks were considered the 1247 healthier options, gaps were found in students nutrition knowledge. Half of students were not 1248 aware of dietary recommendations e.g. increasing wholegrain intake and reducing salt and fat 1249 intake. Fewer than half of participants were unable to identify that breakfast cereals and bread 1250 contained hidden sources of salt. Additionally, students had reduced knowledge on practices 1251 of weight management. This lack of nutritional knowledge may be especially problematic in 1252 LA with food allergies who not only need to understand general nutrition principles, but also 1253 are in need of specific knowledge regarding safe allergen free options and alternatives. In 1254 addition to this, Sogari et al. (2018) discuss barriers to healthy eating in US university students 1255 aged 18-25 years. Through qualitative focus groups, their research identified time constraints, 1256 university related stress, an increased convenience of high calorie foods, easy access to junk 1257 foods and high prices of healthy foods, as the most common reasons why students struggled 1258 to eat healthily. They equally mentioned several facilitators of healthy eating including 1259 improving food knowledge and education, meal planning, getting involved in food preparation 1260 and being physically active. While similar studies have not been conducted in students with 1261 food allergies, for this group meal planning and preparation involves additional considerations, 1262 including allergen avoidance and risks related to cross-contact, potentially complicating their 1263 ability to eat healthily.

1264

Furthermore, the poor access of healthy foods, particularly in and around campus, were also found to be obstacles to healthy eating amongst LA (McGowan et al., 2017; Munt et al., 2017; Sexton-Dhamu et al., 2021). Vending machines present everyday temptations to university students that are easily accessible. They more often than not include snacks and beverages of low nutritional value that are high in salt, sugar and fat, with limited healthy options available 1270 (Byrd-Bredbenner et al., 2012; Grech et al., 2015; Lasala et al., 2022). The availability of these 1271 unhealthy options will consequently encourage the purchase and consumption of such foods 1272 (Grech et al., 2017; Shi et al., 2018; Whatnall et al., 2020). Previous research indicates that 1273 more than half of students (53.3%) use vending machines more than once per week and 1274 greater than 80% use them to snack between meals (Park and Papadika, 2016). Park and 1275 Papadika (2016), examined the nutritional value of goods sold in vending machines in a UK 1276 university. Their results revealed that most vending machine snacks were high in sugar, fat 1277 and saturated fat and beverages were high in sugar. Likewise, Grech et al. (2017) following 1278 an audit of the nutritional composition of vending machine foods in one university in Australia, 1279 found that 95% of snacks and 49% of beverages were considered unhealthy. For food allergic 1280 individuals, the campus food environment including vending machines, rarely offer allergen 1281 free options, forcing them to risk consuming potentially unsafe items which are nutritionally 1282 inadequate or simply go without.

1283

1284 Several interventions have proven successful in increasing the sale of healthy snacks and 1285 beverages in the university setting from vending machines. In a US study Brown et al. (2014), 1286 demonstrated the effectiveness of using colour coded stickers (red = less healthy, yellow = 1287 moderately healthy, green = more healthy). The use of this nutrition information intervention 1288 led to the increased purchase of healthier snack items (green stickered items) and a reduced 1289 purchase of red and yellow stickered foods and beverages. Additionally, Grech et al. (2015), 1290 conducted a systematic review to assess nutrition intervention studies in vending machines. 1291 Of the twelve studies included in their review, five were from a university setting. They found 1292 that reducing prices of healthier foods and increasing their availability in vending machines 1293 encouraged their purchase. Furthermore, Whatnall et al. (2020), evaluated the effectiveness 1294 of nutrition interventions in the university setting, through means of a systematic review. Of 1295 the thirteen studies included, their results revealed that eight reported positive findings. 1296 Promoting and increasing the availability of healthier foods and reducing their prices were the 1297 predominant strategies implemented that proved effective. Lasala et al. (2022), reinforced the 1298 need of including healthier foods in vending machines, suggesting foods such as, fruit, 1299 natural/roasted nuts without added salt, whole-grain sandwiches, breadsticks and cereals low 1300 in sugar and salt. A greater proportion of alternatives to sugar-sweetened beverages such as, 1301 water, natural fruit and vegetable juices, milk, natural yoghurts, and sugar-free soft drinks were 1302 also suggested to be included in vending machines by Lasala et al. (2022). Despite these 1303 efforts to improve the nutritional quality of vending machine foods, no research has 1304 investigated the inclusion of allergen free foods in university campus vending machines, 1305 suggesting a gap in accommodating to the needs of students with food allergies. There is a 1306 growing number of students with food allergies and this emphasises the need for more

inclusive and safe food options on the university campus. Additionally, there is a need for more
 research in this area to prompt the availability of safer food options for food allergic students.

- 1310 In addition to this, the management of food allergies at university presents a uniquely 1311 challenging situation. LA with food allergies will be living independently and will likely for the 1312 first time, be responsible for their individual diet and health. During this time, LA will also be 1313 reliant on the university to prevent and aid the incidence of any food allergic reactions. To our 1314 knowledge, no research has looked at the management of food allergies in UK universities. 1315 However, some US studies exploring this topic do exist. They highlight how universities 1316 themselves, despite the growing number of food-allergic students, are not equipped to provide 1317 the necessary support and guidance for this group (Greenhawt et al., 2009; Choi and 1318 Rajagopal, 2013; Dyer et al., 2018; Bajaj et al., 2023; Wu and Wang. 2023). Specifically, staff 1319 at higher education institutes possess little knowledge and training regarding food allergies 1320 and lack the confidence in providing support to students in the event of an allergic reaction 1321 (Choi and Rajagopal., 2013). Moreover, the campus food environment offer little in the way of 1322 AFF and on campus dining facilities cannot completely guarantee an allergen free food 1323 environment (Greenhawt et al., 2009; Wu and Wang., 2023). To date, no previous research 1324 has mentioned the inclusion of AFF in campus vending machines, despite their increased use 1325 by LA. Thus, further highlighting the limited availability of safe food options on campus. Hence, 1326 it is no surprise why many accounts of fatal food anaphylaxis have been reported in students 1327 at university (Bock et al., 2007; Vuchnich et al., 2015; Mondello, 2023). To ensure inclusivity 1328 universities have a responsibility to support students in managing their food allergies. This lies 1329 in the development of policies and procedures which increase the access of AFF, facilitate 1330 allergy awareness training for staff and encourage self-responsibility and communication in 1331 food allergic students (Choi and Rajagopal, 2013; Dyer et al., 2018; Hassan et al., 2020; Bajaj 1332 et al., 2023; Wu and Wang. 2023).
- 1333

#### 1334 2.3.4. <u>Summary</u>

1335

1336 The transition to university is characterised by dramatic changes in lifestyle. During this time, 1337 LA will perhaps for the first time in their lives be responsible for individual FC. Throughout this 1338 period, many factors will contribute to the FC behaviour of LA. As detailed in the literature, 1339 factors influencing FC in LA include social pressures, academic stress and limited time, which 1340 in turn can impact dietary habits. Despite any good intentions to adopt a healthy diet, the 1341 desire for independence and the pressures of social influence and academic life will lead these 1342 individuals to increase in their risk taking and in their indulgence of unhealthy foods. Equally, 1343 healthy eating will be hindered due to the tempting obesogenic environment and the constant 1344 availability of pre-packed and convenience foods. For LA with food allergies, the added 1345 complexity of navigating allergen free options in a campus environment which often lacks 1346 adequate options can further influence FCs. Existing research indicates that while LA with and 1347 without food allergies are influenced by similar determinants of FC, the unique demands of 1348 managing food allergies may exacerbate the difficulties with maintaining a healthy diet. 1349 Additionally, the limited availability of AFF across campus will reduce FCs in this group and 1350 further increase risk-taking. It is clear that the university has an obligation to promote a more 1351 conducive food environment - one which can safely accommodate for all students, including 1352 those with food allergies. Literature dictates that eating behaviours established during the 1353 period of late adolescence will persist into adulthood (Vilaro et al., 2018). Therefore, in order 1354 to improve and maintain future health outcomes, there is a great need to ensure better dietary 1355 behaviours in this group of individuals.

1356

# 1357 2.4. Food Insecurity

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## 1359 **2.4.1. Prevalence**

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1361 Access to adequate food is a basic right, yet food insecurity is a global public health problem 1362 (BMC Medicine, 2023). Food insecurity has been defined as the inability to acquire sufficient 1363 food to meet nutritional requirements, due to financial or resource constraints (FAO, 2023). 1364 Food insecurity can be divided into three types. 'Marginal or 'mild' food insecurity (the 1365 uncertain access and anxiety in obtaining adequate food), 'moderate' food insecurity (the 1366 inability to afford a balanced diet - this can lead to compromising the quality and variety of 1367 food, reducing quantities of food and skipping meals) and 'severe' food insecurity (the inability 1368 to afford enough food – experiencing hunger) (Sosenko et al., 2022).

1369

1370 Despite the UK being an affluent country, food insecurity is prevalent and has been further 1371 exacerbated by the COVID-19 pandemic (McPherson, 2020). In April 2022, an estimated 7.3 1372 million adults and more than 2.6 million children experienced food insecurity across the UK 1373 (Cretch, 2022). A further report highlights how in June 2023 alone, 9 million adults in the UK 1374 (17% of households) experienced 'moderate' or 'severe' food insecurity because they were 1375 unable to afford or access food. In this same time frame, 16% of adults reported having smaller 1376 portions or skipping meals altogether, 11% reported feeling hungry but not eating and 6% 1377 (equal to 3 million adults) reported not eating for a whole day (The Food Foundation, 2023). 1378 The NW of England is one area where there exists high levels of food insecurity and this can
be attributed to the high levels of deprivation which are present in this region (Mitchell, 2022;
Smith et al., 2022). A UK food security report (2021) revealed extremely low food security in
the NW, with 90% of households in this district experiencing some level of food insecurity.
Further research identified that individuals at university in the NW of England were the most
at risk, with 60% of food insecurity found among students (Armstrong et al., 2023).

1384

## 1385 2.4.2. The Consequences of Food Insecurity

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1387 Food insecurity has negative consequences on health. Many of those who experience food 1388 insecurity will have an increased reliance on processed foods high in fat, salt and sugar due 1389 to their inexpensive nature (Contento, 2011; Hall, 2018; Liem and Russell, 2019; Monterrosa 1390 et al., 2020; Molenaar et al., 2021; Li et al., 2022; Johnstone and Lonnie, 2023). This will 1391 massively impact diet quality with both malnutrition and obesity common occurrences 1392 (Carvajal-Aldaz et al., 2022; Johnstone and Lonnie, 2023). Additionally, individuals with food 1393 insecurity will either develop new physical health conditions or existing conditions will worsen. 1394 For example, levels of food insecurity are associated with vitamin deficiencies, elevated blood 1395 pressure, diabetes, heart disease, iron deficiency anemia, chronic pain and rheumatological 1396 conditions. (Gunderson and Ziliak, 2015; Dush et al., 2020; Larson et al., 2020; Yau et al., 1397 2020; BMC Medicine 2023).

1398

1399 Moreover, poor quality of life is an inevitable outcome for those suffering from food insecurity. 1400 The difficulty in accessing food, particularly in those with dietary restrictions (e.g. food 1401 allergies), will impact social interactions and dining out experiences. Consequently, this will 1402 contribute to feelings of isolation and frustration, reducing overall quality of life (Graham and 1403 Ciciurkaite, 2023; Hanna et al., 2023). Additionally, the development of mental health 1404 conditions is prevalent (Dilley et al., 2018). A UK report on food insecurity found that in LA, 9 1405 in 10 (91%) will worry that their food will run out before they are able to financially buy more, 1406 with more than half (57%) reporting that this is a frequent occurrence (Cretch, 2022). This 1407 insufficient food as well as the subsistence on nutritionally inadequate diets will lead to many 1408 individuals experiencing stress, anxiety and depression (Larson et al., 2020; McPherson et 1409 al., 2020; Pourmotabbed et al., 2020; Wolfson et al., 2021; Cretch et al., 2022). This will most certainly prove detrimental, with suicidal ideation and mental disorders merely a few of the 1410 1411 negative impacts that will arise (Dush, 2020). Furthermore, research from Canada and the UK 1412 found that food insecurity (due to insufficient nutrients obtained from foods, namely Iron and 1413 Zinc) is linked to poorer cognitive ability making it harder for individuals to concentrate, thus 1414 directly impairing academic performance (Ke and Ford-Jones, 2015; McPherson, 2020). 1415 Similarly, securing nutritious food is challenging for food insecure individuals and can influence

1416 immediate and future social development. This will further reduce educational and academic

- 1417 performance and hence economic attainment (Ke and Ford-Jones, 2015; Beyene, 2023).
- 1418

The negative health impacts of food insecurity are clear. A direct result of this will be the increased burden on health and social care services. According to a UK study reported in BMC Medicine (2023), those experiencing food insecurity have an increased likelihood of being admitted for acute care, staying in hospital and being readmitted, in comparison to those who are food secure. In fact, food insecure individuals are also more likely to die prematurely and in cases of severe food insecurity, the life span is reduced by an average of nine years.

1425

# 1426 **2.4.3.** Food Banks

1427

1428 In recent times, the rising levels of food insecurity has caused an overwhelming increase in 1429 the number of food banks being used in the UK (McPherson, 2020; Sosenko, et al., 2022). 1430 Currently, food banks are overstretched and unable to accommodate for the rising demands. 1431 In 2022/23, approximately 2.99 million people used a food bank across the UK – an increase 1432 from the previous year (Clark, 2023). Particularly, food bank usage in the NW has been 1433 notable (Oldman, 2021). In 2021, the Trussell Trust reported providing food to people in the 1434 NW more than any other region. In addition to this, recent data from the Department of Work 1435 and Pensions highlighted the NW as having one of the highest household food bank usages 1436 compared to other areas in the UK (Department for Work and Pensions, 2023). Food banks 1437 do offer a critical role in providing relief to many individuals and families who struggle to access 1438 food (Minaker et al., 2014; Ke and Ford-Jones, 2015; Bazerghi et al., 2016; May et al., 2018; 1439 Loopstra et al., 2019). However, reliance on food banks is not a sustainable safety net and 1440 offer only a temporary solution (Ke and Ford-Jones, 2015; May et al., 2018; BMC Medicine, 1441 2023). In fact, access to foods via food banks may not be readily available 'as and when' 1442 needed and this will result in periods of food deficiency. Those with food allergies experiencing 1443 food insecurity will be placed at an increased risk of food deficiency, as food banks rarely 1444 accommodate for this group, offering limited to no AFF (Fong et al., 2022; Scurlock et al., 1445 2022). In addition to this, many will not be able to access food banks due to geographical 1446 location and the cost of transport (Tam et al., 2014; May et al., 2018). Also, the concept of 1447 food banks relies exclusively on donations, resulting in a limited food supply (Ke and Ford-1448 Jones, 2015; Loopstra et al., 2019; Sosenko, et al., 2022). Moreover, much of the food 1449 provided at food banks lacks nutritional quality. Previous research has revealed that such 1450 foods exceed energy requirements, are extremely high in salt, sugar and carbohydrate and 1451 have inadequate vitamin A and D levels (Bazerghi et al., 2016; Hughes and Prayogo, 2018; 1452 Fallaize et al., 2020; Oldroyd et al., 2022). Thus making it difficult for individuals to achieve

and maintain a balanced diet. Additionally, fresh produce is scarce at food banks and while
there are many long-life food options, these are often nutritionally unsuitable (Campbell et al.,
2011; Ke and Ford-Jones, 2015).

1456

## 1457 2.4.4. Late Adolescents – An 'At Risk' Population

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1459 Food insecurity has the potential to affect people of all ages. However, over the past few years, 1460 there has been a notable increase in food insecurity in those experiencing late adolescence. 1461 Research conducted in the US highlights that food insecurity is present in nearly one in four 1462 individuals between the ages of 18 and 26years (Larson et al., 2020). These individuals will 1463 be in a state of transition from late adolescence to adulthood and have an increased risk of 1464 poverty and food insecurity making them amongst the most vulnerable (Defeyter et al., 2020; 1465 McPherson, 2020; Cretch et al., 2022). Research from both the UK and US further highlight 1466 how over one third of all students at university will be suffering from food insecurity at some 1467 level and since the COVID-19 pandemic, this number is increasing (Defeyter et al., 2020).

1468

1469 Economic constraints are one of the most commonly reported factors influencing food 1470 insecurity and as such, is a constant factor in the lives of many low-income families (Loopstra 1471 et al., 2019). The rising cost of living is one of the most significant contributors to this (Ke and 1472 Ford-Jones, 2015; Loopstra et al., 2019; Cretch, 2022). While seeking autonomy from their 1473 parents and embarking on a journey of self-discovery and identification, LA will often live 1474 independently. This can often leave them in financial difficulty (Defeyter et al., 2020). This is 1475 particularly prevalent in students at university. According to a UK specific study, these 1476 individuals are three times more likely to experience food insecurity than any other population 1477 group (Yau et al., 2020). Likewise, one UK study highlighted how food bank usage by 1478 university students was common, with 1 in 10 using a food bank during the 2021/22 academic 1479 year (Brown, 2022). This is unsurprising given that tuition fees, food, utilities, transport and 1480 accommodation are just some of the many expenditures for students (Ahmad et al., 2021; 1481 Ravel et al., 2023). Often students will supplement their income through part-time, temporary 1482 jobs, which can be difficult to balance while studying. Many will be unable to cope with this stressful situation and as such, will be in a state of constant worry and anxiety (Defevter et al., 1483 1484 2020). Additionally, to afford a nutritious diet of good quality becomes difficult for this group 1485 due to financial restrictions. Previous UK research has illustrated how 54% of LA struggled to 1486 buy food in the year 2022, with this being commonly attributed to the high cost of living (e.g. 1487 rent and energy prices). In vulnerable LA this is worse, with the same research highlighting 1488 how 68% of these individuals will regularly go an entire day without food, due to lack of money.

Similarly, 78% of LA report they cannot afford to eat a balanced meal with almost half (45%)saying this is an often occurrence (Cretch, 2022).

1491

1492 In addition to this, the financial difficulty experienced by LA will present difficult choices. This 1493 group will be attempting to gain control over their individual FCs, while adapting to a life of 1494 independency and thus, will increasingly exercise poor judgement and select suboptimal foods 1495 (Bauer et al., 2016; Larson et al., 2020). For example, Larson et al. (2020), found that LA 1496 experiencing food insecurity in the US were more likely to consume fast food and sugar 1497 sweetened beverages, with a reduced intake of fruits, vegetables and fibre, placing them at 1498 an increased risk of nutritional deficiencies. Physical access to food is necessary in order to 1499 be food secure (UK Food Security Report, 2021). Therefore, one reason for LA being more 1500 inclined to purchase unhealthy foods, is because they are more affordable and easily 1501 accessible (Ke and Ford-Jones, 2015; Loopstra et al., 2019). One UK survey mentions how 1502 62% of LA believed they did not have access to enough safe, nutritious food to develop and 1503 maintain growth and development (Cretch, 2022). This is often the case in the university 1504 campus environment and surrounding areas which have commonly been labelled as 1505 'obesogenic.' (Poobalan et al., 2014; Tanton et al., 2015; Munt et al., 2017; Brennan et al., 1506 2020) This will prove problematic given that firstly, the period from adolescence to adulthood 1507 is one which necessitates heightened nutritional requirements, in order to optimise academic 1508 performance (Maslin et al., 2018; Ravel et al., 2023). Secondly, insufficient nutrient intake can 1509 compromise health status and can reduce productivity at both work and during education (Ke 1510 and Ford-Jones, 2015; Beyene, 2023). In the UK, 23% of LA report missing work or education 1511 due to lack of food (Cretch, 2022). Moreover, those in LA (particular those who are food 1512 insecure) will often possess limited cooking abilities and the reliance on heavily processed 1513 convenience foods is therefore significant (Stok et al., 2016; McPherson, 2020; Harper et al., 1514 2022). Consequently, this will further compound dietary intake and hence nutritional status.

1515

1516 In addition to this, LA will demonstrate a greater degree of risk taking (Steinberg, 2009; Stok 1517 et al., 2016). LA who are subject to food insecurity, are more likely to engage in unhealthy 1518 behaviour. For instance, skipping breakfast, inadequate sleep, consuming alcohol, smoking 1519 cigarettes, substance abuse and binge-eating, are all common practices prevalent amongst 1520 LA experiencing food insecurity. These practices will be further exacerbated in those with 1521 dietary restrictions (e.g. food allergies), consequently having devastating effects for future 1522 health status (Larson et al., 2020). Additionally, despite experiencing high levels of food 1523 insecurity, many individuals in late adolescence will not use food banks to avoid shame and 1524 stigma associated with the reliance on charitable food (Purdam et al., 2015; Fitzpatrick et al., 1525 2016; McPherson, 2020). Likewise, these individuals find it very difficult to accept both formal 1526 and informal support, as this would disrupt their independence. In many cases, LA would go 1527 to great lengths to hide their financial difficulties and would rather go hungry than seek support 1528 (McPherson, 2020; Cretch et al., 2022). Therefore, this will further increase food insecurity 1529 and the consequent negative health outcomes in this group. Often, the financial strain will lead 1530 to many engaging in eating less expensive food, reducing portion sizes and/or the number of 1531 meals per day, purchasing foods on loan and credit and reducing fruit and vegetable intake 1532 as this is thought to be more expensive. In some cases, LA would participate in less socially 1533 desirable coping strategies such as begging and stealing (Fricke et al., 2015; Cretch et al., 1534 2022; Diamini et al., 2023; Yasmin et al., 2023).

2.4.5. Food Allergies and Food Insecurity

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# 1536

1537

1538 The presence of a food allergy will intensify the risk of food insecurity (Dilley et al., 2018; 1539 Guillaume et al., 2021). For these individuals, the cornerstone of management is avoidance 1540 of the offending allergen (Scurlock et al., 2022). While this is both a proven and effective 1541 technique, complete compliance is not only a challenging task, but will naturally lead to limited 1542 food selection, which will directly impact nutritional status (Dilley et al., 2018; Tackett et al., 1543 2019). Additionally, the implementation of restrictive diets, especially if not done with care and 1544 with suitable alternatives, will further place those with food allergies at risk of an insufficient 1545 diet (de Almeida Kotchetkoff et al., 2023). Hence, those suffering from food allergies will 1546 already be at an increased risk of nutritional deficiencies, which in turn will negatively impact 1547 health status.

1548

1549 An adequate and healthy diet is essential to preventing malnutrition. While this is difficult for 1550 those with food allergies due to their dietary restrictions, AFF offer a safe way for those with 1551 food allergies to replace lost nutrients (Pasha-Robinson, 2023) However, purchasing these 1552 foods is difficult for those with food allergies for two primary reasons. Firstly, individuals with 1553 food allergies face a unique challenge in accessing safe AFF within their community. Despite 1554 supermarkets and retailers offering more food possibilities to accommodate for the food 1555 allergic community, enough options are not available for the rising number of people with food 1556 allergies (Searby, 2022). In the UK, these foods are commonly limited to only one section in 1557 supermarkets and are rarely seen in convenience stores, making them difficult to access 1558 (Holroyd, 2022). Research by Frame et al (2022) further support this, highlighting how those 1559 with food allergies in the US had inconsistent access to AFF. They also mention how this 1560 limited access to safe foods was associated with reduced quality of life.

1562 Secondly, while 'free from' foods are a rapidly growing industry specifically designed to 1563 increase safe FC in those with food allergies, these foods are more expensive and not 1564 available via prescription (North and Brown, 2017; Allen and Orfila, 2018; Brown et al., 2020). 1565 One study conducted by the Foods Standards Agency (2022) revealed how households with 1566 food hypersensitivities spent between 12% to 27% more on their weekly food purchases, than 1567 individuals without any dietary restrictions. Specifically their study illustrated how those with 1568 food allergies faced the highest financial burden than other groups with dietary restrictions, 1569 spending an additional 14p more for every pound spent on groceries. Moreover, there is 1570 currently no 'value range' for allergen free products, leaving individuals with food allergies no 1571 choice but to simply spend more (Minaker et al., 2014; Allergy UK, 2023). As the cost of living 1572 continues to rise those with food allergies face extortionate prices to access safe, nutritious 1573 food. For those unable to afford AFF, they are simply left with no choice but to not purchase 1574 them. One Mintel report (2022) reported how half of UK customers would cut back on AFF 1575 when money was tight. In addition to free from foods, individuals with food allergies will have 1576 additional costs. For instance, the cost of medication, nutrition supplements and increased 1577 hospital visits are financially draining (Minaker et al., 2014; Tackett et al., 2018; Foods 1578 Standards Agency, 2022). As such, food insecurity will be significantly increased in this group. 1579

1580 While food banks offer a means of providing access to a wide range of foods at no cost, they 1581 are under-equipped to accommodate for medical dietary restrictions (Fong et al., 2022; 1582 Scurlock et al., 2022). This difficulty in obtaining affordable, quality food that is safe to 1583 consume due to reduced access and increased cost will not only lead to the inability to meet 1584 nutritional needs, but will greatly increase the risk of allergen exposure in those with food allergies. This will consequently increase severe reactions, leading to an increase in 1585 1586 hospitalisations and in many cases, the negative impact on health will be detrimental (Tackett 1587 et al., 2019: Brown et al., 2020).

1588 1589

## 1590 **2.4.6.** Summary

1591 1592

Food insecurity is a widespread phenomenon – one that proves difficult to resolve due to its multifactorial nature. Food insecurity has the ability to negatively impact all populations. However, LA with food allergies who are undergoing the crucial period of transition from late adolescence to adulthood, are perhaps the most vulnerable. Disrupted access to adequate, nutritious, safe food will elicit unhealthy behaviours, consequently leading to nutritional decline and reduced quality of life. Furthermore, poor academic performance is one of the many consequences of food insecurity. This is particularly concerning for LA as behaviours

established during this time are likely to persist into adulthood (Vilaro et al., 2018). Therefore,promoting positive change during this life stage is critical.

1602

1603 The data presented in this section highlights a significant issue for university students - a 1604 demographic who are already under considerable stress due to academic and social 1605 pressures. The dual burden of food insecurity and managing food allergies may increase the 1606 difficulties in maintaining a safe and balanced diet. Given the heightened risk of food insecurity 1607 among university students, particularly in the NW region, there is a need to explore how these 1608 challenges can affect LA with food allergies. Addressing this issue is crucial for understanding 1609 the broader implications on FC, food access, dietary intake and HCA. This focus aligns with 1610 the objective of this thesis in investigating the unique barriers faced by food allergic individuals 1611 and the necessity for more inclusive policies and support systems in the university 1612 environment. Interventions to limit the scale of food insecurity are not only necessary, but 1613 should be prioritised as this may alleviate the existing burden on healthcare services.

1614

1616

# 1615 2.5. Limitations of the Review

1617 The preceding literature review provides valuable insights into the FCs, food access and HCA 1618 of LA with food allergies. However, it is important to consider the limitations associated with 1619 the narrative approach which has been adopted.

1620

Firstly, the selection of studies which have been included in this review could have been influenced by the availability at the time the review was conducted. This could have introduced a degree of bias in the literature review as certain points could have been overrepresented, while potentially overlooking other relevant studies. Likewise, the review may not have comprehensively captured and discussed all the relevant research, especially in rapidly evolving fields such as food allergy management and healthcare access, where new studies are continuously emerging.

1628

Secondly, the literature review includes a diverse set of studies with varied methodologies and populations, including differences in sample size, study design and geographical context. This can make it challenging to draw definitive conclusions. Unlike a systematic review which utilises a predefined method to minimise bias and comprehensively cover relevant studies, the narrative approach used in this review may have resulted in gaps in coverage and variability in the quality of the studies, which could impact the overall validity and reliability of the findings.

Thirdly, the literature review focuses on a broad range of topics, covering various aspects of food allergies, HCA, FCs, eating behaviour, food insecurity and social deprivation. This may have diluted the discussion in certain areas and consequently limited the depth of analysis on specific areas.

1641

Finally, the literature review is reliant upon much secondary data and published studies as opposed to direct empirical data. Therefore, this review may not have fully captured the lived experiences of individuals with food allergies, which could have provided deeper insight into their everyday challenges in relation to FC, food access, HCA and dietary intake. This could therefore have resulted in an incomplete understanding of their experiences.

1647

1648 Despite the limitations of this literature review inherent in its narrative approach, it does provide 1649 a foundation in understanding the challenges faced by LA with food allergies in the context of 1650 their FCs, food access and HCA. The review has also bought to light key areas which require 1651 further investigation, some of which are addressed in this thesis. Additionally, the review has 1652 identified critical gaps that present opportunities for further research aimed at enhancing the 1653 support and overall well-being of LA with food allergies - a demographic which is often 1654 underrepresented in research. Addressing these gaps will be essential in developing more 1655 effective strategies and targeted interventions, tailored to their unique needs.

1656

1658

## 1657 2.6. Overall Summary

1659 In conclusion, this literature review has provided a comprehensive overview of existing 1660 literature in relation to LA with food allergies FCs, food access and HCA. Though advances in 1661 allergy research and clinical practice have significantly contributed to better management and 1662 awareness of food allergies, significant gaps do remain in ensuring equitable access to food 1663 and healthcare for this demographic.

1664

While this thesis does not directly investigate food insecurity in LA with food allergies, 1665 1666 understanding this context provides a crucial backdrop for exploring the unique challenges 1667 faced by food allergic students. Similarly, the discussion on factors influencing eating 1668 behaviours, food banks and social deprivation enriches the understanding of the broader 1669 environment in which LA with food allergies navigate. Additionally, the focus on social 1670 deprivation through the literature review, particularly in the NW of England, provides important 1671 contextual insights. Although the research does not measure social deprivation levels of the 1672 participants, this is a key factor impacting FCs, food and HCA and dietary intake and can 1673 exacerbate the existing challenges faced by food allergic individuals. By understanding these

1674 contextual factors, the thesis gains a deeper insight into the environment which impacts LA
1675 with food allergies, particularly as all participants for each study were recruited from the NW.
1676 This has helped to understand the challenges and more importantly has identified potential
1677 future areas of research. Addressing such areas could prove essential in developing more
1678 effective strategies for LA managing food allergies.

1679

1680 This literature review provides a foundation for the empirical investigations to follow, which will 1681 look at exploring the experiences of LA with food allergies in the NW of England. Specifically, 1682 this research will investigate FC, food access, HCA and dietary intake in this group. By 1683 comparing between individuals with and without food allergies, the subsequent studies will 1684 attempt to highlight the unique challenges faced by LA with food allergies as they transition 1685 from late adolescence to adulthood. The findings provide a foundation for the recommendation 1686 of targeted interventions from the unique perspectives of food allergic patients, their parents 1687 and HCPs - ultimately to improve food and health inequities and dietary intake in this 1688 population. The following chapter (Chapter 3) will focus on exploring the FCs, food access and 1689 HCA in LA with and without food allergies through quantitative methods, as means of gaining 1690 an initial insight into these areas.

# <u>Chapter 3</u> – Current Food Choice, Food Access and Healthcare Access in Late Adolescents (18-25years) With and Without Food Allergies

3

# 4 3.1. <u>Overview</u>

5

6 The period of transition from late adolescence to adulthood is a critical life stage which can 7 dictate future food choices. Additionally, the management of a food allergy during this period 8 can further influence food choice (FC). There is currently limited research investigating FC in 9 late adolescents (LA) with food allergy. While previous studies have investigated the FCs of 10 LA (Beasley et al., 2004; Deliens et al., 2014; Hebden et al., 2015; Kairey et al., 2015; 11 Poobalan et al., 2014; Howse et al., 2018; Sogari et al., 2018; Sprake et al., 2018; Livingstone 12 et al., 2021; Li et al., 2022, Mensah et al., 2022) rarely has the influence of FC been examined 13 in LA with food allergies. In fact, to the best of our knowledge only two previous studies have 14 investigated FC in food-allergic individuals – one in early adolescence (Sommer et al., 2014) 15 and one in late adolescence (Laheri et al., 2022). Therefore, this study explored FC in LA with 16 food allergies, with the results further contributing to our knowledge in this area.

17

18 Specifically this chapter focused on the current FC, food access (FA) and healthcare access 19 (HCA) of LA with and without food allergies. A cross-sectional study was conducted to explore 20 the various factors impacting FC and the current food and HCA available for these individuals. 21 A key aspect of this study involved conducting a comparative analysis between LA with and 22 without food allergies. The inclusion of a non-food allergic group allowed for a more detailed 23 understanding of the unique challenges faced by LA with food allergies. By providing a 24 comparison, this study better identified the specific factors and barriers related to food allergies 25 which may not be present in the general LA population. This comparison provided valuable 26 context, highlighting whether the issues faced by food-allergic individuals are distinct or simply 27 reflective of the broader trends in this group.

28

29 Additionally, the study included both medically diagnosed individuals with food allergies and 30 self-diagnosed individuals with food allergies. There is an increasing prevalence of self-31 diagnosed food allergies with self-reported food allergy reaching up to 20% in the UK (Allergy 32 UK, 2024) and this can still impact individuals FCs and healthcare seeking behaviour. 33 Including both groups reflects the real world diversity of the food allergic population and 34 provided valuable insights into how perceived food allergies, whether medically diagnosed or 35 self-diagnosed, impact FCs and access to food and healthcare. Although no direct analysis 36 was conducted comparing both groups, understanding their experiences ensured that this

study is more inclusive. This approach can help to identify gaps in awareness, accessibility of
safe food options and healthcare support, which can lead to interventions that address the
needs of the entire food-allergic population.

40

Through a quantitative approach, this chapter investigated the current FC, FA and HCA of LA with and without food allergies in North West (NW) England. The findings from this analysis were discussed and based on these results and existing literature, interventions to improve each of these areas for those with food allergies were suggested.

45 46

# 47 3.2. <u>Methodology</u>

48 49

# 50 **Ethical Considerations**

51

52 Ethical approval was obtained from the National Health Service Research Ethics Committee 53 (NHS REC) (REC Reference: 21/EE/0285, Project ID: 303224) and the University of Central 54 Lancashire's (UCLan) HEALTH ethics committee, prior to data collection. Following approval, 55 participants were provided with a participant information sheet, providing them with detailed 56 information regarding the study. The participant information sheet was accessible online via a 57 secure link and detailed the purpose and nature of the study, potential risks and benefits of 58 the research and additionally emphasised participant confidentiality and the right to withdraw 59 at any point. This ensured all participants had all relevant information at hand, allowing them 60 to decide if they would like to participate. Once participants had reviewed the participant 61 information sheet, informed consent was obtained from all those who expressed interest in 62 the study, through an online consent form. Only after consent was given, participants were 63 able to access the survey.

64

# 65 Patient and Public Involvement and Engagement

66

A patient steering group (n=5) comprising of a small sample of the target population was recruited prior to actual data collection. These individuals provided advice and suggestions based on individual experiences with regard to the relevance of the study. They also reviewed any material (e.g. participant information sheets, consent forms, questionnaires) that were seen by prospective participants and determined their suitability. Their feedback was essential in refining the materials to ensure they were clear and understandable to potential participants.

# 74 **Questionnaire**

75

76 To assess the various factors impacting FC behaviour, a quantitative survey was conducted 77 (see Appendix 1). The questionnaire was divided into six sections. Sections one, two and three 78 related to socio-demographic, diet and lifestyle factors. Section four assessed current food 79 and HCA, while section five assessed current FC. FC was determined using ten different 80 categories (sensory, convenience, social, psychological, economic, advertising, university, 81 familiarity, health and labelling). A Likert scale of influence where 1 = not influential and 5 = 82 extremely influential, was used in section 5. Section six related to food allergies and was only 83 completed by those participants with food allergies.

84

85 The questions used in the questionnaire were adapted from established and validated scales, 86 in this case the Food Choice Questionnaire (FCQ) by Steptoe et al. (1995). The FCQ is a well 87 established tool that has undergone multiple rounds of validation in previous studies. Likewise, 88 questions from similar research by Deliens et al. (2014), Sommer et al. (2014) and Ensaff et 89 al. (2015) were also included in the guestionnaire. These studies were chosen for their broad 90 coverage of factors influencing FC as well as the validated measurement approach. The 91 questions were adapted to better suit the target population of LA with food allergies, through 92 modifying the wording of the question and adding specific questions about allergy 93 management, and food and HCA. A mixture of close-ended, open-ended and Likert scale 94 questions were consequently included in the questionnaires. The questionnaire is included in 95 Appendix 1.

96

97 A pilot study (n=18) was conducted prior to data collection, to ensure suitability and 98 effectiveness of the questionnaire. Upon completion of the pilot study, participants felt one 99 questions was ambiguous and needed clarity. Therefore revisions were made to include 100 definitions of what was meant by a 'mild,' 'moderate' and 'severe' food-allergic reaction.

101

## 102 **Recruitment**

103

Individuals between the ages of 18 and 25years with one/more existing food allergies and a control group of participants without food allergies were recruited. Any individuals suffering from other health conditions potentially impacting their diet (e.g. Crohn's Disease, Irritable Bowel Syndrome (IBS), Ulcerative Colitis), were excluded from this research. Likewise, non-English speaking individuals were also excluded.

109

110 The NW of England is a an area with high levels of socioeconomic deprivation and therefore 111 to capture a comprehensive picture of this regions diversity, all data collection took place in the NW in areas of high and low deprivation (Blackpool, Chester, Blackburn with Darwen,Bolton, Preston, Liverpool, Oldham, Lancaster, Manchester, Wigan).

114

115 Allergy charity bodies (Anaphylaxis UK and The Natasha Allergy Research Foundation) 116 assisted in recruitment of LA with food allergies. Both charities shared the recruitment poster 117 via their social media sites. Additionally, Anaphylaxis UK invited all NW members via email, 118 while also sharing details of the study in their monthly newsletter. Furthermore, four NHS trusts 119 in the NW region (Lancashire Teaching Hospitals NHS Foundation Trust, East Lancashire 120 Hospitals NHS Trust, Liverpool University Hospitals NHS Foundation Trust and Mersey Care 121 NHS Foundation Trust) helped in the recruitment of LA with food allergies, by circulating the 122 poster via their social media sites and placing posters across the hospitals. A database search 123 using 'Evolve' and 'Quadramed' was also conducted at the Royal Preston Hospital and 124 Broadgreen Allergy Clinic in Liverpool to identify potential patients aged 18-25 years with food 125 allergies. A text message was then sent to these individuals with a link to the online participant 126 information sheet and after confirming their participation, a link to the consent form and FC 127 survey were also provided to each of the participants. Non-food allergic individuals were 128 targeted through various colleges and universities in the NW. The recruitment poster was 129 placed around campuses and circulated through university social media sites, blackboard 130 portals and via university-wide emails. Potential participants were provided with the online 131 participant information sheet and upon interest were provided with a link to the consent form 132 and survey. Social media (Facebook, Twitter, LinkedIn) also played a crucial role in targeting 133 both LA with and without food allergies. For instance, the recruitment poster was shared with 134 members of the food allergic community and with student group pages to effectively reach the 135 18-25 year demographic. All data collection took place between February 2022 and mid-May 136 2022.

137

## 138 Data and Statistical Analysis

139

140 Data from all questionnaires was analysed using IBM SPSS Statistics Version 28.0. 141 Descriptive statistics (mean and standard deviation) were conducted on demographic 142 information. For HCA, Chi-Squared analysis determined any differences between those with 143 and without food allergies. The Mann Whitney U test determined differences between the food-144 allergic and non-food allergic group, in relation to FC. The analysis for FC was performed on 145 single question scores rather than composite scores. The reason for this approach, was to 146 provide a detailed understanding of individual item responses as opposed to aggregating the multiple items into a composite score, which could have potentially obscured any specific 147 148 variations in the data. The Kolmogorov-Smirnov test was also used to test for normality. All data for this section was non-normally distributed ( $p \le 0.05$ ). Therefore, any differences between the food-allergic and non-food allergic group in relation to FC were determined by the Mann Whitney U test. A power analysis was also conducted prior to collecting data, with a sample size of 80 per group (for food allergic and non-food allergic) and Cohen's d (0.5), giving an actual power of 0.86. An ideal power of 0.86 is considered adequate (Suresh and Chandrashekara, 2012), indicating that 86 participants in each group will deliver sufficient statistical power for robust effects.

156

## 157 3.3. <u>Results</u>

158 159

160 A total of 196 questionnaires were completed by 18-25 year olds. Eight participants reported 161 having a condition that would directly impact FC (Crohn's Disease, Irritable Bowel Syndrome 162 (IBS), Ulcerative Colitis, Urticaria and Postural Orthostatic Tachycardia Syndrome (POTS)) 163 and as such, these responses were excluded. Additionally, a further sixteen responses were 164 excluded with these individuals residing from outside the NW (Huddersfield (n=3), Bradford 165 (n=9), Halifax (n=4)). Therefore, the final data sample included 172 participants (86 food-166 allergic participants and 86 non-food allergic participants). All participants were recruited from 167 NW - Blackpool (n=10), Chester (n=12), Blackburn with Darwen (n=49), Bolton (n=16), 168 Preston (n=31), Liverpool (n=18), Oldham (n=5), Lancaster (n=9), Manchester (n=13), Wigan 169 (n=9).

170

## 171 Participant Demographics

172

173 Categorical variables from sections one to four of the questionnaire were expressed as 174 numbers and percentages. There was a higher number of females (n=102, 59%) than males 175 (n= 70, 41%) who completed the questionnaire. The mean age of participants was  $22.1 \pm 2.2$ 176 years. Body Mass Index (BMI) was computed for each individual by dividing weight (kg) by 177 height (m)<sup>2</sup>. For both groups BMI was found to be similar, with a mean average of  $23.5 \pm 4.1$ 178 kg/m<sup>2</sup> for those with FA and  $22.5 \pm 4.3$  kg/m<sup>2</sup> for those without food allergies (Table 3.1).

179

Participants diet was either vegan, vegetarian, mainly animal based, mainly plant based or pescatarian, with most participants following an animal based diet (n=108, 63%). Supplement use was higher in participants with food allergies (n=35, 41%) compared to non-food allergic participants (n=25, 29%). 43 (25%) participants were taking medication at the time of the study, with 19% coming from the food-allergic group. Most medication was relating to their food allergy and consisted of adrenaline-autoinjectors and antihistamines. Only 19 (11%)

- reported to be current smokers, with 12 (7%) from the food-allergic group. Overall, alcohol
- 187 intake was higher in those with food allergies (n=62, 72%) compared to those without (n=36,
- 188 42%). Physical activity was similar in both groups with majority (n=122, 71%) meeting
- recommended guidelines. Most participants possessed a driving licence (n=120, 70%) with
- 190 just under half (n=85, 49%) having their own vehicle. For those without their own vehicle, the
- 191 most frequent mode of transport when accessing food and/or healthcare was public transport
- 192 (n=32, 62%) followed by car passenger (n=29, 56%). 44% (n=23) had a preference for walking
- 193 with only 6% (n=3) using a bike (Table 3.1).

- **Table 3.1.** Demographic Characteristics for 18-25 year olds, with a food allergy (n=86) and
- 195 without a food allergy (n=86)

	Food Allergy (n = 86)	No Food Allergy (n = 86)
Gender (n, %)		
Male	34 (40)	36 (42)
Female	52 (60)	50 (59)
Age (n, %)		
18	6 (7)	6 (7)
19	2 (2)	5 (6)
20	17 (20)	12 (14)
21	7 (8)	9 (10)
22	9 (10)	13 (15)
23	11 (13)	17 (20)
24	11 (13)	12 (14)
25	23 (27)	12 (14)
ВМІ ( <sup>5</sup> , SD)	23.5 (4.1)	22.5 (4.3)
Ethnicity (n, %)		
White British	43 (50)	31 (36)
White European	9 (10)	10 (12)
White Other	3 (3)	2 (2)
Black: British Caribbean	4 (5)	2 (2)
Black: British African	17 (20)	3 (3)
Black: British Other	1 (1)	1 (1)
Asian: British Indian	2 (2)	25 (29)
Asian: British Pakistani	0	6 (7)
Asian: British Other	0	3 (3)
Mixed Background	3 (3)	2 (2)
Chinese	3 (3)	1 (1)
Indonesian	1 (1)	0

# **Table 3.1.** Continued

	Food Allergy (n = 86)	No Food Allergy (n = 86)
Education (n, %)		
GCSE	2 (2)	2 (2)
A-Level	24 (28)	26 (30)
Bachelors Degree	48 (56)	46 (54)
Post Graduate Degree	12 (14)	12 (14)
Occupation (n, %)		
Part-time Student	3 (3)	7 (8)
Full-time Student	47 (55)	48 (56)
Self-employed	4 (5)	0
Part-time employed	2 (2)	8 (9)
Full-time employed	26 (30)	20 (23)
Unemployed	2 (2)	3 (3)
Apprentice	1 (1)	0
Volunteer	1 (1)	0
Campus (n, %)	25 (29)	17 (18)
Household Composition (n, %)		
1	3 (3)	5 (6)
2	25 (29)	11 (13)
3	23 (27)	22 (26)
4	28 (33)	23 (27)
5+	7 (8)	25 (29)
Living Area (n, %)		
City	53 (62)	36 (42)
Town	26 (30)	47 (55)
Countryside	4 (5)	2 (2)
Village	3 (3)	1 (1)

# **Table 3.1.** Continued

	Food Allergy (n = 86)	No Food Allergy (n = 86)
Type of Diet (n, %)		
Vegan	4 (5)	6 (7)
Vegetarian	16 (19)	11 (13)
Mainly Animal	50 (58)	58 (67)
Mainly Plant	16 (19)	9 (10)
Pescatarian	0	1 (1)
Diet Variety (n, %)		
Different Everyday	40 (47)	40 (47)
Different During the Week	9 (10)	6 (7)
Different During Weekends	13 (15)	15 (17)
Little Variation	24 (28)	25 (29)
Supplement Use (n, %)	35 (41)	25 (29)
Medication (n, %)	32 (37)	11 (13)
Smoking History (n, %)		
Current Smoker	12 (14)	7 (8)
Ex-Smoker	16 (21)	9 (10)
Alcohol (n, %)		
Everyday	3 (3)	1 (1)
3-5 times/week	20 (23)	8 (9)
Once a week	12 (14)	9 (10)
Only weekends	18 (21)	9 (10)
Occasionally	9 (10)	9 (10)
None	24 (28)	50 (58)
Physical Activity - d/wk. (n, %)		
Everyday	14 (16)	13 (15)
3-5 times/week	27 (31)	18 (21)
2-3 times/week	25 (29)	25 (29)
Once a week	11 (13)	13 (15)
Less than once/week	9 (10)	17 (20)
Driving License (n, %)	62 (72)	58 (67)
Own Vehicle (n, %)	43 (50)	42 (49)

#### 198 **Table 3.1.** Continued

	Food Allergy (n = 86)	No Food Allergy (n =86)
Frequent mode of transport (n, %)		
Bike	3 (3)	0
Car Passenger	12 (4)	17 (20)
Bus	9 (10)	7 (8)
Train	8 (9)	4 (5)
Taxi	2 (1)	2 (1)
Walking	9 (10)	14 (16)

199 Table 3.2 highlights additional participant characteristics of those with food allergies. 86 200 participants possessed a food allergy, of which 34 (40%) were male and 52 (60%) were 201 female. More than half were allergic to more than one food (n=52, 60%). Peanut allergy was 202 the most common food allergy amongst participants (n=34, 40%), followed by tree nuts (n=25, 203 29%), milk (n=21, 24%), egg (n=19, 22%), fish (n=15, 17%), soya (n=14, 16%), sesame (n=14, 204 16%), crustaceans (n=10, 12%), gluten (n=9, 10%), molluscs, (n=3, 3%), mustard (n=3, 3%), 205 lupin (n=2, 2%), sulphur dioxide (n=2, 2%) and celery (n=1, 1%). A total of 15 (17%) 206 participants were allergic to other foods including chilli, chickpea, rice, pork, or possessed oral 207 allergy syndrome (allergy to raw fruits/vegetables and/or nuts). Method of diagnosis varied, 208 with 34 (40%) having had a skin prick test, 41 (48%) a blood test and 37 (43%) undergoing a 209 food elimination diet. 10 (12%) had self-diagnosed their allergy, while 12 (14%) were privately 210 tested.

211

Half of all participants suffered from an allergic reaction within the last year (n=45, 52%), with most being female (n=29, 56%). Participants were also asked the severity of their most recent reaction. 37% (n=32) considered their most recent food-allergic reaction to be 'severe/life threatening' (Table 3.2). **Table 3.2.** Characteristics of food-allergic participants (n=86).

	Males	Females
Food Allergy (n, %)	34 (40)	52 (60)
Affected by one/more Food Allergy (n, %)		
Single	13 (38)	21 (40)
Multiple	21 (62)	31 (60)
<sup>a</sup> Food Causing Allergy (n, %)		
Celery	1 (3)	0
Gluten	2 (6)	7 (13)
Crustaceans	5 (15)	5 (10)
Egg	11 (32)	8 (15)
Fish	9 (26)	6 (12)
Lupin	1 (3)	1 (2)
Milk	7 (21)	14 (27)
Molluscs	1 (3)	2 (4)
Mustard	2 (6)	1 (2)
Tree Nuts	5 (15)	20 (38)
Peanuts	14 (41)	20 (38)
Sulphur Dioxide	1 (3)	1 (2)
Soya	6 (18)	8 (15)
Sesame Seeds	4 (12)	10 (19)
Other	0	15 (29)
Diagnosis (n, %)		
Skin Prick Test	9 (26)	25 (48)
Blood Test	10 (29)	31 (60)
Food Elimination Diet	20 (59)	17 (33)
Self-Diagnosed	4 (12)	6 (12)
Private	5 (15)	7 (13)
Prescribed Medication (n, %)	32 (94)	46 (88)
Always Carry Medication (n, %)	5 (15)	18 (35)

<sup>a</sup>Participants had the option of selecting more than one food allergy

#### 217 **Table 3.2.** Continued

	Males	Females
Recent allergic reaction (n, %)		
Last Year	16 (47)	29 (56)
Last 2 years	9 (26)	10 (19)
Last 5 years	7 (21)	3 (6)
Last 10 years	1 (3)	4 (8)
More than 10 years	1 (3)	2 (4)
N/A – No allergic reaction	0	3 (6)
<sup>b</sup> Severity of recent reaction (n, %)		
Mild	9 (26)	6 (12)
Moderate	16 (47)	19 (37)
Severe	9 (26)	23 (44)
°FA impact on daily life (n, %)	14 (41)	33 (63)

<sup>b</sup>A <u>mild</u> reaction was characterised as redness of the skin, runny nose/sneezing and slight cough. A <u>moderate</u> reaction included hives, eczema, itchy mouth, stomach pain and an odd taste in the mouth, while <u>a severe/life</u> <u>threatening</u> reaction included obstructive swelling of lips, tongue and/or throat, trouble swallowing and shortness of breath.

<sup>c</sup>This was based on the following question asked to food-allergic patients – <sup>(Do</sup> you feel your food allergy does impact or has previously impacted your quality of life? If yes, provide details as to how you have been affected

## 218 **3.3.2.** Food Choice

219

220 Section five assessed FC for those with and without food allergy. Thirty-three different 221 determinants of FC were grouped into ten different categories (sensory, convenience, social, 222 psychological, economic, advertising, university, familiarity, health and labelling). Overall, 223 descriptive statistics revealed sensory  $(3.8 \pm 0.6)$  and familiarity  $(3.8 \pm 0.9)$  as having high 224 mean scores, indicating their strong influence on FC. Taste had the highest mean score of 225  $4.5 \pm 0.7$ , making it the most influential factor in FC among all participants. On the other hand, 226 peer influence had the lowest mean of 2.9 ± 1.2 and therefore, was not considered an 227 influential factor of FC for this group.

- 228
- A comparative analysis in relation to FC between those with and without food allergy was also
- 230 conducted. Analysis highlighted no statistically significant differences between groups for each
- of the determinants, with the exception of food labelling and reading food labels (Table 3.3).

232 Participants were also asked how often they 'read the food label' and if they can 'easily 233 understand the food label' to see if labelling of food was a significant factor influencing FC. Of 234 the ten categories, labelling had the third highest mean  $(3.7 \pm 1.1)$ . Only 33% (n=57) reported 235 'always' reading the food label with majority being those with food allergies (n=37, 43%). A 236 smaller percentage of participants reported 'always' understanding the food label (n=46, 27%), 237 with participants with and without food allergy answering similarly (Fig 3.1. And 3.2). A Mann 238 Whitney U test highlighted significant differences between those with and without food allergy, 239 in relation to labelling and FC. Results indicated a statistically significant difference between 240 groups in labelling with food-allergic individuals more concerned with food labelling than non-241 food allergic individuals (U = 3011 (Z = -2.130, p = 0.033). Specifically, this statistically 242 significant difference was associated with 'reading the food label' (U = 2774 (Z = -2.922, p= 243 0.003), with effect size revealing the significance to be small (r = -0.22), in accordance with 244 Cohen's classification of effect sizes. No statistically significant difference occurred between 245 groups in 'understanding the food label' (U = 3514 (Z = -0.586, p = 0.558) (Table 3.3).

- 246 **Table 3.3.** Influence of thirty-three factors in relation to FC, for 18-25 year olds with FA (n=86)
- and without FA (n=86)

					Food	No Food			
					<u>Allergy</u> (n = 86)	<u>Allergy</u> (n = 86)			
<u>Variable</u>	<u>Mean</u>	<u>Median</u>	Mode	<u>SD</u>	Mean	<u>Mean</u>	<u>u-value</u>	<u>z-value</u>	<u>p-value</u>
					<u>Rank</u>	<u>Rank</u>			
Sensory	3.8	3.8	4	0.6	86.5	86.5	3698	-0.000	1.000
Taste	4.5	5.0	5	0.7	84.6	88.4	3533	-0.574	0.566
Smell	3.8	4.0	4	1.0	86.3	86.7	3678	-0.064	0.949
Appearance	3.4	3.0	3	1.0	84.8	88.2	3554	-0.472	0.637
Texture	3.5	3.5	4	1.1	92.1	80.9	3214	-1.539	0.124
Hunger	3.7	4.0	4	1.0	86.8	86.2	3670	-0.091	0.927
Convenience	3.6	3.7	4	0.8	84.7	88.3	3541	-0.487	0.627
Ease of Access	3.7	4.0	4	0.9	86.1	86.9	3665	-0.109	0.913
Cooking Skills	3.5	4.0	4	1.1	85.6	87.4	3618	-0.254	0.799
Time Taken to Prepare	3.6	4.0	3	1.1	84.7	88.4	3539	-0.506	0.613
Social	3.1	3.0	3	1.0	83.9	89.1	3477	-0.682	0.495
Family	3.4	4.0	4	1.3	84.6	88.4	3535	-0.516	0.606
Peers	2.9	3.0	3	1.2	86.2	86.8	3675	-0.072	0.942
Culture	2.9	3.0	4	1.3	82.8	90.2	3378	-1.002	0.316
Psychological	3.4	3.5	4	1.1	92.3	80.7	3201	-1.541	0.123
Emotion	3.4	3.0	3	1.2	89.3	83.7	3459	-0.756	0.450
Stress	3.4	4.0	4	1.2	93.6	79.4	3088	-1.925	0.054
Economic	3.6	4.0	4	1.1	86.2	86.8	3672	-0.083	0.934
Cost	3.6	4.0	4	1.2	85.6	87.4	3622	-0.242	0.808
Income	3.5	4.0	4	1.1	87.8	85.3	4271	-0.324	0.746

\*A Likert scale of influence was used to explore FC with 1=Not Influential and 5=Extremely Influential \*The text in **bold** refers to composite scores, combining the responses from multiple items in that category.

248	Table	3.3.	Continued
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Advertising	2.6	2.5	2	1.1	87.9	85.1	3581	-0.365	0.715
Social Media	2.7	3.0	2	1.1	89.9	83.1	3406	-0.925	0.355
TV Adverts	2.4	2.0	1	1.3	85.0	88.0	3571	-0.403	0.687
University	2.9	3.0	1	1.2	86.7	86.3	3682	-0.049	0.961
University	2.6	3.0	1	1.4	84.7	88.3	3547	-0.477	0.633
Environment									
Student Life	3.0	3.0	4	1.3	86.6	86.5	3694	-0.013	0.990
Exams	3.0	3.0	4	1.4	88.6	84.4	3515	-0.575	0.566
Familiarity	3.8	4.0	4	0.9	88.0	85.0	3567	-0.410	0.682
Previous	3.8	4.0	4	1.0	91.1	81.9	3301	-1.277	0.201
Experience									
Habit	3.8	4.0	4	1.0	85.7	87.3	3626	-0.231	0.817
Health	2.9	2.9	2	1.0	89.9	83.1	3402	-0.907	0.364
No. of Vitamins and Minerals	2.8	3.0	3	1.3	87.1	85.9	3645	-0.166	0.868
How fresh it is	3.6	4.0	4	1.1	90.3	82.7	3375	-1.030	0.303
Ability to control weight	3.0	3.0	3	1.3	89.0	84.0	3480	-0.684	0.494
Energy Balance	2.9	3.0	3	1.2	92.2	80.8	3207	-1.549	0.121
Natural Ingredients	2.7	3.0	2	1.3	89.8	83.3	3419	-0.878	0.380
High Fibre	2.7	3.0	2	1.3	88.2	84.8	3548	-0.471	0.638
Low fat	2.9	3.0	3	1.4	86.8	86.2	3672	-0.082	0.935
Low salt	2.8	3.0	2	1.3	88.3	84.7	3540	-0.495	0.620
Low Sugar	2.8	3.0	2	1.3	85.7	87.3	3626	-0.226	0.821
Labelling	3.7	4.0	4	1.1	94.5	78.5	3011	-2.130	0.033
Reading food label	3.6	4.0	5	1.3	97.2	75.8	2774	-2.922	0.003
Understanding food label	3.7	4.0	4	1.1	88.6	84.4	3514	-0.586	0.558

\*A Likert scale of influence was used to explore FC with 1=Not Influential and 5=Extremely Influential \*The text in **bold** refers to composite scores, combining the responses from multiple items in that category.



Figure 3.1. How often do those with food allergies (n=86) and those without food allergies (n=86) read food labels.



Figure 3.2. How often do those with food allergies (n=86) and those without food allergies (n=86) understand food labels.

## 266 **3.3.3.** Food Access

#### 267

268 Participants were asked the distance travelled to the nearest store to purchase healthy, 269 nutritious food. Figure 3.3 highlights the results. Overall, those with food allergies were found 270 to travel longer distances than those without food allergies. Most individuals without food 271 allergies travelled less than 4 miles (n=74, 86%), with only 12 participants (14%) having to 272 travel a longer distance when purchasing healthy, nutritious food. On the other hand, more 273 than half of participants with food allergy (n=50, 58%) were found to travel greater than 4 miles 274 when purchasing healthy, nutritious food, of which 21% (n=18) reported travelling greater than 275 10 miles (Fig. 3.3). Chi squared analysis revealed a statistically significant difference between 276 both groups ( $\chi^2$  (6) = 42.505, p < 0.001).



Figure 3.3. Distance travelled to the nearest store to purchase healthy, nutritious food for those with food allergies (n=86) and without food allergies (n=86)

279

280

- Furthermore, those with food allergies were also asked the distance travelled to purchase allergen free food (AFF). Only 37% (n=32) of participants reported travelling within 4 miles to access this type of food, while 63% (n=54) travelled more than 4 miles. Most participants with food allergies reported travelling between 4 to 6 miles (n=24, 28%), with 8 individuals (9%)
- travelling greater than 10 miles to access AFF (Fig. 3.4).



Figure 3.4. Distance travelled to purchase allergen free food for those with food allergies (n=86)

- 289
- 290

## 291 3.3.4. Healthcare Access

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Section four assessed participants HCA. The distance travelled to the nearest General Practitioner/health centre is shown in Figure 3.5. Most participants travelled no more than 4 miles when accessing their GP/health centre (n = 135, 78%). Little difference existed between those with and without food allergies, with Chi-Squared ( $\chi^2$ ) analysis revealing no statistically significant difference between groups ( $\chi^2$  (6) = 10.229, p = 0.115).



Figure 3.5. Distance travelled to the nearest GP/health centre to receive healthcare for thosewith food allergies (n=86) and without food allergies (n=86)

311

Distance travelled to the nearest hospital for healthcare is highlighted in figure 3.6. HCA varied among participants, ranging between 1 mile and >10 miles. Majority of food-allergic participants travelled >10 miles (n=32, 37%) to receive healthcare, while most without food allergy travelled between 2 and 4 miles (n=31, 36%). Chi-Squared ( $\chi^2$ ) analysis further confirms this, revealing a statistically significant difference between both groups ( $\chi^2$  (6) = 27.089, p < 0.001), with most food-allergic individuals travelling longer distances.



**Figure 3.6.** Distance travelled to the nearest hospital to receive healthcare for those with food

330 allergies (n=86) and without food allergies (n=86)

331 Participants were also asked if there was any occasion in the last 12 months where they 332 struggled to access medication, specialist care and follow-up care due to financial and travel 333 constraints (through answering yes/no). A total of 56 (65%) individuals with food allergy and 334 37 (43%) individuals without food allergy reported being impacted by financial constraints. In 335 comparison, a total of 55 (64%) individuals with food allergy and 32 (40%) individuals without 336 food allergy were impacted by travel constraints. While both groups were clearly impacted by 337 financial and travel constraints, those with food allergy had greater difficulty in obtaining 338 medication and in particular specialist care and follow-up care, due to financial and travel 339 constraints (Fig. 3.7 and 3.8). Chi-Squared ( $\chi^2$ ) analyses further reinforces this, with results 340 highlighting a statistically significant difference between both groups due to financial ( $\chi^2(2)$  = 341 12.903, p = < 0.002) and travel constraints ( $\chi^2$  (1) = 12.304, p = < 0.001).



Figure 3.7. Impact of *financial* constraints in obtaining medication, specialist care and followup care in those with FA (n=55) and without FA (n=32).



Figure 3.8. Impact of *travel* constraints in obtaining medication, specialist care and follow-up care in those with FA (n=55) and without FA (n=32).

346

347 Those with food allergy were also asked about regular attendance of healthcare services when 348 receiving treatment for their food allergy. A large number of participants reported irregular 349 attendance of healthcare services (n=55, 64%), with most being female (n=36, 65%) (Fig. 3.9). 350 Reasons as to why those with food allergy chose not to regularly attend healthcare services 351 is highlighted in Table 3.4. Two major themes emerged from participants responses explaining 352 irregular attendance. The first was accessibility and waiting times, with food-allergic 353 participants mentioning the allergy clinic being too far away and difficulty in getting 354 appointments with specialists. The second theme was discontinuity in care. Participants 355 mentioned how lack of knowledge from GPs, bad experiences and anxiety discouraged them 356 from actively seeking healthcare.



Figure 3.9. Regular and irregular attendance of healthcare services by food-allergic
 participants (n=86) to receive treatment for allergies

359 360

361 **Table 3.4.** Factors affecting the regular attendance of GP/hospital for those with food allergies362 (n=86).

#### ACCESSIBILITY

'The allergy clinic is too far away.'

'Nearest hospital offering allergy advice was over 70 miles away.'

'Waiting times and difficulty getting appointments.'

'Appointments were recommended every two years but department too busy too accommodate. However was seen around 3 years and passed over to adult team. Now I am 18 I have had one adult appointment no further appointments available unless my circumstances change.'

'Not had any appointments.'

'Its difficult for me to get an appointment with a specialist.'

#### **DISCONTINUITY IN CARE**

'I didn't know I could /don't know what they could do for me.'

'Sometimes reluctant to go as the testing process is intrusive.'

'I've not had the best experience. I saw an allergy service up until the age of 11/12. I was then discharged and told I didn't need an epi-pen. In my 20's I had a severe allergic reaction and only then I was prescribed an epi-pen.'

#### DISCONTINUITY IN CARE

'There's a lack of support when I go. My GP doesn't seem to know all the information'

'Pretty poor allergy advice from my GP. I was told to use YouTube to learn how to use an epi-pen.'

'Anxiety from thoughts of going to the doctors and getting help.'

'I just carry epi-pens, I do not choose to receive treatment.'

'Anxious, don't like hospital environments.'

'It's not always helpful. GP's are not always confident.'

The availability of transition care at their local GP and/or hospital was also reported by those with food allergy. Only 44% (n=38) of food-allergic participants reported having the availability of transition care. In contrast, a larger number of participants reported no transition care availability (41% (n=35)), while 15% (n=13) were unsure if their GP/hospital provided transition care (Fig. 3.10).



Figure 3.10. Access to transition care at local GP and/or hospitals as reported by those withfood allergies (n=86)

- 371 Of the 38 participants who did report the availability of transition care at their GP/hospital, most
- 372 reported the use of e-resources. Participants also mentioned phone hotlines, tailored support
- 373 from HCPs, webinars and workshops as beneficial resources supporting in the management
- of their food allergy (Fig 3.11).



Figure 3.11. Different resources available to support management of food allergy as reported
by food-allergic participants (n=38)

377

# 378 3.4.5. Impact on Daily Life

379

380 The presence of a food allergy and its impact on daily life was also determined. Of the 86 food-381 allergic participants, 46 (53%) reported their food allergy impacted various aspects of their 382 daily life. Table 3.5 further highlights the different ways individuals felt their daily life had been 383 impacted by their food allergy. One major theme which was expressed through participant 384 responses was the emotional and psychological issues associated with their food allergy. 385 Participants felt their food allergy negatively impacted their social life and prevented them from 386 eating out. Mental health issues, such as anxiety and Post-Traumatic Stress Disorder (PTSD) 387 following negative reactions were also common among participants and this was increased 388 during the transitional period. An additional theme which emerged was the impact of FA on 389 dietary habits, which led to nutritional concerns. For instance, some participants revealed their 390 allergy limited food options, which led to reduced nutrients being obtained from their diet.

#### **Table 3.5.** How the presence of a food allergy impacts the daily life of life in food-allergic

392 individuals (n=86)

#### EMOTIONAL AND PSYCHOLOGICAL

Seafood was a massive part of my life and was my favourite food until my allergic reaction when I was 17. I can't enjoy going out for meals without worrying. I never eat at seaside restaurants or takeaways that have shellfish on the menu unless I have to. Friends and family haven't always taken it seriously and it has been guite upsetting.'

'Constant fear and stress has led to mental health issues, PTSD from life-threatening allergic reactions. Makes it very hard when I work abroad as a touring classical musician.'

'It's psychologically draining to be cautious all the time and sometimes people don't take it seriously which can be upsetting.'

'It makes me really anxious - struggle eating out, infact I avoid eating out. '

'I am too scared to eat out, I am even nervous eating with relatives that have known about my allergies all my life.'

'Limits what countries I can safely visit on holiday and experiences I can enjoy. They negatively affect my mental health as I often feel anxious while eating in unfamiliar places.'

'Affected confidence and independence.'

'Prevents me from going out with friends and makes family events difficult.'

'I struggle with being able to trust people in preparing my food so avoid social events and eating out.'

'More reluctant to join in with social situations where food is involved, can result in feeling quite isolated and feel as though people don't want to be friends with you as much, even if that isn't necessarily the case.'

'Was unable to eat at certain restaurants and so missed out quite a bit socially when younger. Anxiety around eating out, can never fully relax when eating unfamiliar food. Worry for example when people eat nuts in uni when they know it is a nut-free zone.'

'My anxiety has increased since I've started living away from home. My roommates don't really understand.'

'Mentally affects your ability to fit in - seeing everyone eating things you can't then proceeding to feel 'sorry' for me. Missing out on different foods that people enjoy. Happiness slightly fades when out with friends and seeing the food they can eat.'

'Previously very confident in myself and did not worry much about my allergies as I am always very careful. Coming to university has really changed things for me. My freshman year\* I called 911 for a friend who was experiencing anaphylaxis and that experience was rather traumatic for me. I know I do the right thing and take the necessary precautions, but this year I have experienced great amounts of anxiety and have started talking to a therapist. The transition to independence has been very difficult for me and I often find myself wishing I could just be "normal"

'Conscious of the impact on others, they have to check food they buy/prepare. Embarrassing in restaurants when in a group, have to ask the serving staff about the food/preparation and be really clear which can take confidence in front of a group of people.'

'Socializing and ease of just grabbing something to go has been made more difficult.'

\*Note that this comment suggests this participant previously lived in the US, however at the time of data collection, they met the study's inclusion criteria having recently moved to the NW of England.

#### DIETARY HABITS AND NUTRITIONAL CONCERNS

'Limits what food I can eat.'

'Reluctant to try certain types of foods (e.g. from specific countries or cultures) due to previous negative reactions.'

'I can't obtain a good meal , due to lack of enough nutrients which I was supposed to obtain from the meals am allergic to.'

'Less likely to try new foods or drinks.'

394 Participants with food allergies also expressed ways in which to improve their current mental 395 health (Table 3.6). Three main themes were identified. Psychological support was considered 396 of great importance, with many participants mentioning the current support in this area was 397 severely lacking. They had little access and where access was available, the waiting times 398 were too long. Participants further expressed the need for this type of support to be ongoing. 399 In addition to professional psychological support, participants with food allergies mentioned 400 increased access to resources such as hotlines, websites and support groups as being 401 beneficial in improving their mental health. The final theme was education. Participants felt 402 there was a need for increased education regarding food allergy at schools and universities. 403 One participant specifically mentioned the importance of increasing awareness of the impact 404 of food allergy on eating disorders and mental health, with limited knowledge surrounding this 405 topic. Additionally, the need for more accommodating laws such as clearer labelling, to provide 406 a more supportive environment for individuals with food allergies was also mentioned.

#### 407 **Table 3.6.** Different ways to improve mental health support for those with food allergies (n=86)

#### ACCESS TO PSYCHOLOGICAL SUPPORT

'Being able to speak to someone who is actually an expert in mental health. I don't remember anyone asking me how I felt about anything, was very matter of fact.. This is your allergy and here are your medications.'

'Having someone to talk to. After having a life threatening reaction I got out of hospital after 2 days and received no help after that. It happened at my workplace and I struggled emotionally going back and when I mentioned this to my GP they said they could put me on a list to talk to someone but the list was long and it would take a while.'

'Professional support by a psychologist that is free when we are diagnosed and in the aftermath of a lifethreatening reaction. Even lots of doctors struggle to understand about food allergy and anxiety.'

'Every person with severe allergies should be offered psychological support for health anxiety and understanding how to be aware of your environment without feeling constantly on edge. I've been to my doctors before about having anxiety regarding my allergic reaction and they didn't help.'

'More widespread offering of ongoing psychological support.'

'Help with social aspect.'

'More people to talk about it. I'm 19 and I've never had a discussion with someone about the anxiety surrounding having an allergy.'

'Mental healthcare needs to be improved across the board but a designated service for allergies would be good. Particularly to support anxiety.'

'People with FA being automatically directed to counselling and dietary assistance.'

'There doesn't seem to be much psychological help up north in the UK.'

'There needs to be quicker support available and specific support for the challenges people with allergies might face, for example social isolation and anxiety.'

'For HCPs to keep checking in with you. Sometimes we get one appointment and that's it.'

'Debriefs after every severe reaction and more psychological support when diagnosed.'

RESOURCES

'Hotlines and access to online websites.'

'Support groups with similar age group.'

#### EDUCATION

'More education in universities about the severity of allergies and how that affects people with it.'

'Allergy awareness in schools at a younger age.'

'More accommodating laws like better food labels to make sure people living with allergies are protected.'

'In terms of mental health, more awareness on the impact of eating disorders. Neither is there much awareness of FA and eating disorders in the South Asian culture such as EDNOS, bulimia nervosa, Anorexia Nervosa, binge eating disorder etc.'
- 408 **3.4.** Discussion
- 409

#### 410 **3.4.1.** Food Choice

411

412 Overall, in relation to FC, no statistically significant differences were found between those with 413 and without food allergy for all factors but one - labelling. These findings are consistent with 414 previous research which indicate the presence of food allergy does not necessarily impact FC 415 behaviour (Sommer et al., 2014; Laheri et al., 2022). Rather, those with food allergy struggle 416 with the feeling of being different and strive to live a similar life to that of their peers. 417 Consequently, they are persuaded by similar determinants of FC as those without food allergy 418 (Sommer et al., 2014; Laheri et al., 2022). Taste emerged as the most influential factor of FC 419 with the highest mean score in both groups, with no statistically significant difference between 420 them. Foods considered to be 'tasty' by adolescents are often associated with high levels of 421 fat, salt and sugar (Liem and Russell, 2019; Bawajeeh et al., 2020). Research has already 422 established the current adolescent diet is largely driven by highly processed and refined foods 423 (Contento, 2011; Hebden et al., 2015; Hall, 2018; Sprake et al., 2018; Liem and Russell, 2019; 424 Larson et al., 2020; Monterrosa et al., 2020; Molenaar et al., 2021; Whatnall et al., 2021). 425 Therefore, this indicates LA may be at risk of consuming a poor diet. Food-allergic participants 426 also reported through open-ended responses that their allergy limits the variety of foods 427 consumed and leads to a reluctance to try new foods. This qualitative feedback indicates that 428 implementing a restrictive diet may potentially increase the risk of nutritional deficiencies in 429 those with food allergy. Therefore, the importance of HCP informing those with food allergy 430 about how to consume a safe diet that is varied following diagnosis, is of extreme importance.

431

432 Peer influence has previously been found to be a rather significant factor influencing FC in LA, 433 as individuals seek a sense of belonging and social identity (Hebden et al., 2015; Stok et al., 434 2016). In contrast, the results of this study revealed peer influence was one of the least 435 influential factors of FC. Quantitative analysis revealed no statistically significant difference in 436 peer influence on FC for either group. However, through open-ended responses participants 437 with food allergy revealed the presence of their allergy impacted their social life. Specifically 438 they mentioned the constant anxiety and stress of potentially fatal reactions and the 439 embarrassment of explaining allergies when eating out with friends was also common among 440 participants. Consequently, individuals chose to simply avoid social events and eating out with 441 friends, explaining why the influence of peers was not necessarily a significant influencer of 442 FC in this study. This lack of socialisation was also a cause of mental health issues as reported 443 by participants in their open -ended responses. It is clear that living a life similar to their peers

444 is of great importance and this also extends to the food they eat. Social relationships built 445 around food can provide positive experiences and has been found to positively impact mental 446 health (Dunbar, 2017). Eating is inherently a social activity and efforts should therefore be 447 made to increase the confidence in eating out of those with food allergy, which could contribute 448 to a better overall experience.

449

450 Labelling of food can directly impact purchasing habits and therefore FC. In this study, labelling 451 was identified as a statistically significant factor of FC in those with food allergies. Despite the 452 importance of labelling, only a small percentage of participants were found to always read food 453 labels with most being those with food allergy. Even fewer participants were found to 454 understand the food label. Many individuals, in particular those with food allergy, are often 455 overwhelmed with the various different statements present on food packaging e.g. PAL such 456 as 'may contain' statement. This often deters purchase due to anxiety or risks accidental 457 ingestion due to confusion and/or inappropriate labelling (Sheth et al., 2010; Cochrane et al., 458 2013). Thus, there is a need to educate participants, in particular those with food allergy, on 459 the necessity of reading food labels. While recent efforts have been made to improve current 460 food allergen labelling practices (VITAL, 2007; Natasha labelling law, 2018), the presentation 461 of allergen information continues to be wide-ranging and inconsistent (Blom et al., 2021). More 462 precise standardisation of food allergen labelling is therefore needed (Fiocchi et al., 2021; 463 Holleman et al., 2021). Marchisotto et al. (2017), suggest the role of HCPs in explaining food 464 labelling to food-allergic patients is crucial and can allow individuals to make more informed 465 decisions, consequently lowering risk of accidental ingestions and improving overall well-466 being. Quite recently, between December 2021 and March 2022, the Foods Standards Agency 467 (2022) undertook a consultation with stakeholders across England, Wales and Northern 468 Ireland, discussing the use of PAL. It was determined through this consultation that PAL 469 should be communicated more clearly and consistently, in a manner which clearly informs 470 labelling decisions of businesses and is also understandable for the consumer. 471 Standardisation of labelling statements was a key concept recognised by stakeholders. One 472 way of achieving this (as discussed through this research) would be through the establishment 473 of allergen thresholds, which only if exceeded would lead to the inclusion of PAL with 474 standardised wording. The information obtained through this consultation will lead to the 475 development of a range of options to enable food businesses to convey meaningful PAL, 476 providing food-allergic consumers with the confidence in choosing products which are safe. 477 While this provides a promising framework for improving food labelling, Madsen et al. (2020) 478 in their research outline that establishing allergen thresholds for PAL as suggested, is far more 479 complex than it may initially appear. They mention how determining thresholds involves 480 numerous factors, including variations in individual sensitivities to allergens, the complexity of

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481 food processing and cross-contact risks. They further discuss how PAL based on such 482 thresholds could create a false sense of security for individuals with food allergies, as it would 483 be difficult to identify a universally 'safe' threshold which would be applicable to all. Rather 484 than simply setting quantitative limits, Madsen et al. (2020) argue that a multifactorial approach 485 which considers comprehensive risk assessments, improved detection methods and clearer 486 communication about the uncertainties involved may be more effective in addressing the 487 complexities of allergen management. PAL standardisation will be a significant step in 488 improving the lives of the food allergic community. However, it must be balanced with robust 489 scientific evidence, to ensure it protects consumers without making labelling overly restrictive, 490 which in turn could limit the variety of safe foods available for consumers.

491

#### 492 **3.4.2.** Food Access

493

494 Food security has been defined as 'a situation that exists when all people, at all times, have 495 physical, social and economic access to sufficient, safe and nutritious food that meets their 496 dietary needs and food preferences for an active and healthy life' (World Food Summit, 1996). 497 In those with food allergies, achieving food security can be far more challenging. The 498 quantitative analysis revealed a statistically significant difference between those with and 499 without food allergies regarding the distance travelled to purchase healthy, nutritious food. 500 These results revealed that those with food allergies travelled longer distances in this regard. 501 A large portion in this group travelled greater than 4 miles with some also reporting travelling 502 as far as 10 miles to access these foods. Similarly, those with food allergies struggled in 503 accessing AFF with most travelling between 4 and 6 miles and some also travelling greater 504 than 10 miles. These findings emphasise the additional burden on those with food allergies in 505 accessing appropriate food.

506

507 These findings suggest that those with food allergies face a twofold issue when accessing 508 food: distance and availability. The greater distance of 10 miles travelled by this group reflect 509 the limited availability of suitable AFF in local stores. Travelling these long distances could 510 pose significant barriers, especially for those who have limited transport options and are 511 restricted by financial constraints. These added difficulties can increase the risk of accessing 512 food, particularly as the cost of AFF are already high (Coleman et al., 2021).

513

514 While food banks offer an excellent opportunity to support those facing challenges in 515 accessing adequate food (Minaker et al., 2014), AFF seldom exist in food banks (Fong et al., 516 2022; Scurlock et al., 2022). Moreover, an increasing trend, particularly amongst LA is to 517 purchase AFF online. While this method can improve access, delivery and service charges 518 are costly causing reluctance amongst many consumers (Coleman et al., 2021).

519

520 Food allergies are undoubtedly rising and with it, the 'free from' food industry has considerably 521 grown over the years (Mintel, 2022). Yet the inclusion of a specialised diet which is both safe 522 and nutritious continues to prove a challenge for many (Scurlock et al., 2022). Due to the rising 523 food costs and the already high cost of AFF (Pasha-Robinson, 2023), the current access to 524 food for those with food allergies is concerning. Half of UK customers revealed they would cut 525 back on free from food products when money is tight (Mintel 2022). This unfortunate outcome 526 can prove detrimental. Firstly, AFF are often fortified with key nutrients and offer a means of 527 improving nutritional status that is otherwise compromised due to the nature of implementing 528 a restrictive diet (Pasha-Robinson, 2023). Secondly, limiting free from foods can increase the 529 risk of unwarranted allergic reactions, as individuals attempt to explore other alternatives 530 which though may be cheaper, may not necessarily be safe to consume (Turits, 2019).

531

532 This financial burden of purchasing AFF and the increased travel distances as revealed in this 533 study indicate that interventions are necessary to improve the availability and affordability of 534 AFF in local stores and supermarkets. Based on existing literature, several interventions to 535 overcome these challenges are proposed. Labelling is highly important for risk management 536 of food allergies and allows for reduced exposure to food allergens. Many individuals are often 537 deterred in purchasing AFF due to much confusion linked with the increased use of PAL 538 (Fiochhi et al., 2021). Therefore, food manufacturers should improve the visibility of AFF 539 through improving current labelling practices. Moreover, individuals with food allergies should 540 be educated on reading food labels, which can reduce the risk of allergic reactions and at the 541 same time reduce time spent shopping – a recognised burden for those with food allergies 542 (Marra et al., 2017). Securing AFF is vital in ensuring both safety and nutritional status for 543 those suffering from food allergies. To allow for successful management of food allergies, AFF 544 must remain affordable (Dyer et al., 2020). Furthermore, initiatives to encourage retailers in 545 both supermarkets and convenience stores to offer a diverse range of AFF which are more 546 affordable is also imperative for those with food allergies, as these products are severely 547 lacking. One beneficial strategy is to provide additional funds to food-allergic individuals, in 548 particular to those of low income families, to ensure they have the means to obtain such foods 549 (Minaker et al., 2014). This concept is not a new one and is currently available to sufferers of 550 coeliac disease, who can access gluten free foods through prescription (Coeliac UK, 2024). 551 Scurlock et al (2022) further suggests AFF should be made readily available in food banks. 552 There has been a steep increase in the number of food banks being used following the 553 coronavirus pandemic. Between April 2021 and March 2022 food banks in the Trussell Trust

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distributed over 2.1 million food parcels – an increase of 14% from the previous year (The
Trussell Trust, 2023). This increase has been particularly noticeable in the NW (Oldman,
2021). Food banks remain a primary point of access for many individuals and including more
AFF can prove life-changing for many sufferers of food allergies.

558

#### 559 3.4.3. Healthcare Access

560

561 The results of this study indicated that those with food allergies travelled significantly longer 562 distances to obtain healthcare than those without food allergy. Additionally, those with food 563 allergy reported greater difficulty when obtaining medication, specialist care and follow-up care 564 due to financial and travel constraints. Currently in the NW only three allergy clinics exist 565 (Preston, Liverpool and Manchester), with most consultations being provided by GPs. 566 Previous research highlights travelling long distances presents an economic burden and 567 therefore individuals in low-income families may choose to limit use of health services 568 (Minaker et al., 2014). The results of this study further support this. Through open-ended 569 responses, participants reported allergy clinics being too far away, waiting times and lack of 570 appointments as some of the main reasons for irregular attendance to GPs/hospitals.

571

572 A large number of participants also reported no transition care was available when seeking 573 healthcare for their allergy, with some participants not even aware of any such resources. 574 Furthermore, participants expressed through open-ended responses how HCPs, in particular 575 GPs, were not entirely helpful and there was a lack of support available. Previous research 576 also confirms limited knowledge of food allergies among GPs (Clement et al., 2020). There 577 currently exists a shortage of specialists and allergy clinics that can provide adequate support 578 in the UK for food allergy, with most requiring extensive travel and presenting economic 579 burdens. Therefore, food-allergic individuals will be reliant on local GPs to provide support, 580 yet they are unable to meet this need (Royal College of Physicians, 2003). Literature suggests 581 GPs should continue to follow guidance and where necessary seek advice and consult 582 specialists. Regular training/courses in allergy education can also prove instrumental in 583 increasing confidence of GPs when delivering food allergy information. (Royal College of 584 Physicians, 2003; Clement et al., 2020; Khaleva et al., 2020; National Allergy Strategy Group, 585 2021). The presence of FA can considerably impact mental health and can also lead to lack 586 of engagement in healthcare services. Through their open-ended responses, participants 587 mentioned limited access to psychological resources and suggested increasing psychological 588 support would be beneficial. There is clearly an unmet emotional need in those with food 589 allergy and HCPs should provide food-allergic patients with advice and support that goes

590 beyond the avoidance of foods. Irregular attendance of healthcare services was also notably 591 high among participants with food allergy (64%). Participants voiced reasons as to why this 592 was the case through their qualitative responses, mentioning anxiety, bad experiences and a 593 lack of perceived benefit from seeking care.

594

595 Interestingly, peer pressure was not statistically significant in this study, which is seemingly 596 because food-allergic individuals may be cutting themselves off from ordinary socialising with 597 peers, particularly eating out, as mentioned in their open-ended responses. This suggests a 598 strong psychosocial component to the deleterious effect on mental health, with isolating 599 behaviours seen as a defensive mechanism against the threat of making the difference of food 600 allergy visible in day-to-day reactions with peers. While this is problematic, it perhaps suggests 601 that supportive interventions designed to include peers could make a positive impact; in effect 602 strengthening peers as a source of informed support. This psychosocial territory also extends 603 to the wider community and educational approaches that engage community entities, such as 604 schools, convenience stores, and restaurants/cafes may also be warranted (Kachru, 2020; 605 Newman and Knibb, 2020; Rubeiz and Ernst, 2021).

606

### 607 **3.5.** Limitations

608

609 This study provides valuable insights into the current FC, FA and HCA of LA with and without 610 food allergies in NW England. However, it is also important to consider the limitations. The 611 data represented here signifies a single point in time, and does not necessarily capture any 612 fluctuations in behaviour or preferences over a period of time. This is a limitation given the 613 transitional stage of late adolescence to adulthood. Therefore, the results may not be 614 representative of the dynamic changes associated with FC, FA and HCA in this critical period. 615 Future research using longitudinal studies could be undertaken which focus on capturing these 616 changes over time and provide a more comprehensive understanding of how these factors 617 evolve throughout this period of transition.

618

This study was also reliant on self-reported data and as such, the data could be prone to social desirability or recall bias, impacting the accuracy of the findings. In addition to this, the study included both medically diagnosed and self-diagnosed food allergic participants. While their inclusion allowed for a reflection of the diverse real-world population of this group, no direct comparisons between groups was actually made. This lack of direct comparison limits the ability to draw specific conclusions about any differences in FC, FA and HCA between groups.

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626 Moreover, multiple comparisons were made during the analysis when comparing the food 627 allergic and the non-food allergic group and this could have increased the risk of Type 1 errors. 628 Consequently, a statistically significant difference may have been found when in reality no 629 difference existed. Despite efforts to maintain rigor through the analysis process, there is a 630 possibility of false positives and care should therefore be taken when interpreting these 631 results. Furthermore, although a power analysis was conducted and adequate statistical 632 power was determined, the sample size may limit the generalisability of the findings beyond 633 the study population. All participants were recruited from NW of England and thus, these 634 findings may not be representative of the LA population in other regions.

#### 635 3.6. <u>Conclusion</u>

636

637 The present study has shown how those with and without food allergies are influenced by 638 similar determinants of FC. In addition to this, this group of individuals struggled to access 639 AFF and adequate healthcare. To our knowledge, this is the first UK study in the NW of 640 England investigating current food and HCA in LA with food allergy. Accessing adequate food 641 is a complex, multifaceted and systemic issue - one which is categorically worse for those 642 with food allergies. Access to safe, nutritious foods is a basic requirement for all individuals, 643 yet the sad reality is that for those with food allergies this fundamental necessity can prove 644 extremely challenging. Similarly, individuals with food allergies require sufficient healthcare to 645 support the management of their food allergy, however adequate support is not available. 646 Research into the geographic access of food, in particular AFF and HCA in LA with food 647 allergies is limited (Coleman et al., 2021). Thus, there is a need for more studies to be 648 conducted. A better understanding of the challenges faced by LA with food allergies in 649 accessing food and healthcare, can allow for the implementation of necessary policies which 650 in turn, can reduce the risk of allergic disease and improve their overall health and well-being 651 (Dyer et al., 2020). The next chapter – Chapter 4, will therefore provide a geographical 652 representation of FA and HCA in LA with and without food allergies using the results obtained 653 in this study.

# <u>Chapter 4</u> – A Geographical Representation of Food Access and Healthcare Access in Late Adolescents (18-25years) With and Without Food Allergies.

#### 4 4.1. <u>Overview</u>

5 This chapter provided a geographical representation of food access (FA) and healthcare 6 access (HCA) for late adolescents (LA) with and without food allergies in North West (NW) 7 England, building upon the foundational insights from Chapter 3. In Chapter 3, it was 8 established that food and HCA is challenging for LA with food allergies, with many travelling 9 long distances to obtain adequate foods and healthcare. This chapter extends these findings by employing geographical software using ArcGIS to highlight a geographical representation 10 11 of these results. The reason for this approach was to reveal any regional disparities which 12 may have been obscured by only quantitative analyses, as was the case for Chapter 3. The 13 specific areas within the NW where access to food and healthcare was difficult, was 14 highlighted based on the four counties where participants were initially recruited from 15 (Cheshire, Merseyside, Greater Manchester and Lancashire). This chapter further discusses 16 how these difficulties in accessing food and healthcare correlate with deprivation levels in the 17 NW and how socioeconomic factors play a crucial role in determining access. The visual 18 representation makes it easier in pinpointing the specific locations where it was most difficult 19 in accessing food and healthcare.

Again, a comparative analysis between those with and without food allergies with regard to food and HCA in the NW of England, was highlighted. This provided valuable insights into which areas those with food allergies struggled most in accessing food and healthcare. Additionally, the comparison emphasised the length in which food and HCA is more difficult in the food allergic group. Moreover, it helped to understand if food allergy status was a key factor in accessing food and healthcare or if the trends observed are consistent with that of the general LA population.

#### 27 4.2. <u>Methodology</u>

Geographical mapping software - ArcGIS (version 10.4.1) was used to visualise the current FC and HCA of LA with and without food allergies. The results were based on quantitative questionnaires distributed in Phase 1 of this research. Data was collected from 18 different cities/towns from four different counties in NW, England. Heat maps were illustrated based on the following four questions asked to participants.

- 33 Q1. How many miles from where you live, do you travel to obtain healthy, nutritious food?
- 34 Q1a. How many miles from where you live, do you travel to purchase allergen, free food?

35 Q2. How many miles from where you live, do you travel to the nearest GP/health centre?

36 Q3. How many miles from where you live, do you need to travel to the nearest hospital to 37 obtain health care?

38

# 39 Step 01: Development of the required files

- 40 Shapefiles were created for each county.
- 41 Personal geodatabase files were created to generate point features for selected county
- 42 locations using longitude and latitude coordinates, provided by the 'outcode' data (first part
- 43 of the UK postcode e.g. *PR* for Preston and *L* for Liverpool).
- 44 Every file was geo-referenced to WGS 1984 UTM zone 30N.
- 45

### 46 Step 02: Multiple-ring buffering

47 Each county was buffered in accordance with the distances travelled by the participants using

48 the multiple-ring buffer tool provided in the ArcGIS analysis tools. Each distance category was

49 assigned a distinct colour code for visualisation purposes.

50

# 51 Step 03: Map generation

To allow for a visual representation of the number of participants who travelled specific distances as previously buffered, pie charts were selected as the symbology method. These charts are particularly useful for illustrating the contribution of individual segments to an overall whole. Consistent with the previous approach, a colour coding scheme mirroring that of the multiple-ring buffering was implemented, to distinctly represent the colour of the participants in each category.

# 58 4.3. <u>Results</u>

59 A total of 172 participants (86 food allergic, 86 non-food allergic) were recruited from four 60 different counties in NW, England (Table 4.1).

61

- 62 **Table 4.1.** Number of food allergic (n=86) and non-food allergic (n=86) participants from each
- 63 county in North West, England

County	Food Allergic Participants	Non-Food Allergic Participants	
Cheshire	4	3	
Merseyside	19	5	
Greater Manchester	29	13	
Lancashire	34	65	

# 64 4.3.1. Healthy Nutritious Food

Figure 4.1 and 4.2 highlight the distances travelled by food allergic and non-food allergic
participants to obtain healthy, nutritious food, in each of the 4 counties: Cheshire, Merseyside,
Greater Manchester and Lancashire in NW, England.

Overall, those with food allergies travelled longer distances than to access healthy, nutritious food than those without food allergies. In both Cheshire (namely Chester, Ellesmere Port and Middlewich) and areas in Merseyside (namely Liverpool) many food-allergic participants travelled greater than 10 miles to obtain healthy, nutritious food. In comparison, most nonfood allergic participants travelled shorter distances mostly within 4 miles. Liverpool and Chorley were the only two towns, where some participants without food allergies were found to travel greater than 10 miles to access healthy, nutritious food (Figures 4.1 and 4.2).



Figure 4.1. Distance travelled by <u>food allergic</u> individuals (n=86) to access healthy, nutritious
food in the counties of (a) Cheshire, (b) Merseyside, (c) Greater Manchester and (d)
Lancashire in NW, England.



Figure 4.2. Distance travelled by <u>non-food allergic</u> individuals (n=86) to access healthy,
nutritious food in the counties of (a) Cheshire, (b) Merseyside, (c) Greater Manchester and (d)
Lancashire in NW, England.

81

# 82 4.3.2. Allergen Free Foods

Figure 4.3 showcases the distances travelled by food allergic participants to access AFF, in
each of the 4 counties: Cheshire, Merseyside, Greater Manchester and Lancashire in NW,
England.

- 86 From the 4 counties, food-allergic participants from Greater Manchester had the greatest
- 87 challenge in accessing AFF, with many travelling up to 10 miles. The greatest difficulty was in
- 88 Salford (n=4), where 75% of participants travelled between 8 and 10 miles, followed by Wigan
- 89 (n=6), where 30% travelled greater than 10 miles (Figure 4.3). Similarly, those from Preston,
- 90 Lancashire (n=10) had to travel greater than 10 miles to access AFF.
- 91 Overall, the data illustrates that access to AFF across the NW is limited.



- 92 Figure 4.3. Distance travelled by <u>food allergic</u> individuals (n=86) to access allergen, free food
- 93 in the counties of (a) Cheshire, (b) Merseyside, (c) Greater Manchester and (d) Lancashire in
- 94 NW, England.

#### 95 **4.3.3.** <u>Healthcare</u>

- 96 Figures 4.4 and 4.5 highlight the distances travelled by food allergic and non-food allergic 97 participants to obtain primary health care (GP's and Health Clinics) and Figures 4.6 and 4.7 98 highlight the distances travelled by food allergic and non-food allergic participants to obtain 99 secondary/tertiary healthcare (hospitals), in each of the 4 counties: Cheshire, Merseyside, 100 Greater Manchester and Lancashire in NW, England.
- 101 Overall, primary health care (GPs/health care clinics) across the NW in most towns and cities,
- 102 was easily accessible. As indicated in Chapter 3, section 3.3.4, the findings revealed no 103 significant differences between food-allergic and non-food allergic groups when accessing
- significant differences between food-allergic and non-food allergic groups when accessing
   their GP/health centre. However, further analysis according to different counties revealed taht
- 105 individuals with food allergies travelled greater distances in Liverpool and Wirral (Merseyside),
- 106 Preston (Lancashire) and Bolton and Bury (Greater Manchester). Some participants without
- 107 food allergies also faced challenges in accessing primary health care, namely in Liverpool and
- 108 Chorley where longer distances of 10 miles were noted (Figure 4.4 and Figure 4.5).



Figure 4.4. Distance travelled by <u>food allergic</u> individuals (n=86) to access primary health
care in the counties of (a) Cheshire, (b) Merseyside, (c) Greater Manchester and (d)
Lancashire in NW, England.



112 **Figure 4.5.** Distance travelled by <u>non-food allergic</u> individuals (n=86) to access primary

health care in the counties of (a) Cheshire, (b) Merseyside, (c) Greater Manchester and (d)

114 Lancashire in NW, England.

However, every town/city within each of the 4 counties in the NW, struggled to access secondary/tertiary health care. This access was more difficult in the food allergic group. Surprisingly at least 30% and 35% of participants in Preston and Liverpool respectively, found it difficult to access secondary/tertiary care, even though both cities possess specialist allergy clinics. Liverpool, Chorley, Blackpool and Preston were areas where both food-allergic and non-food allergic individuals struggled in accessing secondary/tertiary care (Figure 4.6 and Figure 4.7).



Figure 4.6. Distance travelled by *food allergic* individuals (n=86) to access secondary/tertiary
health care in the counties of (a) Cheshire, (b) Merseyside, (c) Greater Manchester and (d)
Lancashire in NW, England.



Figure 4.7. Distance travelled by <u>non-food allergic</u> individuals (n=86) to access
secondary/tertiary health care in the counties of (a) Cheshire, (b) Merseyside, (c) Greater
Manchester and (d) Lancashire in NW, England.

#### 143 **4.4. Discussion**

144 It has already been established that the NW has a large number of neighbourhoods with high 145 levels if deprivation (see section 2.2.2. in Chapter 2). Additionally, the presence of food 146 allergies will most certainly increase the struggle to access both food and healthcare, in comparison to possessing no food allergy at all - findings which were further reinforced 147 148 through this study. While discussing the results of this study, we attempted to also explore if 149 reduced access to food and health care in those with food allergies in NW, England, was 150 due to existing deprivation in each particular county. This was achieved by comparing our 151 findings with the IMD, 2019. A specific focus on food access and specialist allergy service 152 provision within each of the counties was also mentioned.

The NW itself consists of 5 counties: Cheshire, Merseyside, Lancashire, Greater Manchester and Cumbria. For the purpose of this discussion, deprivation relating to the counties of Cheshire, Merseyside, Lancashire and Greater Manchester will be included, as these mirror those areas in which participants were recruited from.

#### 157 **4.4.1.** Food Access

158 Despite the UK being one of the most wealthiest countries, food insecurity levels are 159 widespread and many cannot even afford basic food (McPherson, 2020. Physical access to 160 food is necessary in order to be food secure (UK Food Security Report, 2021. While some 161 urban areas have limited access to supermarkets or grocery stores, across England access 162 to food shops is mostly adequate (UK Food Security Report, 2021). The findings from this 163 study however highlighted that access to healthy, nutritious food of good quality is not easily 164 accessible in many parts of the NW. This could be due to multiple reasons in addition to the 165 high levels of existing deprivation. Many areas in this region have increased concentrations of 166 fast food outlets and this constant exposure to unhealthy foods, which are also more affordable 167 can be enticing (Caraher et al., 2010; Public Health England, 2022; Li et al., 2022; O'Neill, 168 2023).

169 Additionally, this study included 18-25year olds, of which more than half were students at 170 university. The university environment itself is known to promote an obesogenic environment 171 which will negatively impact dietary choices in students (Poobalan et al., 2014; Tanton et al., 172 2015; Roy et al., 2016; Munt et al., 2017; Sprake et al., 2018; Brennan et al., 2020; Li et al., 173 2022). Moreover, recent research in the NW has highlighted how food insecurity is particularly 174 prevalent among students at university (Armstrong et al., 2023). These individuals will already 175 have a tight budget due to additional university expenditures and as such, the affordability of 176 unhealthy, calorie dense foods and the low cost of highly processed snacks within the

177 university environment will make them easier to choose (Ahmad et al., 2021; Cretch et al.,

- 178 2022; Ravel et al., 2023). In those with food allergies, accessing AFF which offer a safe way
- 179 to meet nutritional requirements is challenging, as outlined in this study.

#### 180 Cheshire

181 The county of Cheshire itself is divided into four districts – Cheshire West and Chester (which 182 includes Chester city and Ellesmere Port town), Cheshire East (which includes Middlewich 183 town), Halton and Warrington. Individuals from areas in Cheshire West and Chester, Cheshire 184 East and Warrington took part in this study. Table 3 highlights the overall deprivation in each 185 of the local authorities in the NW, where participants were recruited from. The data reveals 186 that Cheshire county has an overall less deprived population profile in comparison to other 187 areas in the NW, with little difference between 2015 and 2019 (Table 4.3). Similarly, income 188 deprivation within the county of Cheshire was lower in comparison to all other counties (Table 189 4.4). Furthermore, the health profile report for the NW of England, (PHE, 2021), reveals that 190 in comparison to other areas within the NW, Cheshire county has a better health profile. 191 Specifically, the report highlights that Cheshire county has one of the lowest excess mortality 192 rates, has a higher life expectancy, has lower rates of death due to drug misuse and a lower 193 percentage of obesity levels, when compared to other areas within the NW. Additionally, two 194 of the three local authorities found to have increased employment rates in people ages 16-195 64years were in Warrington and Cheshire West and Chester, with the third being Wigan. 196 Therefore in all aspects of health and deprivation, we can conclude that Cheshire county has 197 a significantly better health profile and lower levels of deprivation, in comparison to the other 198 counties across the NW.

199 Despite these relatively lower levels of deprivation, the results from this study highlighted that 200 there is a struggle in accessing healthy, nutritious food across Cheshire and this is more 201 challenging in those with food allergies. Food-allergic participants from Middlewich and 202 Ellesmere Port and half of individuals in Chester travelled greater than 10 miles to access 203 healthy, nutritious foods. The raw data revealed that specifically those in the postcode region 204 of CW10, CH36 and CH65 (Appendix 2) struggled to access healthy nutritious foods the most. 205 Cheshire county is considered a more affluent area within the NW and while levels of 206 deprivation are not as high across this region when compared to other parts of the NW, 207 pockets of deprivation do exist. Many residents in Cheshire county have experienced food 208 poverty due to the rising cost of living (Francis-Devine et al., 2023). The latest Office for Health, 209 Improvement and Disparities figures highlight how 18% of residents in Cheshire West and 210 Chester and 11% of residents in Cheshire East suffered from food insecurity in 2021 alone. 211 Additionally, one in five people in Cheshire West and Chester and one in nine people in

212 Cheshire East were consistently unable to provide their household with healthy food during 213 this period. As such, the number of people accessing food banks in this county has rapidly 214 increased (Farrington, 2023). Rates of deprivation are steadily increasing in Cheshire county, 215 particularly in the city of Chester and the towns of Ellesmere Port (Noble et al., 2019) and this 216 can therefore explain the reduced access to healthy, nutritious food seen in participants from 217 this county.

218 These findings suggest that even in more affluent areas, access to essential resources like 219 healthy, nutritious foods can also be limited. An overall better health and deprivation profile 220 does not guarantee better access for everyone. The difference between groups highlights that 221 the challenge in accessing healthy, nutritious foods is specific to the presence of a food allergy. 222 Therefore, food access is not only influenced by levels of deprivation, but is tied to the 223 individual needs of certain groups. Those with food allergies will actively be searching for AFF 224 which are often difficult to access due to their limited availability and increased expense (REF). 225 This emphasises the need for more targeted interventions and policies to address the unique 226 needs of those with food allergies, consequently ensuring more equitable access.

#### 227 Merseyside

228 Merseyside county is made up of six local authorities – Halton, Knowsley, Liverpool, Sefton, 229 St Helens and Wirral. Overall, one third of the Merseyside population live in the most deprived 230 20% of neighbourhoods in England (Noble, 2019). In this study, participants from areas in 231 Knowsley (Prescot), Liverpool and Wirral took part. The IMD 2019 report highlights that all 232 three of these areas became relatively more deprived in 2019 when compared to 2015. 233 Knowsley ranked as the third most deprived borough in England, followed by Liverpool, which 234 is currently ranked as fourth, with both areas in the worst 20% of local authorities in England. 235 Additionally, both areas have just under half of LSOA's in the most 10% deprived nationally 236 (Table 4.3). With respect to local income deprivation, Knowsley and Liverpool ranked as 2<sup>nd</sup> 237 and 4<sup>th</sup> respectively, indicating high rates of low income across both boroughs (Table 4.4). In 238 comparison, of the six local authorities in Merseyside, Wirral is one of the least deprived areas 239 with only Sefton ranking higher on the average rank scale. Currently, Wirral ranks as 77<sup>th</sup> and 240 though has become relatively more deprived since 2015, is no longer considered amongst the 241 20% most deprived authorities in England (Table 4.3). Despite this, within Wirral, many areas 242 of severe deprivation do also exist and when compared to other areas across the NW, it is still 243 quite deprived.

Public Health reports (PHE, 2020; PHE, 2021; Lewis et al., 2021) further highlight deprivation
 across Merseyside and show how this high level of deprivation has resulted in poorer health

outcomes across the county. Social and health inequalities have worsened throughout
Merseyside and this has further exacerbated existing inequalities in the more deprived areas.
There are higher rates of coronary heart disease, obesity, mental health illness and lower life
expectancy compared to the national average (PHE, 2020; PHE, 2021; Lewis et al., 2021).
The prevalence of these conditions coupled with economic challenges faced by residents
across Merseyside (Table 4.4.), can make it more challenging for individuals to access
healthy, nutritious foods.

253 The findings from this study highlight that individuals with and without food allergies living in 254 Merseyside, particularly Liverpool and Knowsley, face considerable challenges in accessing 255 healthy, nutritious foods. Specifically it was revealed that residents living in the following areas 256 had the most difficulty in accessing healthy, nutritious food – L12, L15, L16, L17, L19, L23 and 257 L34 (Appendix 2). This difficulty can be directly linked to the high levels of deprivation and 258 food insecurity existing in these specific areas. One report revealed how over 78% of 259 households in Merseyside were 'severely' food insecure, with many residents skipping meals 260 owing to financial instability (House of Commons, 2018). Previous data has revealed that in 261 the city of Liverpool, 32% of adults are food insecure (Blake et al., 2021), while in Knowsley 262 this is 57% (Dowdeswell, 2023). Additionally, in Liverpool there exists many food deserts -263 areas where there is a reduced access to affordable, nutritious foods (Titis et al., 2022). 264 Reports highlight how Liverpool is home to half of the 10 most economically deprived food 265 deserts in England Liverpool City Region Combined Authority, 2022), further emphasising why 266 participants from Liverpool travelled longer distances when accessing healthy, nutritious 267 foods. The results from this study highlighted little difference between those with and without 268 food allergies when accessing healthy, nutritious foods. This indicates that the difficulties 269 related to access are more closely linked with high levels of deprivation and food insecurity, 270 rather than the presence of a food allergy. In comparison, both food-allergic and non-food 271 allergic participants from Wirral generally travelled much shorter distances when accessing 272 healthy, nutritious foods, likely owing to the lower deprivation levels in this region. Further 273 emphasising that challenges in food access are likely linked to high deprivation levels and 274 food insecurity in these areas and not only the presence of a food allergy.

#### 275 Greater Manchester

Greater Manchester consists of ten districts and boroughs – Bolton, Bury, Manchester, Oldham, Rochdale, Salford, Stockport, Tameside, Trafford and Wigan. Participants from six areas (Bolton, Bury, Manchester, Oldham Salford and Wigan) took part in this study. High levels of deprivation do exist across Greater Manchester. Five of these six areas became relatively more deprived in 2019 compared to 2015 (Oldham, Salford, Bolton, Wigan and Bury). The city of Manchester is considered the most deprived area within Greater Manchester, with 43% of LSOA's in the most deprived 10% nationally, and also ranks second in terms of deprivation across the entire UK (Table 4.3).

High levels of deprivation exist across Greater Manchester, including high unemployment
rates, low life expectancy and increased levels of child poverty and obesity. Specifically in the
city of Manchester, 42% of children under-16 are currently living in poverty (PHE, 2021;
Manchester City Council, 2022). These high levels of deprivation across Greater Manchester
will have a direct impact on accessing essential resources such as healthy, nutritious foods.

289 The results from this study revealed that those with food allergies travelled longer distances 290 in accessing healthy, nutritious foods in Greater Manchester than those without food allergies. 291 The challenges were more pronounced in the areas of Wigan, Bolton, Bury, Manchester and 292 Salford. This indicates that while deprivation affects all residents, those with food allergies are 293 more severely impacted due to their specific dietary requirements. Even in Bury, where 294 deprivation levels are lower, those with and without food allergies faced barriers in accessing 295 healthy, nutritious foods. This suggests that accessibility issues are not only linked to deprivation but other factors such as , the availability of AFF, the geographic distribution of 296 297 food stores and individual economic barriers, may also play a role. Therefore, this emphasises 298 that food access is both challenging and complex and is influenced by a combination of 299 factors, in addition to deprivation.

300

#### 301 Lancashire

302 Lancashire is home to 14 districts – Burnley, Chorley, Fylde, Hyndburn, Lancaster, Pendle, 303 Preston, Ribble Valley, Rossendale, South Ribble, West Lancashire, Wyre, Blackburn with 304 Darwen and Blackpool. In this study, participants from five areas took part (Blackpool, 305 Lancaster, Preston, Chorley and Blackburn with Darwen). Amongst these districts, there is a 306 clear contrast in deprivation levels. Chorley is one such area where deprivation is quite low. It 307 currently ranks 192<sup>nd</sup> on the average rank scale and has become less deprived since 2015. In 308 fact, only 5% of LSOA's in Chorley are among the most deprived 10% nationally. Similarly, 309 Lancaster is considered an area of lower deprivation when compared to other areas within Lancashire, ranking 112<sup>th</sup> with a small number of 13 LSOA's in the most deprived 10% 310 311 nationally (Table 4.3). Additionally, income deprivation in both Chorley and Lancaster was 312 much lower in comparison to other areas within Lancashire (Table 4.4). In contrast, Preston, 313 followed by Blackburn with Darwen and Blackpool were all areas with higher levels of overall 314 deprivation and income deprivation in Lancashire (Tables 4.3 and 4.4).

315 These high levels of deprivation in Lancashire contribute to poorer health outcomes in this 316 region. For instance, life expectancy across many areas in Lancashire is much lower in 317 comparison to the national average. Rates of obesity in both children and adults are 318 particularly high across Lancashire and are expected to rise. The data reveals that 25% and 319 23% of children are overweight and obese respectively, while 67% and 64% of adults are 320 overweight and obese respectively. Additionally, those living in areas of higher deprivation in 321 Lancashire, e.g. Blackpool and Blackburn with Darwen, are twice as likely to have mental 322 health issues including depression, anxiety, and schizophrenia. Similarly, across all local 323 authority districts in the Lancashire region, mortality rates from chronic conditions which are 324 considered preventable were much higher than the national average (PHE, 2021; Institute of 325 Health Equity, 2022).

326 Participants in this study from Lancashire, struggled in accessing healthy, nutritious foods and 327 this could be attributed to the high levels of deprivation in this region. Overall, the challenge 328 was greater in those with food allergies with these individuals travelling longer distances to 329 access healthy, nutritious foods. This suggests that specific dietary needs can exacerbate 330 food access. The results further highlighted that some participants both with and without food 331 allergies in Chorley, which is relatively less deprived, struggled in accessing healthy, nutritious 332 foods. This suggests that although deprivation is a key factor in determining food access, it is 333 not the only one. The need to travel longer distances in less deprived areas, could reflect 334 individual circumstances and other factors such as the availability of AFF and the geographic 335 distribution of food stores. Thus underscoring that food access is multifactorial and can affect 336 not only those with specific dietary requirements, but also the general population.

#### 337 4.4.1.1. Access to Allergen Free Foods

338 The results from this study revealed that all participants struggled to access AFF across the 339 entire NW region, suggesting that access to AFF was not necessarily linked with living in areas 340 of high deprivation. Even in regions where there existed lower overall deprivation, such as 341 Cheshire, Chorley and Lancaster, participants faced barriers in accessing AFF. Thus 342 suggesting that a better overall health and deprivation profile, does not necessarily mean 343 better access to these specialised foods. When looking at the raw data, those living specifically 344 in the postcode areas of BB3, FY8, PR2, PR4, PR7, LA9, CH28, CH32, CW10, BL3, BL5, M6, 345 M7, M9, WN2, WN3, WN4, L12, L23 and L29 (Appendix 2) travelled the longest distance, 346 indicating that these areas had limited access to AFFs. This reduced access found in 347 participants can be attributed to two main reasons. Firstly, AFF (despite the growing population 348 of the food allergic community) are not widely accessible. Their availability is commonly limited 349 to only one section in large supermarkets and they are rarely present in convenience stores

350 (Holroyd, 2022). In addition to this, the range of AFF which are provided are also only a few, 351 meaning that those with food allergies won't have many options to choose from (Searby, 352 2022). Secondly, even when individuals are able to access these foods, they are considerably 353 more expensive (North and Brown, 2017). Previous research has highlighted how individuals 354 with milk allergy struggled to access safe allergy-friendly foods due to their high cost (Abrams 355 et al., 2020; Fong et al., 2022). In many cases, this expensive nature of AFFs will leave many 356 to simply not purchase them (Mintel, 2022), leading to the inability to meet nutritional needs, 357 a repetitive diet and an increased exposure to allergens, which will all detrimentally impact 358 overall health (Tackett et al., 2019; Brown et al., 2020). In areas of higher deprivation levels, 359 such as Manchester, Oldham, Salford, Blackpool, Blackburn with Darwen and Preston, there 360 was an increased difficulty in accessing AFF, with participants reporting travelling greater than 361 10 miles. Therefore, this does indicate that deprivation was a factor in the limited availability 362 of AFF.

363 In conclusion, the results of this study indicate that food access, especially for those with 364 special dietary requirements is influenced by multiple factors including but not limited to 365 deprivation, food availability and geographic distribution. Efforts to improve the access of AFF 366 within the NW are essential to allow equitable access and improve overall health outcomes.

#### 367 4.4.2. Healthcare Access

368 With regard to HCA, allergy services do currently exist within the NW. However, the data from 369 this study revealed that many participants with food allergies were found to travel considerably 370 long distances to access health care in each of the counties. Multiple reasons can explain this. 371 Although the prevalence, severity and complexity of allergy has been steadily increasing, 372 allergy services continue to remain inadequate (Diwakar et al., 2017). Few specialists who 373 can provide the necessary allergy support currently exist in the NW (RCP, 2010; Sinnott et al., 374 2011). Additionally, GPs who provide the majority of allergy care in the UK lack knowledge 375 and training and are unable to provide adequate support for those with allergies. This lack of 376 knowledge and training will cause patients to be inappropriately referred to specialists, 377 resulting in an increased wait time for specialist appointments. This inadequate care at the 378 primary care level will place an increased burden on the few secondary/tertiary allergy centres 379 in the NW that do exist, further generating long wait times for families. The inability to access 380 adequate care will create unnecessary and unwanted anxiety among patients and families 381 and will dramatically reduce quality of life (Sinnott et al., 2011; Agache et al., 2013; Diwakar 382 et al., 2017; Daniels et al., 2021). Consequently, many will resort to alternative forms of 383 support which though may be easily accessible, will prove more detrimental to health (Morris,

2019; King et al., 2020). Given that primary care physicians are the gatekeepers for secondary
 and tertiary care services, access to specialised allergy care will also be limited.

The findings from this study also revealed that overall, access to primary care was relatively easy with most participants travelling between less than 1 mile to 4 miles. In some areas, there was a greater difficulty in accessing primary care. The raw data revealed that this was specifically in the postcode areas of BB2, PR2, PR4, L12, L16, M11, M6, BL3, BL6, BL8 and CH61 (Appendix 2). The following few sections will focus on access to specialist allergy care by participants at the secondary/tertiary level.

#### 392 Cheshire

393 Those with food allergies in Cheshire did struggle to access secondary/tertiary health care. 394 Particularly, the city of Chester was one such area within the county of Cheshire where 395 individuals were found to travel longer distances to access health care for their food allergies, 396 when compared to other areas within Cheshire. Though deprivation in Cheshire is relatively 397 low, small pockets of deprivation do exist, namely in urban areas in Cheshire county e.g. 398 Chester and Ellesmere Port, thus explaining these findings (Noble et al., 2019). Moreover, no 399 specialist allergy care (tertiary centres) exists within Cheshire specifically for those with food 400 allergies with patients having to travel outside of the county to access services. In fact, 401 Macclesfield District General Hospital (Cheshire East) Warrington Hospital and Countess of 402 Chester Hospital (Cheshire West and Chester) are the only three hospitals within the county 403 of Cheshire where secondary centres providing allergy care exist, with all three focusing only 404 on pediatric allergy services (Table 4.5). Thus, further supporting why 18-25year olds with 405 food allergies from this study, struggled to access healthcare for their food allergies in 406 Cheshire county. Additionally, these findings indicate that a better overall health and 407 deprivation profile does not necessarily guarantee better access to specialised allergy 408 services. While socioeconomic deprivation clearly plays a role in healthcare accessibility, the 409 specific needs of those with food allergies also presents unique challenges that are not always 410 reduced by living in less deprived areas.

#### 411 Merseyside

Accessing secondary/tertiary health care by 18-25year olds with food allergies was found to be difficult by many in Merseyside. Specifically, all participants in Prescot (Knowsley) and 25% of participants in Wirral, struggled to access specialist health care for their food allergy with these individuals travelling greater than 10 miles. Currently, no secondary or allergy services are available in Knowsley, while in Wirral, one secondary centre which has direct tertiary input does exist (Wirral University Teaching Hospital NHS Foundation) (Table 4.5), however, this

centre provides only allergy services for children. This explains the long distances travelled by 418 419 participants in this study. Additionally, the data revealed that 36% of participants in the 420 Liverpool city region also travelled distances greater than 10 miles to access specialist health 421 care for their allergy. Specifically, this was found in participants living in the L12, L19, L23, L27 422 and L34 (Appendix 2) postal code areas. The results are surprising for participants living in 423 the L12 area given that it is close to one specialised allergy and immunology services for adult 424 patient - Royal Liverpool and Broadgreen University Hospitals NHS Trust, which provides adult 425 allergy and immunology services (Table 4.5). Reasons to explain why participants in Liverpool 426 were still found to travel long distances of more than 10 miles, could be due to increased wait 427 times for appointments due to limited allergy services and the lack of allergy specialists 428 available (RCP, 2003; Warner et al., 2006; Finlay and Egner, 2010; RCP, 2010; Diwakar et 429 al., 2017; Daniels et al., 2021). Even though Wirral is a less deprived area, some participants 430 here still faced difficulties when accessing healthcare. Perhaps due to pockets of deprivation 431 which may emulate barriers similar to those found in more deprived areas, indicating that 432 localised deprivation can also reduce efforts in accessing healthcare.

#### 433 Greater Manchester

434 Across Greater Manchester, a proportion of participants in every city/town struggled to access 435 health care for their allergy. Within Greater Manchester, many allergy services for both 436 children and adults are available. However, most of these focus on providing paediatric allergy 437 care. Although three specialised adult allergy services do exist, all are based in the city of 438 Manchester (Central Manchester University Hospitals NHS Foundation Trust, University 439 Hospital of South Manchester NHS Foundation Trust and Wythenshawe Hospital), explaining 440 why many participants living in other parts of Greater Manchester travelled considerable 441 distances to access health care (Table 4.5). Particularly, the results from this study revealed 442 that in the city of Salford there was a great difficulty in accessing health care, with three 443 quarters of participants traveling greater than 10 miles. This is quite surprising given that one 444 specialised adult allergy service does also exist in the city of Salford (Salford Royal NHS 445 Foundation Trust) (Table 4.5). Again, this can be explained by the increased wait times for 446 appointments and/or referrals which many food allergic participants experience, along with the 447 reduced number of allergy specialists that are currently available within the UK (RCP, 2003; 448 Warner et al., 2006; Finlay and Egner, 2010; RCP, 2010; Diwakar et al., 2017; Daniels et al., 449 2021). Furthermore, across Greater Manchester, health conditions such as dementia, stroke, 450 diabetes, coronary heart disease and depression were higher than the national average (Age 451 UK, 2019). This high prevalence of other health conditions in the Greater Manchester area 452 could make it more challenging for food allergic individuals to access timely and appropriate 453 care, as healthcare resources may already be stretched.

#### 454 Lancashire

455 In the county of Lancashire, almost half of participants in each of the cities/towns travelled 456 long distances when accessing health care. Within Lancashire four NHS Trusts providing 457 allergy services do exist. However, three focus on paediatric allergy and offer services only 458 for children (University Hospitals of Morecambe Bay NHS Foundation Trust – Royal Lancaster 459 Hospital, East Lancashire Hospitals NHS Trust and Blackpool Teaching Hospitals NHS 460 Foundation Trust). Only one centre providing services for adults exists in Lancashire (Lancashire Teaching Hospitals NHS Foundation Trust – Royal Preston Hospital) (Table 4.5), 461 462 thus explaining these long distances travelled by participants when accessing health care for 463 their allergy. What is interesting is that some participants within the city of Preston did in fact 464 struggle to access health care and travelled long distances, despite the adult allergy service 465 being based in Preston. Once again, previous research has mentioned that the current care 466 being delivered for allergy patients is inadequate, with many experiencing long waiting times 467 for appointments to see specialists, with incorrect diagnosis/treatment being provided by 468 primary care physicians (RCP, 2003; Warner et al., 2006; Finlay and Egner, 2010; RCP, 2010; 469 Diwakar et al., 2017; Daniels et al., 2021). Hence, leaving them no choice but to travel further 470 distances to seek out alternative health care. Additionally, in areas like Chorley where there 471 exists lower levels of deprivation participants still travelled longer distances, which could 472 indicate that even in less deprived areas, geographical factors such as dispersed services 473 could also increase accessibility challenges. Thus, emphasising the complexity of accessing 474 healthcare in both deprived and less deprived regions.

#### 475 4.5. <u>Conclusion</u>

476 Clearly many individuals in the NW are struggling to access adequate food and health care. 477 This can be attributed to the high levels of deprivation that exist in the North. This particular 478 study focused on physical access to food and health care and measured the distances 479 travelled by LA with and without food allergies. Our results in this and a previous chapter 480 (Chapter 3) highlighted that a significant difference did exist between both groups when 481 accessing healthy, nutritious food and secondary/tertiary health care, with the data indicating that the presence of a food allergy made it more difficult in both cases. With regard to 482 483 accessing primary health care, while the results in chapter 3 found no significant differences 484 between groups, further analysis considering the location of the participants did reveal 485 differences between the food-allergic and non-food allergic group.

Where you live will significantly impact access to food and health care. Furthermore, the presence of a food allergy will significantly increase the challenge in accessing both food and health care - the consequences of which could prove fatal. Additionally, in those with food allergies, access to AFF also proved difficult across the NW, with a large number of participants travelling longer distances to obtain such foods. Certain postal code areas in each county were also revealed in this study, as those specifically lacking in the availability of both food and healthcare.

493 Interventions to improve the accessibility and availability of healthy, nutritious foods in the NW 494 are clearly needed. A specific focus in the areas of poorer access outlined in this study should 495 be prioritised. Local shops which are easily reached are important in accessing a healthy diet. 496 Convenience stores which are ever-present in the community and therefore, more accessible 497 to consumers, play an important role in shaping healthier diets (Foss et al., 2019). Yet, they 498 offer little in the choice of healthier foods (Shaw et al., 2023). It is possible to positively 499 influence the buying and eating habits of consumers at convenience stores, through increasing 500 the access to healthier foods, as highlighted through previous research (Bestway Good Food 501 Wholesale Project, 2020; Haboush-Deloye et al., 2023). Therefore, this is something to be 502 considered within the NW, particularly in those areas where many travelled longer distances 503 to access healthy, nutritious foods.

There is a need to improve the quality of allergy primary care and one fundamental means of achieving this, is through training as highlighted in Chapter 2. Furthermore, the use of nonclinician practitioners, for instance nurses, dietitians, psychologists and pharmacists who each can provide a unique skill set and tailored support for patients with food allergies, are not optimally used. Providing greater access to these various allied health professionals can not 509 only reduce the burden on both GPs and allergy specialists, but will in fact offer a more 510 comprehensive and holistic form of care (Mercer et al., 2015; Skypala et al., 2018, Knibb et 511 al, 2019; Barker et al., 2021; Daniels et al., 2021; Knibb et al., 2023).

512 Overall the results from this study emphasise that those with food allergies in areas of the NW 513 experience challenges when accessing food and healthcare and that this is likely due to a 514 combination of factors – high levels of deprivation, the limited availability of specialised food 515 and health services specific to their food allergy and increased pressure on the few existing 516 allergy services. The findings from this study therefore emphasise the need for more targeted 517 interventions that address both socioeconomic deprivation and the specific needs of those 518 with food allergies.

#### 519 **4.6.** Limitations

520 This study provides valuable insights into the geographic variations in food and healthcare 521 access in those with and without food allergies in the NW of England. It is also important 522 however, to acknowledge the limitations associated with this study, which may have impacted 523 the generalisability of the findings.

Firstly, the study included 172 participants, which may not be large enough to capture the full variability of food and healthcare access across the NW region. In addition to this, the distribution of participants across the four counties – Cheshire, Merseyside, Greater Manchester and Lancashire, was uneven. For instances, some regions like Cheshire had very few participants – only seven in total. This could have limited the ability to make conclusions about access in these areas. The low number of participants included could mean that the results may not fully represent the experiences of the wider population in those areas.

531 Secondly, while this study attempted to cover a wide geographic area within the NW, some 532 areas were not represented or underrepresented in this sample. This could have led to a 533 skewed understanding of the issues in relation to access of food and healthcare and limits the 534 studies comprehensiveness in representing the entire NW region. Thirdly, there was a reliance 535 on self-reported data in this study and issues with recall bias and subjective interpretation 536 could have been present. For instance, participants perceptions of the distance travelled and 537 the difficulty in accessing resources may vary and this could have affected the accuracy of the 538 results.

539 Fourthly, the study focused on only one aspect of accessibility - the physical distance when 540 accessing food and healthcare. Other factors which may affect accessibility were not 541 measured in this study, such as the price and distribution of AFF and the cost of healthcare

- 542 services. Therefore, the findings may not have captured the complexity of the different barriers 543 faced by individuals when accessing food and healthcare for their allergy. Finally, while the 544 role of socioeconomic deprivation was acknowledged in this study, other factors associated 545 with this for example, participants employment status, education level and food security status 546 were not explored in the study population. These factors could have provided unique insights 547 into the food-allergic population and how various socioeconomic factors influence their access 548 to food and healthcare.
- 549 To conclude, while this study provides unique insights into the challenges faced by LA with 550 and without food allergies when accessing food and healthcare, limitations do exist. Further 551 research with a larger sample, broader geographic coverage and a more comprehensive 552 exploration of various socioeconomic factors impacting access to food and healthcare is 553 needed to build on these findings.
- Through Chapter 3 and Chapter 4, the challenges identified in accessing food and healthcare in those with food allergies were identified. It is also crucial to understand the perspectives of HCPs, who are directly involved in providing care for LA with food allergies. Therefore, the next chapter - Chapter 5, will investigate the current HCA in LA with food allergies from the perspectives of HCPs who provide this care. This will help to determine any systemic and structural issues within the healthcare system that may potentially contribute to the difficulties experienced by LA with food allergies.

- 561 **Table 4.3.** Overall deprivation in each of the Local Authorities, across the four counties in the
- 562 NW where participants were recruited from

Local Authority	Average Rank (2015/326)	Average Rank (2019/317)	Number of LSOA's in each Local Authority (2019)	Number of LSOA's in the most 10% deprived nationally (2019)	Percentage of the most 10% deprived nationally (2019)
CHESHIRE					
Cheshire West and Chester	163 <sup>rd</sup>	161 <sup>st</sup>	212	16	7.5
Cheshire East	223 <sup>rd</sup>	216 <sup>th</sup>	234	4	<u>2</u>
Warrington	147 <sup>th</sup>	148 <sup>th</sup>	127	10	8
MERSEYSIDE					
Liverpool	7 <sup>th</sup>	4 <sup>th</sup>	298	145	49
Wirral	103 <sup>rd</sup>	77 <sup>th</sup>	206	<u>721</u>	<u>351</u>
Knowsley	<u>5<sup>th</sup></u>	3 <sup>rd</sup>	98	46	47
LANCASHIRE					
Chorley	186 <sup>th</sup>	192 <sup>nd</sup>	66	3	5
Preston	72 <sup>nd</sup>	46 <sup>th</sup>	86	16	19
Blackpool	4 <sup>th</sup>	1 <sup>st</sup>	94	39	41
Lancaster	125 <sup>th</sup>	112 <sup>th</sup>	89	13	15
Blackburn with Darwen	24 <sup>th</sup>	14 <sup>th</sup>	91	33	36
GREATER MANCHESTER					
Manchester	1 <sup>st</sup>	2 <sup>nd</sup>	282	122	43
Oldham	51 <sup>st</sup>	29 <sup>th</sup>	141	42	30
Salford	22 <sup>nd</sup>	20 <sup>th</sup>	150	45	30
Bolton	64 <sup>th</sup>	47 <sup>th</sup>	177	42	24
Wigan	107 <sup>th</sup>	97 <sup>th</sup>	200	34	17
Bury	132 <sup>nd</sup>	110 <sup>th</sup>	120	12	10

\*Source: Indices of Deprivation, Department for Communities and Local Government, 2015 & 2019

\*Note: The smaller the number for 'average rank' the greater the relative deprivation

<sup>1</sup>Refers to the number of LSAO's in the most deprived 20%, as no data currently mentions the number of LSOA's in the most deprived 10%

- 563 **Table 4.4.** Local income deprivation in each of the Local Authorities, across the four counties
- 564 in the NW where participants were recruited from

Local Authority	Average Rank (2019/317)	Number of LSOA's in the most 20% deprived nationally (2019)	Percentage of the most 20% LSOA's deprived nationally (2019)
CHESHIRE			
Cheshire West and Chester	161st	37	17
Cheshire East	226th	13	6
Warrington	153rd	22	17
MERSEYSIDE			
Liverpool	4th	177	59
Wirral	38th	65	32
Knowsley	2nd	57	58
LANCASHIRE			
Chorley	177 <sup>th</sup>	8	12
Preston	55 <sup>th</sup>	29	34
Blackpool	3 <sup>rd</sup>	46	49
Lancaster	110 <sup>th</sup>	20	22
Blackburn with Darwen	10 <sup>th</sup>	50	55
GREATER MANCHESTER			
Manchester	8 <sup>th</sup>	159	56
Oldham	21 <sup>st</sup>	66	47
Salford	24 <sup>th</sup>	64	43
Bolton	29 <sup>th</sup>	73	41
Wigan	76 <sup>th</sup>	63	31.5
Bury	83 <sup>rd</sup>	30	25

\*Source: Indices of Deprivation, Department for Communities and Local Government, 2019

\*Local Income Deprivation measures the proportion of the population in an area experiencing deprivation relating to low income \*Note: The smaller the number for 'average rank' the greater the relative deprivation

Trust	<u>Region</u>	Service Provided	<u>NHS Service</u>
CHESHIRE			
East Cheshire NHS Trust - Macclesfield District General Hospital	Cheshire East	Paediatric Allergy	Secondary with Direct Tertiary Input
Countess of Chester Hospital	Cheshire West and Chester	Paediatric Allergic Clinic	Secondary
Warrington and Halton Hospitals NHS Foundation Trust	Warrington	Paediatric Allergy Clinic	Secondary
MERSEYSIDE			
Alder Hey Children's Hospital NHS Foundation Trust	Liverpool	Paediatric Allergy and Clinical Immunology	Tertiary
Royal Liverpool and Broadgreen University Hospitals NHS Trust	Liverpool	Adult Allergy and Immunology	Tertiary
Wirral University Teaching Hospital NHS Foundation Trust	Wirral	Paediatric Allergy Clinic	Secondary with Direct Tertiary Input
LANCASHIRE			
Lancashire Teaching Hospitals NHS Foundation Trust - Royal Preston Hospital	Preston	Adult and Paediatric Allergy Clinic	Secondary with Direct Tertiary Input
University Hospitals of Morecambe Bay NHS Foundation Trust - Royal Lancaster Hospital	Lancaster	Paediatric Allergy	Secondary with Direct Tertiary Input
East Lancashire Hospitals NHS Trust	Blackburn	Paediatric Allergy Clinic	Secondary
Blackpool Teaching Hospitals NHS Foundation Trust	Blackpool	Paediatric Allergy Clinic	Secondary

\*Sources:

Sinnott et al., NW NHS Specialised Commissioning Group (2011) British Society for Allergy and Clinical Immunology (2023)

# 566 **Table 4.5.** Continued

Trust	Region	Service Provided	NHS Service
GREATER MANCHESTER			
Southport and Ormskirk Hospital NHS Trust	Southport	Paediatric Allergy Clinic	Secondary
Central Manchester University Hospitals NHS Foundation Trust	Manchester	Adult Immunology (with allergy) paediatric allergy and immunology	Tertiary
University Hospital of South Manchester NHS Foundation Trust	Manchester	Adult Allergy	Tertiary
Salford Royal NHS Foundation Trust	Salford	Adult Immunology (with allergy)	Tertiary
Stockport NHS Foundation Trist	Stockport	Paediatric Allergy Clinic	Secondary
Bolton NHS Foundation Trust	Bolton	Paediatric Allergy Clinic	Secondary
The Pennine Acute Hospitals NHS Trust	Oldham	Paediatric Allergy Clinic	Secondary
Wrightington, Wigan and Leigh NHS Foundation Trust – Royal Albert Edward Infirmary	Wigan	Paediatric Allergy Clinic	Secondary with Direct Tertiary Input
Wythenshawe Hospital	Manchester	Allergy Centre and Paediatric Allergy Clinic	Secondary with Direct Tertiary Input

\*Sources:

Sinnott et al.., NW NHS Specialised Commissioning Group (2011) British Society for Allergy and Clinical Immunology (2023)

# <u>Chapter 5</u> – Healthcare Access in Late Adolescents (18-25years) With Food Allergies – Perspectives of Healthcare Professionals

#### 3 4

# 5.1. <u>Overview</u>

5 6 The period of transition from late adolescence to adulthood represents a shift in responsibility 7 for managing chronic conditions, which can be quite challenging for those with food allergies. 8 Ineffective management during this period can lead to poorer health outcomes and potentially 9 life-threatening allergic reactions. Understanding how current healthcare services support this 10 transition is a key aspect in improving the care for LA with food allergies. This chapter 11 therefore, attempts to explore the current healthcare access (HCA) for late adolescents (LA) 12 with food allergies from the perspective of different healthcare professionals (HCPs). As HCPs 13 play a central role in the management of food allergies, their insights will prove valuable for 14 identifying any gaps in the current care available. Specifically, a key focus on the current 15 training completed by HCPs as well as the current transition care is explored using a cross-16 sectional survey. By focusing on the perspectives of the HCPs, this chapter aims to provide a 17 deeper understanding of structural and systemic issues that may contribute to the difficulties 18 experienced by HCPs when providing care for LA with food allergies.

19

20 In this chapter, the following objectives were explored:

- 21 The current training of HCPs in managing food-allergic patients,
- 22 The availability of transition care resources,
- The communication and co-ordination between local allergy clinics and primary care
   providers
- 25

By exploring the above, this chapter provided insights into the current challenges faced by HCPs in providing care for LA with food allergies in the NW region. The results are then discussed and interventions based on existing literature to improve the delivery of care by HCPs for LA with food allergies, are mentioned.

- 30
- 31 5.2. Methodology

32

33 Ethical Considerations

34

Ethical approval was obtained from the National Health Service Research Ethics Committee
 (NHS REC) (REC Reference: 21/EE/0285, Project ID: 303224) and the University of Central
37 Lancashire's (UCLan) HEALTH ethics committee, prior to data collection. Following approval, 38 participants were provided with a participant information sheet providing them with detailed 39 information regarding the study. The participant information sheet was accessible online via a 40 secure link and detailed the purpose and nature of the study, potential risks and benefits of 41 the research and additionally emphasised participant confidentiality and the right to withdraw 42 at any point. This ensured all participants had all relevant information at hand, allowing them 43 to decide if they would like to participate. Once participants had reviewed the participant 44 information sheet, informed consent was obtained from all those who expressed interest in 45 the study, through an online consent form. Only after consent was given, participants were 46 able to access the survey.

47

#### 48

#### Patient and Public Involvement and Engagement

49

A patient steering group (n=3) comprising of a small sample of each of the target population was recruited prior to actual data collection. These individuals provided advice and suggestions based on individual experiences with regard to the relevance of the study. They also reviewed any material (e.g. participant information sheets) that were seen by prospective participants and determined their suitability. Their feedback was essential in refining the materials to ensure they were clear and understandable to potential participants.

56

#### 57 **Questionnaire**

58

59 To assess the current HCA for LA with food allergies, a structured questionnaire was utilised. 60 The questionnaire is included in Appendix 3. The questionnaire consisted of 21 questions 61 relating to sociodemographic factors, training of participants and the current health care 62 available to LA with food allergies, in the NW. Questions were adapted from a validated 63 questionnaire developed by Khaleva et al. 2020, who conducted a similar study looking at the 64 challenges experienced by HCPs when providing care for adolescents and young adults with 65 allergies, their current transition practices and access to specific healthcare resources. To 66 account for the specific context of the NW region and the unique challenges faced by LA with 67 food allergies, changes were made to the questionnaire. A mixture of close-ended, open-68 ended and Likert scale questions. A pilot study (n=5) was conducted prior to data collection, 69 to ensure suitability and effectiveness of the research. Following this, a few changes were 70 made to the questionnaire. Where participants where asked about transition resources and 71 the age in which transition care starts, the number of responses were increased to capture a 72 broader range of responses that may have existed across different health services.

- 73 Additionally, one question in relation to the responsibility of transition care was considered to
- 54 be ambiguous and was therefore revised before it was included in the final questionnaire.
- 75

# 76 **Recruitment**

77

HCP who assist in the care of LA with food allergies were recruited. Effective care of LA with
 FA requires a multi-disciplinary approach and therefore a range of HCPs were recruited,
 including GPs, allergy specialists, nurses and dietitians. All HCP were recruited from NW
 England – a area with high levels of socioeconomic deprivation.

82

83 In order to target HCPs, a letter of invitation for the study was circulated by local hospitals (i.e. 84 East Lancashire Hospitals NHS Trust, Liverpool University Hospitals NHS Foundation Trust 85 and Mersey Care NHS Foundation Trust). The letter included a link which directed interested 86 participants to the online information sheet, consent form and the HCA questionnaire. 87 Additionally, GP surgeries in the NW were contacted via email/phone to allow for recruitment 88 of GPs. Social media (Facebook, Twitter, LinkedIn) was also used to target HCPs. Specifically, 89 the recruitment poster for his study was shared with members of the food allergic community 90 and researchers with interests in allergy, who circulated this poster through their social media 91 pages. Additionally, NHS trusts (Lancashire Teaching Hospitals NHS Foundation Trust, East 92 Lancashire Hospitals NHS Trust, Liverpool University Hospitals NHS Foundation Trust and 93 Mersey Care NHS Foundation Trust) also shared this poster through social media to boost 94 recruitment of HCPs. All data collection took place between February 2022 and mid-May 2022. 95

# 96 Data and Statistical Analysis

97

Data from all questionnaires was analysed using IBM SPSS Statistics Version 27.0.
 Descriptive statistics was conducted on all demographic information from section one. Chi Squared analysis was conducted on training and attitudes of different HCPs in relation to HCA.

# 102 **5.3.** <u>Results</u>

103

# 104 Participant Demographics105

106  $\,$  A total of 42 questionnaires were completed by HCP who had worked with or currently work

- 107 with 18-25year olds with one/more existing food allergies. All participants were recruited from
- 108 NW (Blackpool (n=3), Chester (n=1), Blackburn with Darwen (n=16), Bolton (n=1), Preston
- 109 (n=6), Liverpool (n=6), Lancaster (n=3), Leeds (n=2) and Manchester (n=4) (Table 5.1).

- 110 **Table 5.1.** Demographic Characteristics for healthcare professionals treating 18-25 year olds
- 111 with one/more existing food allergies (n=42)

	Frequency (II, %)
Gender	
Male	18 (43)
Female	24 (57)
Age	
20-29	6 (14)
30-39	14 (33)
40-49	14 (33)
50-59	7 (17)
60+	1 (2)
Current Profession	
GP	23 (55)
Nurse	7 (17)
Dietitian	6 (14)
Health Care Assistant	6 (14)
Place of Work	
Primary Care	27 (64)
Secondary Care	9 (21)
Tertiary Care	7 (17)
Private Practice	3 (7)
Area of Work	
City	19 (45)
Town	25 (60)
Countryside	8 (19)
Village	10 (24)

#### Frequency (n. %)

# 112 **Table 5.1.** Continued

Specialist Field		
Primary Care	20 (48)	
Paediatrics	4 (10)	
Adult Medicine	5 (12)	
Allergy	7 (17)	
N/A – I do not specialise in any field	5 (12)	
Age Range Covered		
All ages	27 (64)	
0-14	2 (5)	
15-17	6 (14)	
18-24	13 (31)	
25+	9 (21)	
Other	2 (5)	
Years current workplace has treated 18-25yrs with FA		
0-5	19 (45)	
6-10	12 (29)	
11-20	7 (17)	
20+	4 (10)	
Patients 18-25yrs with FA seen in the last year		
0-5	23 (55)	
6-10	7 (17)	
11-15	5 (12)	
16-20	1 (2)	
21-25	3 (7)	
26+	3 (7)	

#### Frequency (n, %)

# 113 **5.3.2.** Training

114

115 Majority of HCP did not receive any specific training for 18-25year olds with food allergies 116 (n=32, 76%). Only few participants reported receiving training for this group (n=6, 14%) (Fig 117 5.1), with Table 5.2 providing details. Chi Squared ( $\chi^2$ ) analysis revealed no significant different between the different types of HCP in this study and training received ( $\chi^2(6) = 9.373$ , 118 p = 0.154). Health care assistants were the only group where no individuals had received any 119 120 training. Despite minimal training amongst participants, most HCP did report some level of 121 confidence when treating 18-25 year olds with food allergies – somewhat confident (n = 16, 122 38%), fairly confident (n=9, 21%) and completely confident (n=3, 7%). 19% of HCP reported 123 no confidence when providing advice/treatment for this age group, with most being GPs (Fig. 124 5.2). However, Chi Squared ( $\chi^2$ ) analysis highlighted no significant differences between all 125 types of HCP and level of confidence in providing specific advice/treatment for LA with food allergies ( $\chi^2(9) = 13.003$ , p = 0.162). 126



Figure 5.1. Training received by healthcare professionals for 18-25year olds with one/moreexisting food allergies (n=42)

#### 145 **Table 5.2.** Specific training as reported by healthcare professionals for 18-25years with

146 one/more existing food allergies (n=6)

#### TRAINING BY HEATHCARE PROFESSIONALS FOR 18-25 YEARS WITH FOOD ALLERGIES

'Attended lectures/patient briefings at conferences regarding adolescence transitions.'

'I have Celiac disease, an egg allergy and sunflower seed anaphylaxis so I can advise to a certain degree.'

'MSc Allergy University of Southampton

'MSc course, annual, national and international conferences and own research.'

'Post grad allergy module accredited by open university. Allergywise for GPs. Learnt by networking and attending national meetings and conferences. None of this specific to 18-25years but considerations for this age group are covered in these activities.'

Training in allergy and immunology for 5 years.'



159 **Figure 5.2.** Healthcare professionals confidence in providing training for 18-25 year olds with

160 one/more existing food allergies (n=42)

#### 161 **Transition Care**

#### 162

163 Participants were also asked regarding transition care of LA with food allergies. The

- 164 responsibility of transferring patients from paediatric to allergy services varied between allergy
- 165 consultants (n=13, 31%), allergy nurses (n=4, 10%), GPs (11, 26%) and the patient 166 themselves (n=11, 26%) (Table 5.3). Most HCP believed transfer of patients should start
- between 15-17 years (n=18, 43) or 10-14 years (n=15, 36%). Despite this, 48% reported no
- 168 transition care existed at their practice. HCP were asked regarding different resources
- 169 available for LA with FA. 57% (n=24) reported no specific resources were available. Of the
- 170  $\,$  resources that were available, E-resources (n=11, 26%) was the most common, followed by
- 171 appointments with practice/service lead (n=7, 17%) and transition guidelines (n=4, 10%)
- 172 (Table 5.3).
- 173
- 174 **Table 5.3.** Transition care for 18-25 year olds with food allergies

	Frequency (n, %)
Who is responsible for deciding when patients should transfer from paediatric to allergy services?	
Allergy Consultant	13 (31)
Allergy Nurse	4 (10)
GP	11 (26)
Patient	8 (19)
Unsure	11 (26)
What age do you believe transition care should begin?	
10-14 years	15 (36)
15-17 years	18 (43)
18-25 years	6 (14)
26+ years	1 (2)
Other	2 (5)
What age does transition care begin at the place in which you work?	
10-14 years	5 (12)
15-17 years	9 (21)
18-25 years	6 (14)
Other	2 (5)
N/A – Currently no transition care	20 (48)

#### 175 **Table 5.3.** Continued

	Frequency (n, %)
How important do you believe transition care is?	
Not important at all	2 (5)
Slightly Important	7 (17)
Important	17 (41)
Fairly Important	6 (14)
Extremely Important	10 (24)
Transition Care Resources	
Designate Phone Hotline	3 (7)
Appointments with designated practice/service lead	7 (17)
E-resources	11 (26)
Workshops	1 (2)
Transition Guidelines	4 (10)
Transition Assessment Tools	1 (2)
N/A – no specific resources	24 (57)

#### 176 <u>Attendance</u>

177

Most HCP reported 18-25year olds with food allergies did not regularly attend appointments for health care. Majority reported irregular attendance by patients would also lead to discharge from their practice (n=31, 74%). The current communication between local allergy clinics and their primary care providers regarding food-allergic patients was also highlighted. Examples of communication include if food allergies patients are ready for discharge or require additional support and discussing protocols and strategies for treatment. Most HCP reported the relationship to be 'poor' (29%) to 'average' (43%) (Table 5.4). **Table 5.4.** Attendance profile of 18-25year olds with food allergies and communication

186 between healthcare providers as reported by healthcare professionals (n=42)

	Frequency (n, %)
Attendance by 18-25year olds as reported by HCP	
0-10%	16 (38)
11-25%	5 (12)
26-50%	3 (7)
51-75%	3 (7)
76-100%	5 (12)
Unsure	10 (24)
Regular attendance leads to patient discharge	
Yes	31 (74)
No	5 (12)
Sometimes	4 (10)
Unsure	2 (5)
Communication between local allergy clinics and primary care providers	
Good	5 (12)
Average	18 (43)
Poor	12 (29)
Very poor	7 (17)

# 187 **5.4. Discussion**

188

189 A large number of HCPs in this study reported no transition care existing at their service, yet 190 believed transition care to be of some importance. Additionally, specific resources to aid in the 191 effective support of transition care for LA with food allergies did exist among health services, 192 but was limited and not consistent among all practices. Previous research highlights how 193 transition care resources can prove extremely beneficial for LA with food allergies undergoing 194 the period of transition (Khaleva et al., 2020; Roberts et al., 2020). Thus, more efforts need to 195 be made across all levels of health care to not only provide greater access of dedicated 196 resources for transition care, but to ensure the use of existing resources. Furthermore,

standardising transition care resources across practices is essential, as this will allow for the
 availability of consistent, comprehensive and quality care that will assist LA with the necessary
 guidance to manage their food allergies independently.

200

201 Majority of HCP had received no specific training in the care of LA with food allergies. For the 202 few that did receive training this included attending courses, lectures and conferences. One 203 participant was reliant on personal experience of food allergies to provide information to 204 patients, while another reported that while they did receive training in food allergies this was 205 broader and not specifically tailored for 18-25year olds. This lack of specific training and 206 support can significantly reduce quality of care and is something already voiced by food-207 allergic participants in phase 1 of this study (see Chapter 3). This will consequently lead 208 individuals to limit use of health care services (NICE, 2011) and is further emphasised through 209 results of this study – HCP reported only a small percentage of food allergic 18-25year olds 210 regularly attending appointments, with irregular attendance causing patients to be discharged. 211 Previous research by Filippidou et al. (2014), which was undertaken in North London also 212 supports the notion that irregular attendance is a common issue within UK health services. It 213 should be noted here that while the study by Filippidou et al. (2014) provides useful insight, 214 caution should be taken when making direct comparisons, as their study focused on a different 215 region with potentially different healthcare dynamics and infrastructure and different 216 socioeconomic factors influencing access and use of the health services.

217

218 The results of this research also revealed the relationship between local allergy clinics and 219 their primary care providers as mainly average or poor. Effective communication between 220 primary care providers and specialist allergy clinics is key in allowing for smooth and 221 successful transition (Protudjer et al, 2019; Khaleva et al, 2020). For example, emotional and 222 psychosocial stress are commonly associated with food allergies (Larson et al., 2020) and 223 many food-allergic participants have already expressed a need to be signposted to expert 224 psychologists and dietitians that can provide developmentally appropriate support for their 225 allergies (See Chapter 3). Healthcare services should therefore consider an integrated 226 approach, whereby information/feedback regarding patients food allergies is easily 227 transferable between clinicians and where needed, input from specialists can be made easily 228 available.

229

Furthermore, in the previous chapters (Chapter 3 and Chapter 4) it was found that access to healthcare services for LA with food allergies was a challenge. Specifically, while primary healthcare services were more easily accessed, secondary/tertiary health services were more difficult. This disparity in accessing healthcare services illustrates a crucial gap in the 234 healthcare system for the management of food allergies. Moreover, despite the presence of 235 some specialised allergy services within the NW, many participants still struggled in accessing 236 this care, suggesting that these services are under significant strain. Perhaps due to 237 increasing pressures on the few services that currently exist to meet the demands of the 238 growing food-allergic community, or even the increased wait times for appointments and/or 239 referrals which many food allergic participants experience, along with the reduced number of 240 allergy specialists that are currently available within the UK (RCP, 2003; Warner et al., 2006; 241 Finlay and Egner, 2010; RCP, 2010; Diwakar et al., 2017; Daniels et al., 2021). This along 242 with the results of this study reinforce the need for a more accessible network of specialised 243 health services to support those with food allergies. Even though primary healthcare is more 244 easily accessible, this may not compensate for the specific care required for food-allergic 245 patients, as many GPs in the UK are under qualified in this field, lacking knowledge and 246 training that is needed to provide adequate support for this group (Daniels et al., 2021). This 247 is further reinforced by the findings from this study, where GPs themselves highlighted little 248 training in providing care for LA with food allergies. There is a need to address the current 249 healthcare infrastructure for patients with food allergies, to ensure that tailored services are 250 available and accessible to meet the needs of this growing population. Improving the 251 capabilities of primary care practitioners and increasing the access to secondary/tertiary 252 services will be an essential component of providing comprehensive and continuous care for 253 LA with food allergies.

254

#### 255 **5.5.** Conclusion

256

257 To our knowledge, this is the first UK study investigating the current transition care for LA with 258 food allergies, from the perspective of the HCP. The findings from this study indicate that HCP 259 are unable to meet the specific needs of LA with food allergies. Lack of resources, training 260 and poor communication between health providers were all barriers mentioned in providing 261 sufficient care for this group. Often inadequate funding, particularly in GP settings, will pose a 262 significant challenge for HCP. This can hinder the implementation of necessary services and 263 training programmes, affecting the delivery of proper care in LA with food allergies (Owen et al., 2019). Greater awareness is therefore needed and collaboration with healthcare 264 265 organisations, key stakeholders and advocacy groups is vital, in an effort to secure funding 266 which will enhance the quality of care for LA with food allergies

- 267
- 268
- 269

- 270 **5.6.** Limitations
- 271

This study provided valuable insights into the current HCA available for LA with food allergies and the challenges faced by HCPs in providing care for this group. It is also important to consider the limitations associated with this study that could impact their generalisability.

275

276 The study sample included only four different types of HCPs – GPs, dietitians, healthcare 277 assistants and nurses. This narrow representation may not fully capture the spectrum of 278 perspectives within the healthcare system as various other HCPs such as, pharmacists, 279 psychologists and allergy specialists, also play a crucial role in the management of food 280 allergies. Including a broader range of HCPs could provide a more comprehensive 281 understanding of the systemic challenges in healthcare access for patients with food allergies. 282 There was also a limited sample size with only 42 HCPs from the NW taking part. This may 283 make it difficult to draw conclusions and generalise the results to the wider population. 284 Additionally, the limited sample size means that the findings may not be representative of all 285 HCPs who manage food allergies. Moreover, there was a reliance on self-reported data and 286 participants may have provided answers which were socially desirable rather than their actual 287 practices or beliefs. This study also focused on solely quantitative data, which may not have 288 fully captured the depth and complexity of the experiences and challenges of HCPs when 289 delivering care for LA with food allergies. Using qualitative methods such as interviews and/or 290 focus groups could provide richer data and insights into the challenges this group face when 291 delivering care for LA with food allergies. Furthermore, this study was conducted specifically 292 in the NW region, which may have unique characteristics in terms of the healthcare provided 293 here and the different socioeconomic factors that could potentially impact HCA and the 294 delivery of healthcare by HCPs. Therefore, the findings may not be directly applicable to other 295 regions in which the healthcare system may differ. Further research should therefore aim to 296 address these limitations by recruiting a larger number of HCPs which also includes 297 representatives of all HCPs working with food-allergic patients. Additionally, a mixed methods 298 approach should be considered to capture a more comprehensive understanding of the 299 current HCA available for LA with food allergies and the challenges HCPs face when delivering 300 care.

301

To further understand these issues, and building upon Chapters 3, 4 and 5 the next chapter – Chapter 6, will explore FC, FA and HCA in LA with food allergies in the NW of England through qualitative focus groups. This approach will allow for a deeper understanding of the lived experiences of LA with food allergies and the challenges they face, offering valuable insights that will complement the quantitative data presented in earlier chapters.

# <u>Chapter 6</u> – Exploring Food Choice, Food Access and Healthcare Access in Late Adolescents (18-25years) with Food Allergies in North West England, through Qualitative Focus Groups

#### 4 6.1. <u>Overview</u>

5

6 The management of food allergies for LA presents a unique set of challenges that are linked 7 with their food choice (FC), food access (FA) and healthcare access (HCA). This research 8 builds on the previous chapters (which primarily employed quantitative methodology) by using 9 a qualitative approach to explore each of these aspects. The unique perspectives and lived 10 experiences of food-allergic patients (FAP), parents/carers (P/C) of children and/or young 11 adults with food allergies and healthcare professionals (HCPs) with previous experience in 12 providing care for 18-25 year olds with food allergies are all considered. Exploring and 13 understanding these factors are crucial in developing strategies that can support LA with food 14 allergies – a group who face unique challenges as they attempt to navigate their allergies in 15 the critical period of transition from LA to adulthood.

16

In this study, we include P/C of children with food allergies of any age rather than those only in LA. Parents play a key role in providing care throughout their child's life and their influence will likely continue into LA. The decision to focus on a broader age range was to capture a more comprehensive view of the parental role. The management of food allergies at different stages can offer insights into the long-term implications of food allergies, with parents able to highlight any changes in FC, FA and HCA as their children grow older.

23

24 Through qualitative focus groups, this current chapter delved deeper into the current FC, FA 25 and HCA of LA with food allergies. The qualitative insights gained through this chapter 26 complement the quantitative data from the previous chapters, providing a richer understanding 27 of how these factors impact the everyday lives of LA with food allergies. Thematic analysis 28 was employed as means of analysing the data and the results were then discussed in relation 29 to the emergence of the overarching themes and subthemes for FC, FA and HCA. Based on 30 the findings of the studies in this chapter, interventions informed by existing literature were 31 discussed, as potential means of improving the current FCs, FA and HCA of LA with food 32 allergies.

- 33
- 34
- 35

#### 36 6.2. <u>Methodology</u>

37

#### 38 Participants

39

40 Three different groups of participants took part in the focus group sessions. Participant criteria 41 for the first group of participants included individuals between the ages of 18 and 25 years who 42 were clinically diagnosed with one/more existing food allergies. Those individuals who were 43 unable to provide confirmation of clinical diagnosis or who were self-diagnosed, were excluded 44 from the study. Similarly, any individuals suffering from any additional health conditions that 45 would impact FC, FA and HCA were also excluded. The second group of participants included P/C of a child or late adolescent with one/more existing food allergies. The final group of 46 47 participants included HCPs who had experience in providing care for LA with food allergies. 48 Additional requirements for all groups of participants was to reside in NW England and to 49 fluently speak and understand English. Any individuals not meeting these criteria were not 50 included within the final sample.

51

# 52 Focus Group Topic Guide Development

53

Topic guides (Appendix 4) were created and utilised in each of the focus groups to prompt discussion. The topic guide was based on a similar study (Sommer et al., 2014) and adapted to suit the purpose of this study. These questions were simply used to guide the focus group sessions with the development of the conversation being largely driven by the participants themselves. Therefore removing any preconceptions and allowing for unexpected perspectives and themes to emerge.

60

# 61 Mock Focus Group

62

Prior to actual data collection, a mock focus group was also conducted. This was overseen by colleagues at the University of Central Lancashire. The purpose of the mock focus group session was to ensure that delivery of the focus groups by the lead researcher was sound, having not engaged in this methodology before. Following the session, feedback was provided and areas of strength and weakness were identified which were then considered for the main focus groups.

69

#### 70 Recruitment

71 Food allergic participants who took part in the initial food selection questionnaire from Phase 72 1 of this study (questionnaires), were invited to take part in the focus groups. For parents of 73 food-allergic individuals, the main recruitment took place by asking food-allergic participants 74 if their parents would be interested in participating. For HCPs, four NHS trusts in the NW 75 region (Lancashire Teaching Hospitals NHS Foundation Trust, East Lancashire Hospitals 76 NHS Trust, Liverpool University Hospitals NHS Foundation Trust and Mersey Care NHS 77 Foundation Trust) shared details of the focus group study to relevant practitioners. A 78 recruitment poster was also created and shared via social media (Facebook, Twitter and 79 LinkedIn) through food allergy community groups and NHS pages as means of boosting 80 recruitment for all three groups of participants.

81

#### 82 **Ethical Considerations**

83

84 Ethical approval was obtained from the National Health Service Research Ethics Committee 85 (NHS REC) (REC Reference: 21/EE/0285, Project ID: 303224) and the University of Central Lancashire's (UCLan) HEALTH ethics committee, prior to data collection. Following the initial 86 87 ethical approval, it was decided to use MS Forms to obtain demographic information from the 88 participants. This required minor amendments to the ethics and a reapproval process was 89 undertaken. Following final approval, participants were then provided with a participant 90 information sheet, which included detailed information regarding the study. Three different 91 participant information sheets were created to suit the demographics and needs of each 92 participant group. The participant information sheet was accessible online via a secure link 93 and detailed the purpose and nature of the study, potential risks and benefits of the research 94 and additionally emphasised participant confidentiality and the right to withdraw at any point. 95 This ensured all participants had all relevant information at hand, allowing them to decide if 96 they would like to participate. Once participants had reviewed the participant information 97 sheet, informed consent was obtained from all those who expressed interest in the study, 98 through an online consent form. Only after consent was given, participants were able to take 99 part in the focus groups.

100

#### 101 Focus Groups

102

All data collection took place between mid-November 2023 and concluded in early December
 2023. Focus groups were used to gain a greater, more detailed understanding of the impact
 of food allergies on FC and diet as well as food and HCA in LA with food allergies. Previous
 studies looking at similar research areas have also employed focus group methodology

107 (Sommer et al., 2014; Moen et al., 2019; Memauri et al., 2022). Furthermore, this qualitative 108 technique allowed for participants to engage in a stimulating discussion while in a relaxed 109 group setting, encouraging them to explore the relevant research questions. This method 110 therefore drew upon the thoughts and behaviours of the individuals though group interaction. 111 Consequently, providing a holistic viewpoint from participants, otherwise not obtained through 112 individual interviews or quantitative methods alone. This beneficial nature of using qualitative 113 focus groups has been highlighted in previous literature (Nyumba et al., 2018; Gundumogula, 114 2022).

115

Each participant was initially asked to complete an MS Form which asked them to provide socio-demographic information, including age, gender and ethnicity. In addition to this, foodallergic patients were asked to provide details of their allergies and current education status. Likewise, P/C were asked to also provide this information for their child. HCPs were asked to additionally include details of their profession.

121

A total of four focus groups took place, each with a maximum of 10 participants. The first two sessions included food-allergic participants and explored their FC, FA and HCA in relation to their food allergies. The third session considered the perspective of the parent and explored diet and HCA in relation to their child's food allergies. The fourth focus group included HCPs who had previous or current experience of delivering care for food-allergic patients between 18-25years. This session focused on exploring facilitators and barriers experienced by HCPs in providing care for LA with food allergies.

129

130 Each of the focus group sessions took place online via MS Teams, as this was most 131 convenient for all participants. The focus groups lasted for approximately one hour. To begin 132 the focus groups, an overall outline of the research project and the purpose of the focus group 133 was provided to participants. The confidential nature of the discussion and the right to leave 134 at any point during the session was also emphasised to participants. With all focus groups 135 being conducted virtually, participants were encouraged to turn on their cameras to emulate 136 an 'in person' focus group setting. As the moderator, I actively and carefully listened to each 137 of the participants. I also encouraged them where needed and this was achieved both verbally 138 and non-verbally. In each of the focus group sessions, a note-taker was also present. Their 139 role consisted of taking relevant notes and recording the session. All participants received a 140 £25 voucher via email to thank them for their time, following completion of the focus group 141 session. This was in accordance with NIHR payment for participants and public contributors 142 in research (NIHR, 2022). Each of the focus group sessions were transcribed using MS

143 Teams. Immediately after the sessions, transcriptions were checked against the original audio144 recordings to ensure accuracy.

145

#### 146Data Analysis

147

#### 148 Thematic Analysis

149

150 The analytical approach of thematic analysis was chosen for this study. Thematic analysis is 151 a widely used qualitative analytic method whose purpose is to identify, analyse, organise, 152 describe and report themes within data (Braun and Clarke, 2006; Braun and Clarke, 2022). 153 The analysis of this study was guided by Braun and Clarkes six step framework for thematic 154 analysis (Figure 6.1). Step one is to familiarise yourself with the data. Upon completion of each 155 of the focus group sessions, transcribed data was read and re-read several times. Through 156 this process initial concepts, themes and impressions were noted. The second phase involved 157 producing initial codes from the data. This was achieved through the use of the software NVivo 158 (version 14). All transcribed data was input into the NVivo database and organised into 159 meaningful groups i.e. coded. Each transcribed document was systematically worked through, 160 without overlooking any of the data. Both deductive coding (themes are based on pre-existing 161 theories or concepts) and inductive coding (themes emerge from the data itself, without pre-162 defined structures) are used in focus group data analysis (Braun and Clarke, 2006; Braun and 163 Clarke, 2022). For this research, a deductive coding approach was initially used based on 164 themes outlined in existing literature. This provided an initial framework for the analysis of the 165 data. Specifically, the data was first mapped onto three pre-defined domains relevant to the 166 study – Food Choice, Food Access and Healthcare Access. This deductive approach ensured 167 that the analysis of the data aligned with already established theories and concepts. However, 168 through the process of coding new themes also emerged and an inductive coding approach 169 was also considered at this point, as certain parts of the data did not neatly fit into the pre-170 defined themes. This inductive analysis was applied after the data was already mapped onto 171 the three domains, allowing for the identification of additional themes that were not initially 172 considered. This combination of both deductive and inductive approaches further enriched the 173 overall analysis of the data, thus providing a more comprehensive understanding. The 174 purpose of this phase was to also reduce the data into a more manageable format. This led 175 to the third phase - searching for themes, where the initial codes were placed into potential 176 themes that captured something interesting or significant in relation to the research questions. 177 While going through this process, any codes that did not fit into a theme were temporarily 178 labelled as a 'miscellaneous' theme. At this stage, a preliminary thematic map was created

179 highlighting the emergence of initial themes. The fourth phase looked at reviewing these initial 180 themes and refining them to produce overarching themes and subthemes. This involved the 181 re-reading of all transcribed data to ensure nothing was missed. There was potential for bias 182 to occur through the coding process. To overcome this, the data from the mock focus group 183 was coded to practice and refine the coding process. Additional reflective practice was 184 regularly employed throughout the coding process to recognise and address any influences 185 from my decisions. In phase 5, the existing themes were clearly defined and further refined to 186 capture the 'essence' of the theme. This was achieved through a short summary which 187 highlighted the significance of each theme and why. A final thematic map was produced at 188 this stage. The final stage of the analysis as outlined by Braun and Clarke (2006; 2022), was 189 the write-up of the report. This provides a narrative to the reader of the main themes that 190 developed through the qualitative focus groups, in relation to the key research questions.



- 191 **Figure 6.1.** Braun and Clarkes (2006; 2022) six step framework to Thematic Analysis
- 192

# 193 Statistical Analysis

- 194 IBM SPSS Version 29.0 was used to conduct all statistical analysis. All categorical variables
   195 were expressed as numbers and percentages.
- 196

# 197 6.3. <u>Results</u>

198

# 199 6.3.1. Food Allergic Participants

200

# 201 Participant Demographics

202

203 A total of four focus groups took place. The first two focus groups included food-allergic 204 patients. Each focus group consisted of 10 food allergic participants. Table 6.1 highlights their 205 demographic information. Three quarters of participants were males, with only 5 of the 20 206 being female. All participants were between the ages of 18-25 years, with most being 19 years 207 of age (n=7, 35%). Majority of the group were Black British (n=13, 65%). All participants lived 208 in urban areas. All participants were also studying at university and were students living on 209 campus. Most participants had multiple food allergies (n=18, 90%), with only 2 participants 210 (10%) reporting suffering from a single allergy. All participants also underwent a clinical 211 diagnosis to confirm their allergy (Table 6.1).

- 212
- 213

Table 6.1. Demographic characteristics for 18-25year olds with food allergies (n=20)

	FAP (n=20)
Gender (n,%)	
Male	15 (75)
Female	5 (25)
Age (n,%)	
18	4 (20)
19	7 (35)
20	2 (10)
21	2 (10)
22	0 (0)
23	3 (15)
24	0 (0)
25	2 (10)

# **Table 6.1.** Continued

# 

	FAP (n=20)
Ethnic Background (n, %)	
White British	2 (10)
Black: British African	10 (50)
Black: British Caribbean	3 (15)
Asian British	1 (5)
Chinese	1 (5)
Mixed	3 (15)
Living Area (n, %)	
Urban	20 (100)
Student Status (n, %)	
Student (Living on Campus)	20 (100)
Education Status (n, %)	
Foundation Year	2 (10)
Undergraduate	16 (80)
Postgraduate	2 (10)
Type of Food Allergy (n, %)	
Single	2 (10)
Multiple	18 (90)
Food Causing Allergy (n, %)	
Peanut	7 (35)
Tree Nuts	3 (15)
Fish	4 (20)
Shellfish	2 (10)
Milk	14 (70)
Egg	7 (35)
Soy	10 (50)
Wheat Diagnosis (n %)	6 (30)
Skin Prick Test	20 (100)
Blood Test	13 (65)
Food Elimination Diet	6 (30)
	0 (00)

# 1 Thematic Maps

2

Following analysis of the data through the software NVivo, thematic maps for each focus group were generated. For food-allergic patients, a total of three main domains (FC, FA and HCA) and eight overarching themes were generated from the two focus group discussions. To maintain anonymity, participant details are indicated in brackets – this follows for each section in this chapter).

8



- 9
- 10 **Figure 6.2.** Thematic map for food-allergic patients
- 11
- 12

# 13 FOOD CHOICE

14

# 15 Theme 1: The Social Challenges in Food Choice

16 In this study several LA from both focus groups reported how their food allergies did present

17 significant challenges, impacting their ability to fully engage in social activities. However, while

18 it was challenging to navigate their food allergy in a social setting, for many this did not stop

them from going out. Rather, to manage the situation and reduce the risk of an allergic reaction, the easiest and safest option was simply to just not eat at all. This decision was likely due to anxiety over potential exposure to allergens and the perceived lack of understanding from peers with regard to the severity of their condition.

23

'Yeah I mean I do take part in social activities, you know I will go but it doesn't mean
I'll eat. Yeah there'll be periods where I'll be hungry but its worth it. At least this way I can
enjoy some time with my friends.' (FAP 2, Male, Milk Allergy)

27

28 Some participants also mentioned that the challenge in eating out when engaging in social 29 activities, was due to the lack of allergen information and limited staff knowledge. This 30 uncertainty of whether a meal was safe to eat often led to increased anxiety and fuelled the 31 decision to abstain from eating, further liming their FC. Additionally, participants felt that many 32 people failed to understand the serious nature of their food allergy and were unable to safely 33 accommodate their dietary needs, which further restricted their FC. There was a sense of 34 feeling misunderstood and this was a common theme among participants, who felt that friends 35 and staff did not fully appreciate the risks involved with their food allergies.

36

37 'Sometimes I just don't feel comfortable going to a restaurant because well not 38 everything is clear on the menu and the staff are not always helpful. They think I'm asking too 39 many questions and that I'm fussy about my food. Sometimes if I do end up going out though, 40 I'll just order drinks. Maybe there's one thing on the menu which I know for definite is okay for 41 me so then I'll stick with that. But to be honest I can't trust it so most times I don't bother 42 eating.' (FAP 4, Female, Wheat, Soy and Egg Allergy)

43

One participant with a milk allergy also reported that it was easier to not eat when going out, as the fear of having a reaction, which would physically show on the face, was too embarrassing. This fear of public judgement illustrates the emotional burden and social stigma associated with food allergies. The potential for physical display of their allergic reaction was a source of anxiety, directly influencing social behaviour in this group.

49

<sup>50</sup> 'I do tend to stay indoors most of the time but sometimes I will go out, but well I have <sup>51</sup> a milk allergy, so if sometimes by accident I take milk if it is hidden and I don't know it shows <sup>52</sup> the reaction on my skin. So eating outside is kind of embarrassing, so I just tend to avoid <sup>53</sup> eating really when I'm out. It's just easier that way.' (FAP 12, Male, Milk, Egg and Egg Allergy) <sup>54</sup> Food allergic participants also mentioned that navigating food allergies in a social environment was dependent on the level of association with that person. All participants agreed that eating was easier with family as they were more understanding and supportive. This supportive environment reduced the anxiety around eating and also led to improved dietary habits, as family members often went out of their way to prepare meals which met their specific dietary needs.

61

62 'My family have been really supportive. Whenever we get together they make sure that
63 my food is not prepared with any of my allergies, so I think at home I'm really more in comfort
64 of my allergy. I don't have to worry at all really.' (FAP 16, Male, Shellfish, Milk, Soy Allergy)

65 'When its just me I'll just eat the same few things really. But when I go to my parents, 66 they really go all out. I definitely feel like my diet is better when I eat at home.' ((FAP 2, Male, 67 Milk Allergy) ' (FAP 4, Female, Wheat, Soy and Egg Allergy)

68

In contrast, eating with friends was considered more challenging. Participants frequently described feeling like a burden or being perceived as overly demanding and this discomfort led to the same strategy of avoiding food when in the company of friends. This highlights the emotional toll of managing food allergies in social settings, where individuals will often feel alienated or pressured to conform. These different experiences shared by participants with friends and with family indicate the significant impact that social relationships have on FC.

75

'Some of my friends don't really understand my food allergy. So it's only me in my
group and sometimes it's like I'm a burden to them or they feel like I'm requesting special
treatment.' (FAP 13, Male, Milk and Soy Allergy)

79

Overall, the social challenges in FC were a significant aspect in the lives of food-allergic individuals. The need to balance social activities with the risk of allergic reactions led many to adopt strategies of simply not eating in social settings. Although this was effective in managing their food allergies, it also limited their social experiences leading to feelings of isolation. The contrasting experiences with friends vs family emphasise how social support plays an essential role in assisting individuals with food allergies navigate their dietary choices.

86

# 87 Theme 2: The Impact of the University Environment on Food Choice

The impact of the university environment on FC was also discussed. A common theme which emerged was the limited number of safe food options at the university, that were suitable for those with food allergies. This led to many food allergic participants avoiding eating on campus.

- 92 'Practically all the foods around campus have milk and egg and that's some of my
  93 allergies so I just have to avoid eating there.' (FAP 7, Male, Soy, Peanut and Tree Nut Allergy)
  94
- 95 A large number of participants additionally mentioned that the limited availability of suitable 96 foods on the university campus led to them exploring other options. One frequent response 97 discussed by participants, involved going outside of the campus environment to purchase 98 foods. Many participants agreed that while this increased the number of options they had, 99 these foods were more expensive and the limited time due to the busy nature of the university 100 schedule made it difficult. This often led participants to rely on fast foods which were 101 considered to be cheaper or in some cases, they would go through periods of irregular eating. 102 This highlights a crucial issue – the intersection of financial constraints and dietary needs, 103 forcing students to compromise their nutritional well-being due to limited resources and time.
- 104

105 'And even though there are actually more options outside of campus, I find that it is
106 quite expensive and it just takes more time to get it.' (FAP 6, Male, Soy and Egg Allergy)

107

108 'Sometimes I won't eat too, because it does get quite expensive then. I've had like
109 periods where I won't eat because I can't afford it.' (FAP 8, Female, Peanut and Milk Allergy)
110

111 The limited number of suitable foods offered on campus caused many participants to take a 112 more proactive approach. This involved planning ahead, packing suitable foods and cooking 113 their own meals. This highlights the increased level of vigilance and consideration needed for 114 those with food allergies, to maintain a safe and balanced diet in an environment that is not 115 conducive to their dietary needs. While this allowed participants to gain more control in their 116 FCs, this was more challenging and not always possible. Again the cost of buying suitable 117 ingredients which were more expensive and the time needed for preparation, especially during 118 exam weeks and deadlines, were two of the main barriers experienced by food allergic 119 participants at university. This approach further emphasises the additional time, energy and 120 stress students with food allergies must undergo, to manage their dietary needs which could 121 potentially detract from their academic and social experiences. Some participants also 122 mentioned they had limited knowledge of cooking and this led to a repetitive diet.

123

124 'I always try to make sure I cook something from home before I leave but it means I
125 have to wake up very early to cook my food so this is a challenge and sometimes I dont have
126 enough time because of my studies so then I just don't eat.' (FAP 13, Male, Milk and Soy
127 Allergy)

128

Sometimes there is no time to source the foods I need. And I don't always have time
to cook everyday so this is challenging. I also don't really know how to cook many foods. I
mean I'm still learning but it does mean I eat the same stuff all the time.' (FAP 7, Male, Soy,

- 132 Peanut and Tree Nut Allergy)
- 133

134 Overall the university environment significantly impacted FC in students with food allergies. 135 The limited availability of safe foods on campus and the additional financial and time 136 constraints experienced by participants were some of the challenges mentioned. This forced 137 participants to adopt certain strategies that although were effective in managing their allergies, 138 came at the cost of convenience, nutritional quality and overall well-being. Clearly, there is a 139 need for greater support and accommodation within the university setting, as students with 140 food allergies navigate the pressures of academic life and the management of their food 141 allergy.

142

#### 143 Theme 3: 'Labelling Makes It Hard'

144 Food labelling is an important tool allowing those with food allergies to make safe and informed 145 choices (Fiocchi et al., 2021). All food allergic participants in this study mentioned difficulty in 146 interpreting food labels. This caused them to avoid many foods, which in turn limited their FC. 147 The complexity and inconsistency of labelling practices left participants feeling confused and 148 led to mistrust of food labels, forcing many to avoid certain food altogether rather than risk an 149 allergic reaction. Participants also highlighted the stress of constantly scrutinising food labels, 150 which added an extra layer of difficulty in managing their food allergy. This indicates both the 151 emotional and psychological toll of unclear food labelling, leaving many with food allergies to 152 adopt restrictive eating habits out of fear of an allergic reaction

153

154 'And plus the labelling really confuses me. Sometimes it says its got no peanuts in but
155 then it will also say that it might have this or it might have that and then it just gets really
156 frustrating and it stresses me out. I don't really trust a lot of the foods now.' (FAP 9, Male, Soy,
157 Mil, Peanut and Tree Nut Allergy)

158

159 'It's very necessary to go through the labels to know if what your eating is right for your 160 food allergy, but it's really hard. The labelling does confuse me and I've had some bad 161 experiences, so now I'll just avoid the food when I don't understand.' (FAP 9, Male, Soy, Mil, 162 Peanut and Tree Nut Allergy)

163 In some instances, participants also mentioned that the act of reading food labels was too time 164 consuming and on many occasions they would risk purchasing foods hoping that no reaction would follow. This was more common in familiar foods. This behaviour highlights the difficult
balance that individuals with food allergies must maintain between exercising caution and
managing the practicalities of their daily lives.

168

169 'Sometimes, when the time is too less I'll just still get the food, and hopefully there's
170 no reaction. If it's something I've had before then I won't bother reading the food labels. I've
171 been okay so far.' (FAP 6, Male, Soy and Egg Allergy)

172

Participants faced significant challenges with food labelling and this in turn impacted their FCs, leading to increased caution, increased anxiety and the implementation of restrictive diets. The ambiguity and inconsistency of labelling practices created a sense of mistrust in participants, forcing them to avoid food they may have otherwise consumed. These challenges emphasise the need for clearer and more consistent labelling practices, which can better support those with food allergies.

179

# 180 FOOD ACCESS

181

#### 182 Theme 4: Barriers in Accessing Allergen Free Foods

Allergen free foods (AFF) offer a safe and suitable means of enjoying a variety of food options,
while avoiding necessary allergens for those with food allergies (Frame et al., 2022; PashaRobinson, 2023). Despite this, the cost and limited availability of AFF presented significant
challenges for food allergic participants in this study.

187

Almost all participants in this study felt that purchasing AFF was too expensive and this was particularly a struggle due to already existing costs associated with university. Some participants mentioned how they would lower food intake in order to manage their finances, while other's would keep a look out for offers and purchase AFF in bulk. Individuals with food allergy are burdened with significant financial stress owing to the high cost of managing their dietary needs while balancing daily living expenses.

194

195 'Since I moved away for uni it's been more difficult. The expenses, there is a lot and
196 sometimes I can't afford AFF all the time. It can get really frustrating, I mean why do they have
197 to be more expensive. It's actually not fair because well it's not like we chose for the food
198 allergy.' (FAP 10, Female, Milk, Soy and Wheat Allergy)

199 In addition to the high cost of AFF, many participants felt that these foods were not as easily

200 obtainable due to limited availability and stock in supermarkets and convenience stores, which

201 further complicated access. This often led to feelings of frustration and anxiety among 202 participants, with one respondent mentioning periods of depression due to the lack of 203 accessing sufficient foods. This emphasises the impact of these barriers of accessing AFF on 204 participants mental health, where often the struggle to maintain a safe and balanced diet can 205 lead to feelings of helplessness and isolation. One option exercised by participants was to 206 purchase these foods online, however this came with added costs. While a wider selection of 207 products were available, the additional cost of delivery made this option less practical for those 208 students already facing financial difficulties. In those with food allergies, even simple solutions 209 can increase the burden as opposed to alleviating it.

210

211 'It's just quite limited you know, it's not like it can be found in virtually every place which 212 is frustrating. It takes me longer to just do my shopping and I'm not driving yet so I have to 213 wait on someone to take me, its frustrating to be honest. It does stress me out at times and 214 sometimes when I don't have enough food I feel depressed sometimes. It's hard.' (FAP 13, 215 Male, Milk and Soy Allergy)

- 216
- 217

'There are more options for AFF online but it can actually add up because the delivery 218 charge is super expensive.' (FAP 4, Female, Wheat, Soy and Egg Allergy)

219

220 Overall, the barriers of accessing AFF (cost and limited availability) clearly impacted 221 participants ability to effectively manage their food allergy. While strategies were employed to 222 overcome this, such as accessing AFF online, this was compounded by financial sacrifices 223 and increased stress. These barriers were linked with an increased emotional and 224 psychological toll which highlights the need for more accessible options of AFF, especially for 225 students who are managing the financial demands of academia alongside their food allergy.

226

#### 227 Theme 5: 'Allergen Free Doesn't Mean It's Safe'

228 Through the focus group discussion, participants also discussed how in instances where AFF 229 were accessible, the food still caused an allergic reaction. This led to distrust in certain food 230 products by participants and also deterred participants from purchasing these foods in the 231 future. In addition to this, the constant fear of being exposed to an allergic reaction, left 232 participants feeling anxious and this also led to a reduced quality of life. The inconsistency of 233 what was promised on the label and the actual safety of the product itself reduced the 234 confidence of participants who were reliant on these foods to manage their food allergies. 235 There was also an emotional toll associated with these experiences, further increasing the 236 anxiety in food allergic individuals lives. The unpredictability of AFF caused participants to

remain more vigilant concerning these foods, which contributed to a reduced sense of safetyin their dietary choices and increased stress in their daily lives.

- You know its like you think that you have to be careful with all the foods except for the
  allergen free ones, but actually there is still a fear of accidental exposure or an allergic reaction
  with these too and this makes me anxious all the time and it impacts me everyday.' FAP 16,
  Male, Shellfish, Milk, Soy Allergy)
- 243

The unpredictability in the safety of AFF led to increased anxiety and mistrust in these products by food-allergic participants, which impacted the quality of their daily life. Participants were forced to increase vigilance even surrounding foods that were supposed to be safe, which contributed to ongoing stress and limited FC. There is a need for better safety assurances in the production and the labelling of AFF, in the hopes of increasing trust and reducing anxiety amongst the food allergic community and ultimately their FC.

250

#### 251 Theme 6: 'My Diet Is Affected.'

- 252 Restricted FC and limited access to appropriate foods will have an impact on dietary intake of 253 those with food allergy. One common theme which also emerged from the focus group 254 discussion, was how reduced FC, the struggle of accessing food and finding suitable 255 alternatives made it difficult for participants to maintain a well-balanced diet. Participants 256 additionally felt that the quality of AFF was poor. Consequently, this also negatively impacted 257 participants health. Participants mentioned that their diets were compromised due to avoiding 258 a wide range of foods in order to prevent allergic reactions. This led to inadequate nutrient 259 intake and unintentional weight loss. These challenges highlight the real-world consequences 260 related to limited FC, where for those with food allergies, the need to prioritise safety can lead 261 to poor dietary choices. The quality of AFF was also expressed as a concern. Although AFF 262 are fortified with certain nutrients, they also contain high levels of salt, sugar and fat. This 263 raises concerns about the long-term health implications of relying on such foods which are 264 supposed to be a safe option for those with food allergies. It is unsurprising therefore that 265 participants felt they struggled in maintaining a balanced diet.
- 266
- 267 'I just have to avoid lots of foods but my weight has dropped a lot cos my diet isn't
  268 really that great. So yes I would say that my nutrition has been affected.' (FAP 8, Female,
  269 Peanut and Milk Allergy)
- 270

271 'Yeah and for me I do feel like even when I have AFF and that's supposed to help my
272 diet, the quality is still not that great. We were checking that time and the salt and even the

sugar was a lot more, like almost double so that worried me.' (FAP 6, Male, Soy and EggAllergy)

275

The restricted FCs and poor quality of AFF significantly impacted the dietary intake and overall health of participants with food allergies. There is an increased challenge in obtaining safe, nutritious foods that are of high quality for this group, which will inevitably impact health. Better access to more nutritionally balanced and safe food alternatives is therefore needed for individuals with food allergies, without which they will continue to struggle in maintaining a well-balanced diet that could have long-term health implications.

282

# 283 HEALTHCARE ACCESS

284

#### 285 Theme 7: Challenges in Accessing Adequate Healthcare – GPs and Specialist Care

286 Accessing good quality health care is crucial for those with food allergies. In the UK majority 287 of allergy care is delivered by GPs (Diwakar et al., 2017). In this study, some participants 288 mentioned how accessing their GP was relatively easy. In some cases (for example during 289 emergencies) participants did indicate a struggle in obtaining an appointment with their GP. 290 However, on these occasions participants also mentioned being able to have a consultation 291 over the phone or through virtual means, which was particularly helpful. This suggests that 292 where GPs are more knowledgeable about food allergies and they are more accessible, they 293 can play a key role in supporting patients with food allergies.

294

295 'I think that I have necessary care that I need for my food allergy. I think from the 296 community pharmacy, I'm able to get drugs that I require in case of an emergency and then 297 also my GP has helped me too. He's doing a great job in making sure that I am able to manage 298 my condition very well. He's told me about going to some support groups and that's helped 299 me cos its just not me you know.' (FAP 4, Female, Wheat, Soy and Egg Allergy)

300

301 'I've found it quite easy to access my GP actually, because well I also deal with mine
302 too, you know, online. So we just talk and sometimes I call him on the phone to tell him if I
303 have any complications and then we tend to talk about it virtually.' FAP 10, Female, Milk, Soy
304 and Wheat Allergy)

305

306 While some participants felt their GP provided sufficient support, other's did not find it 307 adequate. Participants reported bad experiences following consultations with their GP, which 308 'put them off' as quoted by one participant. Additionally, many participants also felt their GP had a lack of knowledge in food allergies and were not able to provide suitable support. The inability to access appropriate care from primary care physicians, often deterred many participants from meeting with their GP again, with the alternative either going online or simply attempting to manage the food allergy themselves.

313

314 'They cant really help me that much because it feels like they don't really know that 315 much, it's actually quite scary. I feel like there isn't any point going to them anymore cos they 316 don't really provide solutions.' (FAP 9, Male, Soy, Milk, Peanut and Tree Nut Allergy)

317

The inconsistency in GP care highlights a crucial gap in the reliability of primary care for those with food allergies. Not only will the quality of care that patients receive be affected but also there are serious implications for their overall health and well-being.

321

322 The challenges did not stop at primary care. Participants also encountered significant barriers 323 when attempting to access specialist allergy care. Almost all participants agreed that this was 324 difficult to access, with only one participant sharing their previous positive experience. Three 325 main barriers as mentioned by participants in accessing specialist allergy care emerged 326 through the discussion. These included cost, distance and increased waiting time for 327 appointments. These barriers not only reduced access to necessary specialist care but also 328 had profound emotional and psychological effects on the participants, with many expressing 329 feelings of stress, frustration, annoyance and helplessness.

330

331 'OK, for me it's quite difficult as, the hospital is quite far from where I live and so 332 sometimes I have to go up and go down the stairs it makes it difficult to meet up with the 333 appointment 'cause of the distance which can get quite annoying and then trying to get 334 transportation because I don't drive and it's quite expensive, so this makes it quite difficult 335 really. Sometimes I might not even go because getting there, it's too far and the transport well 336 sometimes it is quite difficult financially.' (FAP 16, Male, Shellfish, Milk, Soy Allergy)

337

338 'I get frustrated and stressed quite a lot. The appointments take too long so it's difficult 339 in the period in between. And then when you do get it after that it takes ages to get another 340 appointment so I just don't bother sometimes cos it means I'll have to take time out from Uni 341 and I've already missed so many weeks, especially at the beginning.' (FAP 13, Male, Milk and 342 Soy Allergy)

343

344 These barriers mentioned by participants indicate a key gap in the healthcare system to 345 provide reliable, timely and effective care for individuals with food allergies. The inconsistencies in GP care and the barriers in accessing specialist care suggest a need for improved training, increased resources and accessibility at both the primary and secondary/tertiary level. If such gaps are not addressed, it is likely patients with food allergies will continue to face challenges in the management of their food allergy, potentially leading to reduced health outcomes.

351

#### 352 Theme 8: 'The Best Option Is To Manage It Myself'

Given the difficulties in accessing high quality healthcare, as outlined by food-allergic participants in this study, many agreed that the best option, was the self-management of their food allergies. For most participants, this included an increased reliance on using the internet to manage allergies, which was thought to be both quick and useful. Participants did acknowledge the importance of HCPs in providing support but where this was not always possible, accessing relevant information online was a good enough alternative.

359

Well, to me online is just the first place to go, it's just the fastest way to get information. Before anything I'll try to find information online before even contacting the doctor, because they'll be busy and there's no time to go to the hospital.. So yeah I have been able to find resources or information online. I mean it would be really great to always go to the HCP but that's hard and well for me online is enough.' (FAP 4, Female, Wheat, Soy and Egg Allergy) 365

366 This reliance on the self-management of food allergies through online resources raises 367 questions about the quality and reliability of the information being obtained. Despite the 368 internet offering a wealth of information, there are also risks involved such as misinformation 369 possibly leading to inadequate management. There is clearly a gap in the healthcare system 370 as patients with food allergies feel that the current system is not enough, leaving them to take 371 matters into their own hands. Better support and more accessible healthcare options for 372 patients with food allergies are needed to ensure they are not left alone to navigate their 373 condition.

374

#### 375 6.3.2. Parents/Carers

376

#### 377 Participant Demographics

378

The third focus group consisted of P/C of a child or young adult with one/more existing food allergies. Overall, a total of 9 P/C took part in this focus group session. All P/C had a child with one/more existing food allergies (Table 6.2). **Table 6.2.** Demographic characteristics for parents/carers of a child/young adult with food383 allergies (n=9)

	Parent/Carer (n=9)
Gender (n,%)	
Male	7 (78)
Female	2 (22)
Age (n,%)	
25-35	2 (22)
36-45	2 (22)
46-55	4 (44)
56-65	1 (11)
Ethnic Background (n, %)	
White British	2 (22)
Black: British African	4 (44)
Black: British Caribbean	2 (22)
Mixed	1 (11)
How old is your child with food allergy (n, %)	
<10	2 (22)
18	1 (11)
19	3 (33)
20	1 (11)
21	2 (22)

386

387

Parent/Carer	(n=9)

*Which food allergy/allergies does your child have?	
Peanut	1 (11)
Tree Nut	2 (22)
Fish	1 (11)
Milk	6 (67)
Egg	5 (56)
Soy	2 (22)
Wheat	2 (22)
Diagnosis (n, %)	
Skin Prick Test	9 (100)
Blood Test	9 (100)
Food Elimination Diet	9 (30)

388 \*Parents/carers had the option of choosing more than one food allergy

389

390

391

# 392 Thematic Maps

393

Following the focus group discussion with P/C and thematic analysis through the software NVivo, a total of three main domains and five overarching themes were generated. The themes which emerged are quite similar to the FAP. However, it is important to consider these from the perspective of the P/C.



#### 398 **Figure 6.3.** Thematic map for Parents/Carers

399

#### 400 FOOD CHOICE

401

#### 402 Theme 1: 'It's Challenging To Make Sure My Child Has a Balanced Diet'

403 It has been well established that eating outside of the home is challenging for those with food 404 allergy and it is often the case that many food allergic individuals will avoid eating out 405 (Mackenzie et al., 2010; Stjerna, 2015; Barnett et al., 2018; Feng and Kim, 2019; Newman 406 and Knibb, 2020). This avoidance is often linked with safety concerns and the limited 407 availability of suitable food options, which makes maintaining a balanced diet difficult. One 408 common theme which emerged from this focus group discussion with P/C was the challenge 409 in ensuring their child was able to maintain a balanced diet while managing food allergies. P/C 410 felt restricted in providing a diverse range of foods, which often compromised the quality of 411 their child's diet. All P/C had dietary concerns when choosing foods for their food allergic child 412 and this was related to not being able to source suitable replacements. Consequently, this left 413 P/C feeling that their child's diet was limited and lacked essential nutrients. Additional barriers 414 mentioned included limited options of good quality safe foods and little help from HCPs in 415 providing dietary advice. Many P/C also voiced concerns of their child meeting dietary 416 requirements when starting university, where the FCs were now out of their control and the

- 417 period of independence was one of carelessness and increased privacy. P/C are left trying to
  418 balance the need to ensure their child's safety while respecting their independence, often
  419 fearing their child may not be fully equipped to make safe and healthy FCs on their own.
- 420

421 'So yeah, it's really does compromise the quality of the food because you have limited 422 options of foods and you want to make sure your child is eating the best, but sometimes the 423 quality you want is not what you can give because that is the only thing he or she can eat and 424 you don't have a choice.' (P/C 1, Female)

425

426 'I think one important thing that which is also challenging is letting them manage FCs 427 independently and be able to manage the situation on their own when they're in university. 428 Because now you have almost a full grown adult and then trying to interrupt and or trying to 429 help them manage their diet aswell, so striking that balance could also be a problem. So it's 430 basically a communication challenge. How do you communicate with them because now they 431 don't tell you everything. It's a real challenge.' (P/C 5, Male)

432

433 P/C of children with food allergies face challenges in ensuring their child is able to maintain a 434 balanced diet while navigating their food allergy. Challenges in sourcing suitable alternatives 435 which were of good nutritional quality, limited help from HCPs and increased anxiety over their 436 child's ability to manage FCs independently were all mentioned. These concerns highlight the 437 need for better access to safe, high quality foods, more comprehensive support from HCPs 438 and education for their children and LA in managing their dietary needs independently. 439 Addressing these factors can potentially reduce parental anxiety and ensure that children with 440 food allergies are able to maintain a balanced diet throughout their lives ,while managing their 441 food allergy.

442

# 443 Theme 2: 'Labelling Is Challenging and Limits Food Choice'

444 Difficulty in making sense of food labels was something which all P/C experienced in this 445 study. The main challenge was the diligence required to constantly read food labels which 446 took additional time, followed by the confusion in interpreting them. Not only did this reduced 447 understanding of food labels limit FC, but in some cases foods of lower nutritional quality were 448 inadvertently chosen and inappropriate foods were selected, which then led to accidental 449 reactions. The constant need to scrutinise and interpret food labels adds a significant burden 450 for P/C. There is likely increased anxiety about the safety and nutritional adequacy of the food 451 they choose for their children, which could further limit FCs.

452

453 *'Well, I think it's not really easy, but it's quite challenging because you try to acquire a* 454 product by reading the labelling which can be confusing and then you won't bother getting it 455 because your not too sure. And quite unfortunately at times you get it wrongly for them. So it's 456 quite a challenge for me.' (P/C 7, Male)

457

458 'It's something I always do, though it's might be time consuming. Tiring. You know, I 459 need to put in extra effort. Imagine going to the shopping mall to get groceries, groceries and 460 then just stop with reading each and every label before picking. So it's really time consuming 461 but we have to do it for our children.' (P/C 1. Female)

462

P/C also face challenges with regard to labelling that impact the FCs for their children. Efforts
to improve clarity on labelling is needed, as this may reduce the time spent interpreting them,
enhance understanding and increase the range of safe food options for families managing
food allergies. Educating P/C on how to interpret food labels could additionally help to reduce
these challenges and allow P/C to effectively interpret food labels, consequently increasing
FC.

- 469
- 470 FOOD ACCESS
- 471

# 472 Theme 3: 'It is Difficult To Access Allergen Free Foods Because of the Limited 473 Availability'

474 AFF offer a means of improving dietary quality which is safe. Despite this, P/C mentioned an 475 increased difficulty in accessing these types of foods, with supermarkets not providing enough 476 options. This limited access will often lead P/C to seek out larger stores, which can be time 477 consuming and inconvenient and can further compound their ability to provide a well-balanced 478 diet for their children. All P/C further acknowledged that AFF were expensive, but were still 479 willing to purchase them to ensure their child was able to obtain a 'proper' diet while 'staying 480 safe.' This willingness on the part of the P/C to purchase AFF, highlights the commitment to 481 their child's wellbeing, even when faced with financial burdens and limited food options. Some 482 participants additionally mentioned how the quality of these foods were lacking. This further 483 indicates that AFF, though a safe option for those with food allergies, may not necessarily 484 meet nutritional requirements. This could pose a dilemma for P/C who must choose between 485 safety and nutritional quality.

486

487 'And then I would also like to add that we should have more options being made
488 available because we have less availability of AFF, it's very difficult to access. You have to go
489 to really big shopping stores before you can find it.' (P/C 7, Male)
- 490 'They are more expensive a lot more actually but I think for me the big issue is the
  491 availability and then the quality too. Sometimes, it doesn't have all the nutrients or in the past
  492 I have actually found that the AFF they have much higher sugar in them.' (P/C 5, Male)
- 493

The findings indicate that P/C also face challenges in accessing affordable, high-quality AFF, which are limited and often of poorer nutritional quality. It is clear that more availability and accessibility of AFF is required, for instance in local supermarkets, which could help to reduce the burden on families managing food allergies. It is also important to consider improving the nutritional quality of AFF while keeping them affordable, to address concerns raised by both FAP and P/C in this study in relation to cost and health-related concerns.

500

## 501 HEALTHCARE ACCESS

502

# 503 Theme 4: 'Good Allergy Healthcare Is a Challenge'

504 P/C of FAP discussed their previous experiences when accessing healthcare for their child 505 with food allergies. The main theme which emerged from the discussion was the struggle in 506 accessing good quality healthcare and this was primarily due to lack of knowledge of GPs in 507 this field, inadequate resources, the increased costs associated with obtaining healthcare and 508 a limited number of allergy specialists who were available. GPs provide the first point of 509 contact in healthcare and therefore, the concerns outlined by P/C highlight a key issue in 510 primary care which can lead to delays in being referred to specialists, delaying necessary 511 treatment and thus increasing anxiety for P/C. Similarly, the inadequate resources can also 512 lead to delays in diagnosis and treatment which can complicate the management of food 513 allergies. Additionally, the financial struggle in accessing allergy services can impact families 514 receiving timely and appropriate care. These issues are further compounded by the limited 515 access to allergy specialists. Without this expert care, families will be left to manage food 516 allergies without enough guidance and support that may, potentially leading to inadequate 517 management and health risks.

518

519 'Yeah, I actually think that the whole process of having to see a GP before we get 520 some sort of referral is quite difficult as sometimes GPs I feel don't have the best amount of 521 knowledge really and they are not quite familiar with the severity of allergies and sometimes 522 this causes some delay factors in referring you to see a specialist. So I really don't feel 523 comfortable when a GP gives me certain procedures or advice to follow. I prefer a referral, a 524 referral to an allergy specialist, but you cant get that without the GP so it is really challenging.' 525 (PC 2, Male) 526 When I spoke to the GP it was quite difficult getting the referral to an allergist and even 527 when we got referral to NHS Hospital for allergies, it was a long waiting list and was really a 528 challenge for me because this was my first experience. And so it was really difficult. And then, 529 when we actually got booked for the testing, then the whole process, the whole skin prick test 530 of blood test and food challenge, was really costly and we experienced some delays and that 531 was challenging when accessing healthcare generally. And I think there must be quite limited 532 specialists for allergy because the whole process wasn't really great.' (PC 7, Male) (Note here 533 that allergy tests within the NHS are free and the participant is referring to indirect costs 534 associated with travel. The term 'costly' may also be used broadly here to reflect the overall 535 burden of the experience and not just the financial expenses.)

536

537 The challenges outlined by P/C in accessing healthcare for their child's food allergy associated 538 with lack of knowledge at the primary care level, inadequate resources, cost and reduced 539 access to specialist care have previously been mentioned by FAP in this study. This indicates 540 a persistent issue within the current healthcare system and emphasises the importance of 541 making improvements. There is a need to improve the current quality of allergy healthcare 542 and addressing these specific challenges can benefit families managing food allergies, 543 ensuring they receive timely and appropriate care.

544

# 545 Theme 5: 'Managing My Child's Food Allergy Has Psychologically Impacted Me'

546 An underlying theme which emerged from the focus group discussion with P/C was the lack 547 of psychological support being offered. Many P/C expressed feelings of worry, stress and 548 anxiety due to the management of their child's food allergy, which directly impacted their daily 549 life. There is an emotional burden associated with consistently ensuring the safety of their 550 child's diet. The daily task of reading food labels and preparing safe, nutritionally adequate 551 meals can lead to increased stress affecting P/C mental health. P/C further mentioned 552 experiencing anxiety even when their children gained independence, suggesting that the 553 psychological impact of food allergy can continue to affect P/C long-term. Consequently, all 554 P/C agreed that more psychological support from HCPs was needed, with this areas often 555 overlooked.

556

557 'It's more like you both share the allergy the food allergy because you have to make 558 sure you choose the right foods that are suitable and the label will make it confusing and then 559 the extra preparation, sometimes you are restricted to eat whatever they eat and then 560 sometimes you have to cook the meals separately. I'll make a mistake and then I'll restart and 561 sometimes it gets to me. It's hard, really hard.' (P/C 9, Female)

563 'Recognising the psychological impacts of allergies in parents is really important. It 564 definitely has affected me, my whole has changed too. Mental health support services are 565 really needed us the parent and it would be really good if more research of this natures can 566 be done because I think there's close relationship between food allergy and mental health.' 567 (P/C 2, Male)

568

569 P/C revealed how the management of their child's food allergy had a profound psychological 570 impact, which negatively impacted their daily life. To better support families, there is a need 571 for HCPs to provide more psychological support and for HCPs to be further trained in this area 572 so as to provide tailored services for families managing food allergies and FAP. This in turn 573 could help to reduce the current psychological burden associated with navigating food 574 allergies.

575

It is also important to note here that although this study included P/C of children with food allergies across different ages groups, no differences occurred in FC, FA and HCA based on the age of the child. This indicates that P/C who manage food allergies for their child face similar challenges throughout this care period, irrespective of their child's age. This further suggests that any differences in FC, FA and HCA may be more noticeable in the child themselves as they move to a period of independence, rather than in the experiences of the parents.

583

# 584 6.3.3. <u>Healthcare Professionals</u>

585

# 586 **Participant Demographics**

587

588 The fourth focus group was made up of HCPs, all of whom had previous experience in

- 589 providing care for 18-25year olds with food allergies. There was a total number of 10 HCPs in
- this group. A diverse group of HCPs were involved as shown in Table 6.3.

**Table 6.3.** Demographic characteristics for healthcare professionals with experience of 592 providing care for 18-25 year olds with food allergies (n=10)

		HCP (n=10)
	Gender (n,%)	
	Male	5 (50)
	Female	5 (50)
	Age (n,%)	
	25-30	5 (50)
	31-35	3 (30)
	36-40	1 (10)
	41-45	1 (10)
504		
J94	Ethnic Background (n. %)	
		2 (22)
	White British	6 (60)
	Black: British African	2 (20)
	Black: British Caribbean	1 (10)
	Mixed	1 (10)
	General Practitioner	3 (30)
	Dietitian	4 (40)
	Nurse	2 (20)
	Social Worker	1 (10)

# 599 Thematic Maps

In this focus group discussion, HCPs discussed barriers and facilitators of providing care to
 LA with food allergies. A total of two main domains and six overarching themes were
 generated following thematic analysis through the software NVivo.



045

626 **Figure 6.4.** Thematic map for healthcare professionals

627 628

629 BARRIERS

630

# 631 Theme 1: Challenges with Patient Engagement

Through this focus group discussion, HCPs expressed that one of the biggest concerns in providing care for LA was their failure to attend, which directly impacts the effective management of food allergies. Some of the main reasons for this was the lack of seriousness about their food allergy and financial difficulties on the part of the patient. This lack of attendance by FAP is a key issue as it will likely disrupt the continuity of care for patients with food allergies and additionally will limit HCPs in providing continuous and comprehensive treatment.

639

640

641

642 'No, I'm always having appointment with someone, then he or she is not able to turn 643 up due to some reason. Maybe you know, sometimes they will call and say that they do not 644 have enough financial support to come. Maybe transportation fee or something. And that stops 645 them from coming. So that's one of the challenges I've faced, like not try not meetings up with 646 the appointments I have with them.' (HCP 2, Social Worker)

647

648 One of the GPs within the focus group also mentioned how there was little they could do if 649 patients did not attend, owing to little time and the pressures of workload. This quote reflects 650 the systemic pressures in primary care settings where increased workloads limit follow ups, 651 which can further complicate patient care.

652

653 'And then also for me some of my patients won't come consistently so it can be hard
654 and we don't really have time to chase them up, because we have other patients. It means
655 that we'll just have to leave them which is difficult because you know that they need the help.'
656 (HCP 3, GP)

657

Engaging with patients is a key aspect of managing food allergies. However, HCPs in this study highlighted that missed appointments due to financial issues and a lack of perceived seriousness regarding food allergies were significant barrier in providing care for LA with food allergies. There is a need to encourage patient engagement through educating patients on the importance of consistent care and the severity of their food allergy, as well as addressing financial barriers to ensure they have the necessary resources to regularly attend appointments.

665

# 666 Theme 2: Challenges with Providing Psychological Support

667 HCPs themselves acknowledged the lack of services available to support the psychological 668 aspect of managing food allergies. Most HCPs included in the focus group, felt they lacked 669 the competency to adequately provide this type of support due to limited time, resources and 670 specific training in this area. The psychological aspects of food allergy are often overlooked, 671 despite it being a key aspect in the management of food allergy. There is a gap in the training 672 of HCPs which focuses mainly on physical health rather than the holistic needs of patients, 673 including mental well-being. Additionally, the lack of resources to adequately deliver 674 psychological care highlights the lack of support systems currently in place for managing all 675 aspects of food allergy.

676

677 'It's also really important to have a good understanding of the social, emotional and 678 behavioural impacts of food allergy and the physical and nutritional needs too. This is something we don't really get taught and will be really helpful for us as HCPs. I think it will
really improve patient care.' (HCP 4, Nurse)

681

682 *'We have time constraints and limited resources, which can make it difficult to provide* 683 *individualised care, especially for the psychological aspect of it. It becomes a lot more difficult* 684 *particularly for adolescents with multiple food allergy.' (HCP 3, GP)* 

685

686 Only one participant from this focus group discussion – a social worker, mentioned that 687 psychological support was available in some capacity in the place in which she worked. This 688 indicates that accessing psychological support is sometimes available, highlighting the 689 inconsistencies across different healthcare settings. Further underscoring the gap in 690 comprehensive care for the management of food allergies.

691

692 'There is mental health support for people with allergy at my practice, we have some
693 resources and then we'll refer them to support groups, which they can decide to attend.
694 Sometimes, it can be limited and depending on the schedule we might not always be able to
695 refer the patient to psychologist, but we do have this available.' (HCP 2, Social Worker)

696

697 HCPs highlighted how the challenge in providing adequate psychological care for patients with 698 food allergy was a barrier in the management of food allergies. While HCPs are aware of the 699 importance of providing this care, they are unable to meet the needs of patients in this regard 700 owing to insufficient training, time and resources. Additionally, the inconsistency in the 701 availability of this care was also highlighted indicating an uneven distribution across different 702 healthcare settings. It is crucial to address these gaps through incorporating some form of 703 psychological training into the professional development of HCPs. Moreover, establishing 704 more robust support systems that can address the physical and psychological needs of 705 patients with food allergies may also prove beneficial. Furthermore, ensuring that 706 psychological support is more consistently available across all healthcare settings can ensure 707 the delivery of holistic care that can assist in the effective management of food allergies.

708

# 709 Theme 3: Issues with the Referral System

Many of the HCPs additionally felt that inappropriate referrals wasted a lot of time and played a big part in reducing the quality of care for FAP. Some HCPs mentioned how the healthcare needs of patients with food allergies could easily be managed earlier and didn't necessarily require specialist support. The outcome of this is likely inefficiencies in the healthcare system as HCPs will have to spend additional time resolving issues that could have been addressed in primary care settings. HCPs further acknowledged that the issues with the referral system 716 was due to a lack of knowledge and training, emphasising the need for more education and 717 continued ongoing professional development to ensure primary care providers have the 718 necessary skills to manage allergy cases effectively.

719

'Sometimes we don't really get really enough information from whoever they have been
referred by, so maybe it's the GP or the nurse and then it is quite a long process and does
take extra time to sort which we don't always have.' (HCP 7, Dietitian)

723

Inappropriate referrals can act as a barrier for HCPs in providing comprehensive care for FAP.
It is often a lack of training and education which results in these unnecessary referrals, draining
both time and resources which can impact the quality of care being provided. Therefore,
improving the education and training of GPs and additionally improving the communication
between different levels of care is a crucial aspect of ensuring patients receive timely and
appropriate care. This can also enhance the efficiency of the healthcare system by making
sure that the patients receive the right care at the right time.

731

# 732 **Theme 4: Inconsistent Use of Transition Guidelines**

733 The management of food allergies during the transitional period of late adolescence to 734 adulthood is challenging, due to the many psychosocial changes which occur (Huntley et al., 735 2023). Transition guidelines offer a means of providing necessary tailored support, for the 736 unique challenges presented in this age demographic (Khaleva et al., 2020). Despite this, 737 HCPs in this focus group discussed how the current guidelines at their practice were not 738 particularly useful. HCPs felt that the current transition guidelines at their practice were not 739 detailed enough to be considered useful. This often deterred them from being used, 740 highlighting the need for more thorough and useful practical guidelines that are clearly defined. 741 HCPs in this study also felt the need for more improved transition guidelines at their practice 742 which could facilitate better care, further reinforcing the need for more clear guidelines that 743 can ensure better quality care.

744

745 'Sometimes the transition guideline is not clear and comprehensive so this can be 746 challenging. It's really important that the plan includes specific goals and objectives as well as 747 timelines and milestones. Sometimes there is not proper policies and procedures in place to 748 ensure continuity of care such as a formal handover process and a system for transferring 749 medical records. This is actually quite poor at the moment for us.' (HCP 3, GP)

- The fact that HCPs mentioned *'we just know they are ready to move on so then they will go to the adult allergy clinic' (HCP 8, GP)* indicates that the transition process is not treated as a carefully managed handover that provides LA with the necessary support during this critical transitional period, but rather as a routine administrative process.
- 755

HCPs highlighted that the current transition guidelines at their practice were not clear and comprehensive and this led to little use. Transition guidelines can provide a crucial means of smooth transition from pediatric to adult allergy services. It is important therefore, to improve these guidelines ensuring there use is consistent, to provide continuous and effective care for LA with food allergies. Educating HCPs on how to effectively implement these guidelines will also prove beneficial in maintaining the standard of care during this period.

762

# 763 **FACILITATORS**

764

## 765 Theme 5: Ongoing Professional Development

766 It has been well established that sufficient knowledge and appropriate training are essential 767 factors for ongoing professional development and can improve the level of care provided to 768 patients with food allergies (Skypala et al., 2018; Barker et al., 2021; Daniels et al., 2021). In 769 this study, HCPs differed in their level of knowledge and training. Those who received specific 770 training found it useful and felt they were able to competently deal with their patient's needs. 771 HCPs mentioned that where training was accessible, they felt more confident and competent 772 in managing their patient's needs. This indicates the importance of continuous education and 773 training, which can clearly improve the quality of care.

774

775 'The hospital where I work, they do this thing every year where they produce some 776 brochures or material videos that they share to all of us that are taking care of patients with 777 food allergy. This material contains up to date research and provides us with better ways to 778 understand and take care of our patients. It's been really useful for me.' (HCP 5, Dietitian) 779

On the other hand, many of the HCPs in this group also experienced barriers in providing care to their FAP, due to lack of knowledge and limited training opportunities, which highlights inconsistencies in the training provided across different healthcare settings. HCPs believed that without regular, comprehensive training, they would struggle in providing the level of care needed to effectively manage their patient's needs.

Well for me I think that, so I'm a dietitian and my role involves mainly managing diet
plans with patients and when to introduce foods. But I think more training is necessary for me
to improve my care for LA with FA and it should include more information and knowledge
about FA especially for patients with multiple FA and I'm not always confident in the elimination
diets so this for me is an area I need to work on.' (HCP 7, Dietitian)

791

'Sometimes I won't be able to answer all of the questions asked by the patient. We
don't have many opportunities for specific training and it wasn't, I cant recall being taught it
while studying. Sometimes we have to do an e-learning course, but it's not all the time and it's
certainly not compulsory.' (HCP 9, GP)

796

797 HCPs through this study revealed that while training is extremely beneficial in enhancing care 798 for patients with food allergies, the lack thereof can act as a significant barrier. The variation 799 which currently exists in knowledge and training among HCPs highlights the need for ongoing 800 professional development to allow for the successful management of food allergies. 801 Standardising and enhancing the current training opportunities across healthcare settings for 802 HCPs who treat patients with food allergies, is an essential aspect of improving patient 803 outcomes. This can help to empower HCPs in the management of food allergies, allowing 804 them to provide consistent, high quality care.

805

#### 806 Theme 6: Support Networks

One area which helped to improve the care provided by HCPs, was directing FAP to support groups. All HCPs were able to provide details of community support groups and online forums, which based on feedback from some of their patients proved useful. This highlights that across the board support networks are a valuable tool in assisting in the management of food allergies. Not only do they provide practical advice, but also emotional support which fosters a sense of community that can enhance and complement the care provided by HCPs.

813

614 'There are these online support groups which former patients are a part of. So the new 615 patients are also advised to be added to the online community where they can ask questions 616 about how they're feeling, share their experiences and reactions and they will be able to have 617 a discussion with some of our older patients.' (HCP 4, Nurse) 610

818

Despite the beneficial nature of support groups, HCPs discussed how patients will not always
join support groups and further mentioned how more efforts need to be made in encouraging
LA to attend. This indicates a key challenge regarding patient engagement. The reluctance to
join could also stem from multiple factors such as a lack of awareness of the benefits,

misconceptions about what support networks may offer and even time or accessibility issues.
Addressing these factors is important along with exploring alternative forms of support for
example, one to one support or even digital platforms where this support can be offered to
those less willing to attend traditional groups.

827

Sometimes the patient is reluctant to join the support group so encouraging them more
and exposing them to it more is needed, because it can really help to provide a sense of
community and understanding among other's who have similar experiences with food allegry.
It offers an opportunity to share tips, advice and even provides emotional support' (HCP 8,
GP)

833

834 While support networks are clearly of benefit for FAP, it is also important to consider how 835 these can also support HCPs. Professional networks, for instance the British Dietetic 836 Association (BDA) Food Allergy Specialist Group (BDA The Association of UK Dietitians) 837 offers a platform for dietitians working in food allergy to share experiences, discuss 838 challenges, offer continuous professional development opportunities and even keep them 839 informed of the latest food allergy research. Although this aspect of support networks for HCPs 840 was not specifically discussed by HCPs in this study (with the focus primarily on improving 841 patient care), it is an essential component of supporting HCPs in their roles. Engaging in such 842 professional support networks can improve their skills and knowledge and allow them to be 843 better equipped in providing more effective care for FAP.

844

Support networks play a crucial role in the management of food allergies. Not only do they offer patients with practical advice and emotional support, but they are equally valuable for HCPs presenting them with opportunities for professional development and knowledge sharing. Patient engagement in these networks is often a challenge due to multiple factors. It is essential to address these barriers to ensure that FAP and HCPs can fully benefit from these networks, as they can lead to the better management of food allergies and improve overall patient outcomes.

852

#### 853 6.4. Discussion

854

There currently exists a paucity of research in LA with food allergies, despite this being a unique life stage, which can jeopardise or optimise future health (Vilaro et al., 2018; Huntley et al., 2023). The use of in-depth focus groups, offer a much needed valuable lens into the attitudes, feelings, experiences and beliefs of each individual group. The focus groups centred

- on three main elements FC, FA and HCA, with the primary objective of improving each one
   consequently allowing food-allergic LA to take effective control of their allergic disease.
- 861
- 862 6.4.1. Food Choice
- 863

# 864 The Social Impact

865

866 Three main factors of FC were explored in this group of LA with food allergies. The first was 867 the social impact of FC. Eating is inherently a social activity and previous research has 868 indicated how the presence of a food allergy will limit social gatherings and lead to social 869 isolation in LA (Stjerna, 2015; Feng and Kim, 2019; Newman and Knibb, 2020). Interestingly, 870 the findings from this study differed to that of existing literature. A common theme which 871 emerged from the discussion with FAP, was the continued involvement in social activities 872 despite the management of food allergies. LA hold social ideals in high regard (Dix et al., 2022; 873 Friedman et al., 2022) and the need for this group to socialise together is one of great 874 importance, with peer interaction considered to be crucial for development (Herman, 2017; 875 Orben et al., 2020).

876

877 The beliefs of peers are an important factor in shaping LA eating behaviour. Food allergic 878 participants in this group felt that managing their food allergy around friends was a struggle. 879 General feelings of unacceptance and being misunderstood by friends were highlighted and 880 the perception of being 'fussy' in FC and being seen as 'different' was burdensome. As a 881 result, this discouraged eating behaviour in this group. Maintaining social connections play a 882 vital role in the development of LA (Herman, 2017; Orben et al., 2020). Communication is key 883 and informing peers and friends of the severity of FA has the potential to reduce risk taking in 884 this group (Sampson et al., 2006). While this choice allowed for the fulfilment of social and 885 emotional needs and ensured safety in preventing allergenic reactions, food intake was 886 limited. In some instances, participants felt that the lack of clear information on menus and the 887 limited knowledge and flippant attitude of staff made not eating the easy option - findings 888 which mirror that of existing research (Monks et al., 2010; Barnett et al., 2018).

889

Those with food allergy will already have a reduced intake of foods due to the nature of an avoidance diet. The outcome of further limiting food intake due to mistrust will pose greater concerns, leading to nutritional imbalance and potential health issues (Sommer et al., 2014; Skypala and McKenzie, 2019; Leone et al., 2022; de Almeida Kotchetkoff et al., 2023). P/C also highlighted similar concerns with regard to the diet of their children, noting that there was 895 an increased difficulty in sourcing AFF of high quality. This added to the difficulty in maintaining 896 a balanced diet – a worry of both FAP and P/C which was expressed in this study. Substantial 897 efforts therefore need to be made to implement and monitor changes which improve the social 898 aspect of eating out in those with food allergies. Through their research Barnett et al. (2018), 899 found that for FAP, the best dining out experience involved 'knowledgeable' and 'attentive' 900 staff. Thus, increasing allergen awareness of employees through providing specific training 901 will prove valuable in achieving this. In addition to this, the simple proactive approach of staff 902 themselves enquiring about consumers dietary requirements holds considerable value with 903 food allergic consumers, making them feel more confident and trusting in their FC (Begen et 904 al., 2016; Barnett et al., 2018). In the same way, FAP should also be more proactive in sharing 905 their allergies with personnel, to ensure a safe dining experience. HCPs play a key role in 906 facilitating this, through educating and encouraging FAP about the potential risks involved with 907 limiting food intake, rather than allowing fear to be a barrier (Begen et al., 2016; Newman et 908 al., 2022). The importance of proactive communication was further emphasised by HCPs in 909 this study, who mentioned how lack of patient engagement was a challenge they had 910 experienced and how more efforts were needed to encourage patients in regularly attending 911 appointments, through informing them of the benefits of adherence and risks of non-912 attendance.

913

914 Beliefs about navigating food allergies in different social environments were also discussed. 915 Food allergic participants felt that the management of their food allergy in the presence of 916 family was easier. Feelings of comfort and relax were expressed, with FAP happy to leave the 917 responsibility of their safety to family who were 'understanding', 'supportive' and 'careful'. 918 These findings are similar to that of previous research where the studies reinforce the 919 perceptions of family home as the safest food allergy environment for FAP (Sommer et al., 920 2014; Stjerna et al., 2015). Participants additionally agreed that food intake was better when 921 eating in the company of family in comparison to eating alone. Where parents are in control 922 and select the foods of the family diet, food intake will naturally be improved (Poobalan et al., 923 2014; Scaglioni et al., 2018). In contrast, when eating alone simple and quick meals will 924 frequently be chosen and this discourages a well-balanced diet (Chae et al., 2018).

925

For LA who are living independently and are imposed by the added expenses of university
life, financial difficulties will arise (Defeyter et al., 2020; Ahmad et al., 2021; Ravel et al., 2023).
To manage situations, LA will often compromise food intake through the selection of
suboptimal foods (Bauer et al., 2016; Larson et al., 2020) or in some instances, portion sizes
and/or the number of meals per day will be reduced (Cretch, 2022). Educating food allergic
LA on how to make informed FC and providing them with cooking skills is a key responsibility

932 for parents, which can empower LA to acquire and eat healthier foods (Harper et al., 2022). 933 Food vouchers provided by institutions, particularly to food-insecure students through this 934 period of independence, could additionally help to combat the financial restrictions. Not only 935 will this enhance access to quality foods but simultaneously will improve academic attainment 936 (Broton et al., 2023). While many universities in the NW have taken this approach, the current 937 cost of living and the price of food will mean that vouchers alone will not provide a long-term 938 solution (Vittozzi, 2023). Perhaps governmental policy change is needed to ensure access to 939 adequate nutritious meals for all university students.

940

# 941 The University Environment

942

943 The second factor in relation to FC which was discussed by food allergic participants, was the 944 impact of the university environment. All participants mentioned the limited availability of safe 945 foods in the university, which is in line with previous research (Greenhawt et al., 2009; Wu 946 and Wang., 2023). Not eating on campus was a common theme discussed as a result of the 947 challenge in accessing AFF. Food allergic participants were consequently forced to look for 948 alternative options. The majority of food allergic participants in this study explored seeking 949 foods outside of the campus environment. While this did provide more options, these foods 950 were considered more expensive and the added time required to purchase them was an 951 inconvenience. Some participants further mentioned how the availability of 'lots of fast food 952 places' outside of campus made it easier to access foods. The inexpensive nature of such 953 foods made them more tempting. This is worrying as the overconsumption of takeaway foods, 954 which is a common practice among LA, has been strongly linked to lower dietary quality and 955 increased nutritional deficiencies (Larson et al., 2020; Racine et al., 2022). Planning meals 956 and cooking can allow LA to take control over their FCs while improving diet and especially in 957 those with food allergies, can ensure safety. Although this proactive approach was taken by 958 some participants from this study, managing time constraints while preparing and sourcing 959 foods was a challenge. Some participants expressed concerns of limited cooking knowledge, 960 which made navigating food allergies at university difficult. Providing education in relation to 961 meal preparation strategies, including batch cooking and knowledge of simple and quick 962 recipes, can provide food allergic individuals with a more manageable approach while 963 simultaneously maintaining a safe quality diet (Sommer et al., 2014; Sicherer et al., 2023). 964 Additionally, universities themselves have a responsibility in supporting food allergic students. 965 One way to ensure the dietary needs of food allergic students are met, is through the 966 promotion of AFF both in campus dining areas and in vending machines. Additionally, clear 967 signposting of designated allergy safe spaces and improved visibility of food labelling, 968 particularly in dining areas, is needed (Dyer et al., 2018; Wu and Wang., 2023). Furthermore,

969 some participants mentioned feeling anxious in relation to managing food allergies in the 970 university setting. This mirrors the perspectives of the P/C who also reported experiencing 971 anxiety even when their children gained independence, suggesting that the psychological 972 impact of food allergy can continue to impact P/C long-term.

973

# 974 Labelling

975

976 An additional theme which impacted the FC of this group also emerged through the discussion. 977 Firstly, both FAP and P/C expressed concerns with current food labelling practices. Much 978 literature has reported the difficulty which food allergic individuals and their families experience 979 with food labels (FSA, 2001; Joshi et al., 2002; Noimark et al., 2009; MacKenzie et al., 2010; 980 Barnett et al., 2011; Walkner et al., 2015; Fiocchi et al., 2021) and the results from this study 981 further add to these findings. Many participants in this study expressed feelings of 'confusion' 982 when reading food labels and found it 'difficult' to interpret them. Participants further 983 communicated feelings of distrust in food products due to the lack of clarity on packaging. P/C 984 additionally felt that the inadequate labelling was an obstruction in purchasing healthier foods. 985 Moreover, the increased time spent screening food labels to determine safety was 'tiring' and 986 led to feelings of frustration and increased stress in participants. The outcome for many led to 987 simply avoiding foods, which limited both FC and food intake. The complexity of food labels 988 further deterred individuals in reading them and resulted in two risky outcomes in food allergic 989 participants, leading to accidental ingestion. Either food allergic participants were reliant on 990 the same foods over and over, which could cause them to miss any possible changes in 991 ingredients (Versluis et al., 2023), or they disregarded food labels and took a chance with 992 foods in the hopes of no reaction. Ignoring food labels is a common practice among LA with 993 food allergies (Barnett et al., 2011; Marchisotto et al., 2017), which was dissimilar to P/C 994 behaviour in this study, who felt they had a 'responsibility' to continuously check food labels 995 despite it being 'tiring' and 'complicated'. Overall both FAP and P/C did struggle in navigating 996 food labels indicating a shared burden that exists in ensuring a safe and nutritionally, adequate 997 diet. This challenge also emphasises the need for more clearer and consistent labelling 998 practices to better support FAP and their families in making more informed choices.

999

A vital aspect in the everyday life of food allergic individuals is reading and correctly interpreting food labels, to effectively identify and avoid ingredients which could pose health risks (Barnett et al., 2013; Martinez-Pineda and Yague-Ruiz, 2022). Yet the current labelling system makes this difficult. It is a priority to ensure clearer and standardised labelling practices to reduce the confusion that currently exists across labelling practices. This obligation lies with 1005 food manufacturers, government bodies and policy makers, all of whom play a crucial role in 1006 helping FAP and their parents to gain more confidence in food decision making (Barnett et al., 1007 2013; Newman et al., 2022). There is a need to harmonise current labelling practices and 1008 Holleman et al. (2021), recommend the use of only one Precautionary Allergen Labelling 1009 (PAL) (e.g. may contain) wording to reduce labelling confusion. Furthermore, through a recent 1010 study with key stakeholders, the FSA (2022) propose the use of standardised PAL on 1011 packaging, only when certain allergen thresholds are exceeded. This will allow for meaningful 1012 information on food labels, further increasing FAP and parents in greater confidence and trust 1013 in food products and will consequently assist them in making better dietary choices.

1014 1015

## 1016 6.4.2. Food Access

1017

- 1018 <u>Cost</u>
- 1019

1020 Food allergies pose a significant economic burden for all those affected and their families. 1021 Increased hospital visits, medication and nutrition supplements are some of the expenses 1022 faced by this group (Minaker et al., 2014; Diwakar, 2017; Tackett et al., 2018; Foods Standards 1023 Agency, 2022). A necessary component of managing food allergies is the inclusion of AFF, 1024 which offer a safe means of improving diet (Frame et al., 2022). It is well known that AFF are 1025 difficult to access for the food allergic community and one of the primary reasons for this, is 1026 cost. AFF are considerably more expensive than non-allergen counterparts and multiple 1027 studies have highlighted this (Bollinger et al., 2006; Groetch et al., 2013; Gupta et al., 2013; 1028 Sommer et al., 2014; Bilaver et al., 2016; Polk and Dinakar, 2017; Bozen et al., 2020; Hurst 1029 et al., 2021; FSA, 2022; Memauri et al., 2022; Allergy UK, 2023). The results from this study 1030 further add to this collection of literature, with all food allergic participants echoing the high 1031 cost of AFF. While the management of food allergies pose a financial problem to all those 1032 suffering, some groups, namely low-income and minority individuals, are at an increased risk 1033 (Scurlock et al., 2022; Tepler et al., 2022). While socioeconomic status was not determined in 1034 this study, we can assume that this group of participants were of lower income. This is because 1035 all participants were students living at university, which is a period of high expenditure owing 1036 to the added costs of tuition fees, utilities and accommodation (Ahmad et al., 2021; Cretch 1037 2022; Ravel et al., 2023). In fact, one of the primary reasons for the struggle in accessing AFF 1038 mentioned by participants in this study, was due to the added expenses of university. In 1039 addition to this, a large percentage of food allergic participants in this study (90%) reported 1040 suffering from multiple food allergies, which have been associated with higher rates of allergic comorbidities, for example asthma, atopic dermatitis and allergic rhinitis (Raimundo et al.,
 2021). Managing both multiple food allergies and allergic comorbidities require multiple
 medications (Memauri et al., 2022) and will further exacerbate the already existing financial
 strain in this group.

1045

1046 This theme of financial strain is a recurring one among all groups and is not only associated 1047 with the cost of AFF. While FAP struggled with balancing the financial pressures of academia 1048 and the management of their food allergy on campus, P/C noted the high cost associated with 1049 AFF and the overall economic burden of food allergies on families. HCPs also recognised the 1050 impact of financial difficulties which often led to missed appointments and inconsistent care, 1051 which negatively impacted the effective management of food allergies. Consequently, this 1052 shared financial burden voiced by all groups highlights the increased economic challenges 1053 that are linked with the management of food allergies.

1054

1055 Clearly there is a huge financial burden in the management of food allergies. As such, many 1056 individuals will have to prioritise their spending in order to manage finances. Often food will be 1057 compromised with medication naturally given greater importance (Bilaver et al., 2016). Similar 1058 findings were reported in this study, with a large number of food allergic participants reducing 1059 food intake in order to 'save.' At present, there is little support available to support the huge 1060 financial burden experienced by FAP and their families. In particular, strategies to improve the 1061 access to AFF through improving their affordability and availability is needed. Dietitians should 1062 provide guidance to FAP in finding appropriate substitutes, which are less expensive than 'free 1063 from' counterparts, while maintaining dietary requirements (Leone et al., 2022).

1064

## 1065 Availability, Safety and Diet Quality

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1067 Both FAP and P/C felt that AFF were limited to large supermarkets and rarely available in 1068 convenience stores. Previous literature has also mentioned this limited availability of AFF 1069 (North and Brown, 2017; Polk and Diwakar, 2017; Tepler et al., 2022), suggesting it is 1070 widespread and a shared concern for the entire food allergic community. Moreover, on 1071 occasions where AFF were able to be obtained, concerns over the safety of these products 1072 were raised by FAP. Many individuals experienced allergenic reactions following consumption 1073 of these foods, despite the product clearly stating it was 'free from.' Food allergic individuals 1074 place great trust in AFF. The claim of a product to be 'free from' should guarantee its safety, 1075 yet countless AFF products have been recalled due to the presence of undeclared food 1076 allergens (Bedford et al., 2020; Martinez-Pineda and Yague-Ruiz, 2022). Even if any individual 1077 with food allergies were to exercise all safety measures, there is still a chance of an allergic 1078 reaction, which will cause increased fear among sufferers. The inability to obtain sufficient, 1079 safe foods in individuals with food allergies, will lead to reduced nutrient intake and an 1080 increased exposure to allergenic reactions. It will also present psychological issues, with 1081 increased stress, anxiety and depression common occurrences mentioned by participants.

1082 Furthermore, one common finding in both P/C and food allergic participants, which arose 1083 through the focus group discussions, was that the quality of AFF were poor and their inclusion 1084 made it difficult to maintain a well-balanced diet. AFF are designed to replace lost nutrients 1085 due to FA while also maintaining safety (Pasha-Robinson, 2023) and therefore, these results 1086 are surprising. Some studies have reported the reduced nutritional quality in gluten-free foods 1087 (Saturni et al., 2010; Missbach et al., 2015; Hosseini et al., 2018). However, there is no 1088 mention of this in 'free from' foods for those with specifically food allergies and as such, further 1089 investigation into the quality of AFF is warranted.

1090 A major theme which also emerged from the focus group discussions, was the negative impact 1091 of food allergy on diet. One central aspect in the long-term management of food allergies, 1092 involves the implementation of avoidance diets. While this is necessary, it can often lead to 1093 nutritional inadequacies (Steinman et al., 2010; Mehta et al., 2014; Meyer et al., 2014; Hossny 1094 et al., 2019; Groech and Venter, 2020; Leone et al., 2022; de Almeida Kotchetkoff et al., 2023). 1095 As expected, the findings from this study added to this existing literature, with many food 1096 allergic participants expressing concerns over their diet, following the avoidance of a 'lot of 1097 foods'. The restricted FCs and difficulty in accessing safe and nutritious foods (as was the 1098 case for many participants in this study) impacted the diet variety of food allergic participants, 1099 with many consuming 'the same stuff all the time.' These findings are supported with previous 1100 research, which also mention how restrictive FC in those with FA will lead to a monotonous 1101 diet (Polloni et al., 2013; Sommer et al., 2014; de Almeida Kotchetkoff et al., 2023). The 1102 implementation of avoidance diets, poor FCs and a repetitive diet can cause inadequate 1103 nutrient intake, which can directly impact health (Leone et al., 2022). FAP themselves 1104 commented on this, specifically mentioning weight loss as one negative outcome.

1105

There is an essential need to increase the availability of AFF and improve the diet quality of FAP. The role of the dietitian is key to ensure the adequate intake of nutrients and improving the overall diet of those with food allergies. They can offer nutrition education, advice on reading and interpreting food labels, monitor food elimination diets and offer appropriate alternatives of foods where needed (Mazzocchi et al., 2017; Groetch and Venter, 2020; Leone et al., 2023). In one study conducted by Memauri et al. (2022), who interviewed a range of 1112 HCPs, dietitians themselves recommended providing supermarket tours, cooking classes and 1113 meal preparation sessions to individuals with FA and their families, which could additionally 1114 help to improve the nutritional profile of allergy suffers. This will particularly benefit LA with 1115 food allergies who are undergoing the transitional period of late adolescence to adulthood, as 1116 they will likely be managing their food allergy for the first time. The role of the dietitian is clearly 1117 invaluable for FAP. However, they are currently limited in the field of allergy (Venter et al., 1118 2012) and greater efforts must be made to improve their availability. Additionally, even when 1119 accessible, dietitians are often limited in their knowledge around food allergy management 1120 (Memauri et al., 2022) and so, greater food allergy education is needed in this group. HCPs 1121 should also emphasise the importance of food variety in the diet of those with food allergies, 1122 as an unvaried diet is a common practice among FAP (Polloni et al., 2013; de Almeida 1123 Kotchetkoff et al., 2023).

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# 1125 6.4.3. Healthcare Access

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## 27 The Perspective of the Patient and the Parent

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1129 In addition to FC and FA, the current HCA in FAP and P/C were explored. Overall, good quality 1130 health care for allergy was difficult to access. Specifically, both groups of participants 1131 responded how allergy care at the primary level was poor and this was particularly attributed 1132 to the lack of knowledge perceived in GPs. This common theme among both FAP and P/C 1133 highlights a systemics issue in allergy management at the primary care level. While GPs were 1134 easily accessible, participants felt they did not possess enough knowledge to deliver sufficient 1135 care, with some participants describing their previous bad experiences. The results obtained 1136 through this study mirror that of existing research, which additionally illustrate the inadequate 1137 knowledge of GPs to competently deal with allergy patients (RCP, 2003; Levy et al., 2004; 1138 Agache et al., 2013; Diwakar et al., 2017; Ryan et al., 2017; Daniels et al., 2021). GPs are the 1139 first point of medical contact and bad experiences will often deter patients from seeking further 1140 help. The use of remote consultations (which have increased post Covid (Mold et al., 2021)) 1141 were found to be of particular benefit and allowed quick access, with one participant stating 1142 'technology has made everything easier.' One exception to this was in the event of 1143 emergencies, where food allergic participants found a greater difficulty in reaching the GP. 1144 The mixed response in GP care mentioned by FAP in this study, highlight how allergy care at 1145 the primary level is not consistent and is likely dependent on the individual knowledge of the 1146 primary care physician.

1148 In comparison to primary allergy care, specialist allergy care was more difficult to access in 1149 majority of participants. Reasons which contributed to this increased struggle as revealed 1150 through the study, were cost, distance, inadequate resources, increased waiting times for 1151 appointments and the limited number of allergists – barriers which have all been previously 1152 mentioned in existing literature (Diwakar et al., 2017; Khaleva et al., 2020). A small number of 1153 participants in the food allergic group did mention that accessing the allergist wasn't a 1154 challenge as 'everything is just right at my doorstep.' The NW is home to three specialist-led 1155 services (Liverpool, Manchester and Preston), indicating that where access to specialist 1156 allergy care was easier for participants, they were likely living in these areas. Geographic 1157 variations do exist in the delivery of UK allergy care (Chong et al., 2023) and will lead to 1158 inconsistent health care experiences in FAP – findings which are supported by this study. The 1159 consequences of these findings extend to P/C who will also have to navigate these logistical 1160 challenges in accessing care for their children.

1161

1162 In the food allergic group, one consequence of the inability to access sufficient allergy care 1163 led to the self-management of their food allergy. Notably the use of online resources were 1164 mentioned, with participants highlighting this was both 'guick' and 'easy. The online search of 1165 health related information is a common practice among younger demographic groups (Central 1166 Statistics Office, 2018; Sitaru et al., 2023), particularly in the case of allergy related 1167 information, which is challenging to access (King et al., 2020). While this information is free 1168 and easily accessible, the internet is unregulated and so provides much inaccurate, non-1169 evidence based information on allergies and their management (Ryan et al., 2005; Halls et 1170 al., 2018: Morris, 2019). This trend in the use of online resources poses risks for both FAP 1171 and their parents. In fact, reliance on such information will lead to poor management of allergic 1172 disease. A negative impact on the health of patients will be seen and there will be an increase 1173 in hospital visits which will prove counterproductive. Consequently, this will contribute to the 1174 already high burden on primary care and specialist allergy services (King et al., 2020).

1175 Reduced access to quality health care can cause psychological issues. FAP and P/C further 1176 shared feelings of the psychological impact of food allergy management. Increased stress, 1177 anxiety frustration and annoyance were common feelings reported by participants. The 1178 psychological burden of managing food allergies is another significant parallel between both 1179 groups, with this study highlighting that both FAP and P/C encounter similar emotional 1180 struggles when managing food allergies. In fact, P/C mentioned how the management of their 1181 child's food allergy contributed to a reduced quality of life, with a common feeling of 'sharing' 1182 the allergy with their child. Many studies have also reported the significant impact of food 1183 allergy on the quality of life of P/C, with increased stress and anxiety levels commonly seen in

1184 this group (Primeau et al., 2000; Bollinger et al., 2006; Akeson et al., 2007; Springston et al., 1185 2010; Morou et al., 2014; Birdi et al., 2016; Feng and Kim et al., 2018). University years are 1186 characterised by an increasing level of independence. The relationship between the parent 1187 and the child changes, with adolescents exercising more privacy and parents unable to readily 1188 monitor their child. P/C in this study further mentioned increased levels of worry and fear, 1189 when the main control of the food allergy moved to their child. This is a common feeling among 1190 food allergic P/C, with previous research also highlighting the additional concern parents face 1191 during the transitional period to adulthood (Feng and Kim, 2018; Moen et al., 2019).

1192 Literature also indicates that mothers are more likely to be impacted than fathers and present 1193 an increased psychological burden being the primary carers (King et al., 2009; Rouf et al., 1194 2012). Hoehn et al. (2017) posit that this increased psychological distress seen in mothers is 1195 because they are seen as the traditional caregivers and are more likely to take part in food 1196 allergy studies. Interestingly, the majority of P/C in this study were fathers (78%), suggesting 1197 that this particular group had an increased responsibility in managing their childs food allergy. 1198 Earlier research has mentioned a divided responsibility between parents, where mothers 1199 primarily take on the caregiving role and fathers were more likely to deal with financial 1200 expenses (Mitchell et al., 2007). Further research highlights that fathers are taking more of a 1201 central role in the direct care of their child's health (Knop and Brewster, 2016). In their study 1202 Hoehn et al. (2017), did find that while mothers were the primary care givers for their food 1203 allergic child and had increased psychological distress, where fathers were more involved, 1204 they would also experience their child's health as more burdensome. More recent research by 1205 Acaster et al., (2020) highlights that both mothers and fathers experience similar levels of 1206 psychosocial burdens in the management of food allergy. In their study, both parents were 1207 equally anxious and suffered the same level of negative career impact, productivity and health-1208 related quality of life when caring for their child's peanut allergy, thus challenging the traditional 1209 view of caregiving roles. There currently exists limited research in fathers of children with food 1210 allergy and thus, the findings of this study contribute to filling this research gap.

1211

1212 Despite the increased psychological impact experienced by P/C of children with food allergy. 1213 little psychological support was offered to this group. These results are unsurprising as while 1214 some psychological support is offered in tertiary centres in the UK, not much exists in the NW 1215 region. A wide body of literature further highlights the limited availability of psychological 1216 resources for both FAP and their parents (Mandell et al., 2005; Mercer et al., 2015; Young 1217 and Minshall, 2016; Feng and Kim, 2018; Knibb and Semper, 2013; Knibb et al., 2019; Santos 1218 et al., 2023). Patients and parents face a unique challenge in food allergy management which 1219 is clearly burdensome. Both FAP and P/C highlighted how the scarcity of psychological

1220 support increased stress and anxiety levels. Therefore, quality psychological health care for 1221 food allergies is therefore an essential component to reduce maladaptive and risky behaviours 1222 and to promote overall health. Feng and Kim, (2019), highlight the beneficial nature of support 1223 groups which can offer a vital platform in fostering a supportive environment for both patients 1224 and parents, to navigate the challenges of food allergy. Furthermore, Barker et al. (2021) 1225 recommend the inclusion of psychosocial aspects of allergy within the undergraduate 1226 curriculum of medical students to increase the accessibility of psychological support at the 1227 primary care level.

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# 1229

#### 9 <u>The Perspective of the Healthcare Professional</u>

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The barriers and facilitators experienced by HCPs in delivering care for LA with food allergies were also explored. The perspective of the GP, dietitian, nurse and social worker were all considered in this study. The challenges which were identified by HCPs in this study such as the absence of psychological support and barriers in attending appointments, are similar to the experiences reported by FAP and P/C in this study. Consequently, this indicates a systemic issue within the current healthcare framework, where both patients and healthcare providers face similar struggles.

1238

1239 One key barrier outlined by HCPs was the failure for LA to attend appointments. Non-1240 attendance of healthcare appointments by patients can lead to several consequences, 1241 including challenges in managing individual health, exacerbation of existing health conditions 1242 and the development of new conditions, which can contribute to an increased cost to the 1243 healthcare system (Paterson et al., 2010; Naqvi et al., 2018; McQueenie et al., 2019). LA will 1244 often struggle to prioritise healthcare and missed appointments are a common occurrence in 1245 this group (Neal et al., 2001; Masding et al., 2010; Paterson et al., 2010; Davey et al., 2012; 1246 Ellis et al., 2012). In this study, HCPs mentioned that the main reason for non-attendance was 1247 related to the financial constraints of patients. Both FAP and P/C echoed this, also mentioning 1248 the struggle in balancing the costs of managing food allergies with other expenses. This is a 1249 common theme emphasised in previous research (Bedford et al., 2020; Dawkins et al., 2021; 1250 Chapman et al., 2022). LA will often experience increased financial insecurity owing to the 1251 pursuit of independence, managing expenses and student expenditures (Ahmad et al., 2021; 1252 Tepler et al., 2022; Ravel et al., 2023). The management of food allergies during this period 1253 will further contribute to this economic burden (Minaker et al., 2014; Tackett et al., 2018). 1254 There is a marked geographical variation in allergy service provision across the UK and 1255 offering services closer to home (for instance the inclusion of allied health professionals or 1256 General Practitioners with Extended Roles (GPwERs) at the primary care level) can help to

combat financial difficulties and support the ability for patients to attend (Angier and Jay,
2019). HCPs additionally felt that LA were not serious about their condition and this contributed
to their lack of engagement in health care appointments. Crosby et al. (2009) suggest
providing education relating to the risks of missed appointments and the consequent negative
impact on health can help to facilitate attendance.

1262

1263 Another main barrier which emerged through the focus group discussion was the inability to 1264 provide adequate psychological support to patients, which was seen as a necessary 1265 component of their healthcare needs. HCPs felt limited in their ability to offer psychological 1266 support to their patients due to limited time, resources and training, barriers which have all 1267 been repeatedly mentioned in previous literature (Feng and Kim, 2018; Knibb et al., 2019; 1268 Memauri et al., 2022). This limitation can be directly related to the limited psychological 1269 support reported by FAP and P/C in this study, both of whom expressed a need for better 1270 psychological support to assist in their management of food allergies. Allied health 1271 professionals have a key role in supporting the delivery of psychological support in those with 1272 food allergies. Primary care physicians should foster collaborations with psychologists (who 1273 are trained in coping strategies e.g. cognitive behavioural therapy), social workers (who can 1274 address social and emotional aspects), dietitians (who can provide personalised dietary 1275 guidance) and nurses (who can reinforce education and support medical encounters), each 1276 of whom can provide tailored support, to create a more comprehensive and supportive 1277 environment for patients and reduce the burden associated with food allergy management 1278 (Mercer et al., 2015; Memauri et al., 2022). Vazquez-Ortiz et al. (2023), through their 1279 development of a 'toolbox' present a range of resources to help HCPs address the 1280 psychological needs of their patients. Web resources, self-help initiatives and cognitive 1281 behavioural therapy were some of the resources identified. There is a clear unmet need in the 1282 psychological management of food allergy and the regular implementation of such resources 1283 can provide crucial assistance to HCPs and consequently for FAP and their P/C.

1284

1285 Incorrect referrals were additionally identified as barriers in optimising the care for FAP. Not 1286 only did this waste a lot of time, but HCPs in this group (namely dietitians, some of whom 1287 worked alongside allergists) felt that incorrect referrals unnecessarily delayed patients in 1288 receiving appropriate care. This frustration in delayed care was also expressed by FAP and 1289 P/C in this study, who as a result experienced increased stress and anxiety. Much research 1290 has previously reported how GPs had difficulty in the referral process and this was owing to 1291 the lack of knowledge and training in this group (Levy et al., 2004; Ryan et al., 2005; Agache 1292 et al., 2013; Conlon et al., 2015; Diwakar et al., 2017; Ryan et al., 2017). In the primary care 1293 setting, the inclusion of GPwER's where physicians will have an increased level of specialist training can allow for more accurate assessments and ensure patients are directed towards
the right specialists/services at the right time (Levy et al., 2009; El-Shanaway et al., 2019).
Thus, improving the overall management of food allergy and reducing the burden on tertiary
centres.

1298

1299 Between the ages of 18 and 25 years there occurs many developmental changes and this 1300 transitional period from late adolescence to adulthood is a unique life stage (Roberts et al., 1301 2020). The needs of this group differ to that of the child and the adult and hence this period is 1302 one which requires tailored support (Beresford and Stuttard., 2014). Transition guidelines can 1303 help to address the specific needs of LA with food allergies, but they are lacking in the field of 1304 allergy (Khaleva et al., 2020). The findings in this study were no different, with HCPs 1305 expressing a need for improved transition guidelines at their practice, which were unclear and 1306 thought to not provide enough guidance. Some HCPs mentioned how despite the existence 1307 of transition guidelines at their workplace they were not regularly used. This inconsistent use 1308 of guidelines reinforces the inconsistency in care experienced by FAP and P/C who reported 1309 different experiences. Consequently, this highlights a gap in the continuity of care for FAP, 1310 which can significantly impact the health of the patient. The use of specific transition resources 1311 can support health care providers in strengthening the consistent care across all services, 1312 which will ensure the effective and successful long-term management of allergies (Knibb and 1313 Gore, 2020; Vazquez-Ortiz et al., 2023). Health providers should therefore be encouraged to 1314 regularly adopt and follow such guidelines, which will improve patient outcomes during this 1315 unique life stage of late adolescence. Recent allergy research has led to the development of 1316 a selection of targeted and practical transition resources to support the needs of the HCP, the 1317 patient and their families (Vazquez-Ortiz et al., 2023). The implementation of these resources 1318 should be considered across all health care settings. Regular reflection and reviews by HCPs 1319 should also be undertaken to facilitate improvement in service provision and optimise the level 1320 of care provided to LA with food allergies.

1321

1322 Training was considered to be both a barrier and facilitator in this group of health providers. 1323 Where participants mentioned they received specific training, they felt more confident in 1324 delivering the care to food allergy patients. This is consistent with previous research which 1325 highlights how training interventions can enhance knowledge and therefore confidence of 1326 professionals, improving the provision of care to patients with allergies (Sinott et al., 2011). In 1327 contrast, some HCPs found that they did not possess enough knowledge and were limited in 1328 providing care for this group. This lack of training directly correlates with the issues raised by 1329 FAP and P/C in this study, who frequently expressed dissatisfaction with the care they had 1330 previously received. At present, allergy barely features in the undergraduate medical

1331 curriculum, leaving qualified physicians with little to no knowledge in treating FAP (RCP, 2003; 1332 RCP, 2010; Diwakar et al., 2017; Busse et al., 2012; Reid et al., 2019). Through the 1333 discussion, dietitians also expressed feeling inadequate in providing nutritional support to 1334 patients and recognised the need for more training. Memauri et al. (2022) report these same 1335 findings and further illustrate how this is a common trend among other HCPs, including nurses 1336 and even allergists. This gap in training for HCPs explains why FAP were compelled to self-1337 manage their allergy, as the care they received was inadequate, owing to the lack of training 1338 of HCPs. Health professionals in this study further mentioned that despite this lack of training, 1339 few opportunities were available to enhance their knowledge and of the little which was 1340 offered, it was not mandatory.

1341

1342 Interestingly, none of the HCPs who took part in the focus group session mentioned any 1343 awareness or use of the recently published EAACI toolbox and transition guidelines (Vazquez-1344 Ortiz et al., 2023). This toolkit which has been specifically designed for HCPs, patients and 1345 P/C to improve the management of food allergies during the transitional period of late 1346 adolescence to adulthood, serves as a means of providing more structured guidance and a 1347 more holistic form of care. Therefore, this points to a potential lack of awareness of HCPs, 1348 where these resources could greatly benefit all groups as they attempt to navigate the 1349 management of food allergies in the crucial transitional period. This further indicates that there 1350 is an absence of these guidelines by HCPs, which could have contributed to the variation in 1351 care experienced by FAP and P/C. Consequently, this emphasises the urgent need for better 1352 education and awareness to allow for the effective implementation of these beneficial 1353 resources in healthcare settings.

1354

1355 In addition to training, HCPs highlighted the value of support groups which had helped in 1356 improving the level of allergy care provided to their participants. The beneficial nature of 1357 support groups for FAP and their families have been emphasised before (Sharma et al., 2012; 1358 Feng and Kim, 2019). One issue highlighted through the focus group discussion with HCP, 1359 was the difficulty in ensuring LA would regularly attend these support groups. Through the 1360 unique period of transition into adulthood, the acceptance of support for LA is for many, a 1361 means of admitting vulnerability or disrupting independence and this will often lead to 1362 disengagement in this group (Salaheddin and Mason, 2016; McPherson, 2020; Cretch et al., 1363 2022). Support groups offer a platform for food allergy patients and parents to share similar 1364 experiences, offer valuable emotional support and share practical advice. They additionally 1365 provide a sense of community for this group, who often will exhibit feelings of isolation during 1366 the management of their food allergy (Feng and Kim, 2019). Therefore, there is a need for 1367 HCPs to educate patients on the beneficial aspects of support groups, in order to encourage

1368 attendance. HCPs play a key role in facilitating engagement with support groups as this can 1369 directly influence the quality of care received by FAP and P/C. By fostering their active 1370 participation, HCPs can ensure FAP and their families are able to gain valuable emotional 1371 support and practical advice, which in turn can allow them to better manage their food 1372 allergies.

1373

1374 Through this study we sought to better understand the health care experiences of the patient 1375 and the professional, during the unique transitional period from late adolescence to adulthood. 1376 What is clear, is that LA with food allergies are at an increased risk of inconsistent, untimely 1377 care, often delivered by practitioners with lack of training and limited resources. This can 1378 impact HCPs, FAP and P/C, leading to a shared struggle in the management of food allergies. 1379 Although multiple studies highlight the need for improved resources and increased training in 1380 HCPs (Skypala et al., 2018; Demoly et al., 2019; Daniels et al., 2021; Memauri et al., 2022), 1381 the implementation of these guidelines have seldom been seen. As such, there is a continued 1382 reliance on self-management among patients (as mentioned in this study) who feel they 1383 cannot rely on the current healthcare system to provide consistent, high-quality care. One 1384 potential reason for this is due to competing financial priorities and constraints. Allergy service 1385 provision does not receive the same level of attention in comparison to other health conditions, 1386 e.g. obesity and cancer (Levy et al., 2009; Sinnott and Dudley-Southern., 2011; Vance et al., 1387 2021).

1388

1389 To address the unmet educational need in HCPs, the British Society for Allergy and Clinical 1390 Immunology (BSACI) Allergy Education Network have recently developed a National Allergy 1391 Education Strategy – the first of its kind, to be implemented in the UK (Vance et al., 2021). 1392 The strategy, which has been written by a multidisciplinary team of HCPs, focuses on 1393 improving their education and training in undergraduate, community and hospital settings. 1394 Allied HCPs are a central aspect to the strategy and the competencies outlined by the 1395 European Academy of Allergy and Clinical Immunology (EAACI) will be incorporated (Skypala 1396 et al., 2018). The development of this strategy will produce an increased number of educated 1397 and trained health professionals, thus allowing for the delivery of high quality care for allergic 1398 patients. Through this, a greater allergy awareness will be raised and thus, it is hoped that this 1399 will lead to an increase in funding and investment to allow for the delivery of optimal, cost-1400 effective healthcare (Vance et al., 2021). A more recent advance in allergy research in the 1401 UK, has led to the development of a GPwER framework, to create a network of specialist GPs 1402 who are trained in the field of allergy. This new framework will aim to standardise training for 1403 GPs to support the delivery of allergy care and improve the quality of services at the primary 1404 care level. This will be achieved through ensuring GPs have better access to training and

1405 allowing them to understand and develop the required knowledge and skills beyond their role 1406 as a generalist. Consequently, enabling them to become more suitably qualified in 1407 demonstrating competence when delivering allergy care. As such, this initiative aligns with the 1408 broader need for improved HCA and quality, whose lack thereof has been consistently 1409 mentioned by FAP and P/C in this study. This scheme is set to be trialled and piloted in 1410 December 2023 by two GP members. Following this pilot phase, it is hoped that a UK map of 1411 GPwERs in the field of allergy will be created and linked to existing pediatric and adult allergy 1412 networks (BSACI, 2023).

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# 1414 6.5. <u>Conclusion</u>

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1416 This qualitative study is one of the first to explore FC, FA and HCA in specifically LA with food 1417 allergies from the diverse perspectives of the FAP, the P/C and the HCP. Overall it was found 1418 that the social environment, university life and labelling each play a crucial role in shaping the 1419 FCs and eating behaviours of LA with food allergies. Additionally, FAP and P/C faced 1420 challenges in accessing AFF due to their high cost, limited availability and uncertainty in their 1421 safety all of which negatively impacted their diet quality. The research further highlights how 1422 the struggle in accessing specialist allergy care, particularly psychological support is a 1423 common theme in FAP and P/C. This study also provided rare insight into the lived 1424 experiences of HCPs who discussed barriers and facilitators when providing care for LA with 1425 food allergies. The challenges identified by the entire group underscore the need for more 1426 comprehensive solutions in the management of food allergies and the perspectives of the 1427 FAP, the P/C and HCPs will be vital in achieving this.

1428

# 1429 **6.6.** Limitations

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This study provides valuable insights into the current FCs, FA and HCA of LA with food allergies through the unique insights of the FAP, P/C and HCPs. However, it is important to also consider the limitations associated with this study, which could have impacted the findings.

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First, the nature of this study was qualitative and due to time constraints and for the convenience of the participants, each of the focus groups took place online via MS teams. This may have influenced the dynamics of the discussion. For instance, participants may not have easily shared their thoughts and feelings in a virtual setting compared to an in-person environment. Consequently, this could have limited the depth of the data collected. Second, only two focus groups for FAP and one each for P/C and HCPs were conducted and thus, saturation of focus groups was not reached. The limited number of focus groups means that potential additional themes may not have been identified and explored, affecting the comprehensiveness of these findings.

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Third, thematic analysis was used as the approach for data analysis and for this study involved both deductive and inductive methods. This dual coding process could have introduced researcher bias in the identification and development of themes. Although a mock focus group was conducted and reflective practices were employed to reduce this, the subjective nature of thematic analysis means that different researchers could have identified different themes or interpreted the data differently.

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Fourth, when sharing their experiences on FC, FA and HCA, participants may have been unintentionally subject to recall bias. They may have inaccurately shared details or presented them in ways they felt were more socially acceptable, which could have then impacted the accuracy of the results.

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Finally, it is also important to note here that all participants were recruited from the NW of England and the regional focus in this area may not have fully captured the diversity of experiences for LA with food allergies in other areas. Therefore, this limits the generalisability of the results, especially in relation to FC, FA and HCA which may differ based on factors such as socioeconomic deprivation and differences in healthcare infrastructure. Therefore, further research should consider these regional variations to capture a more comprehensive understanding of the various factors influencing FC, FA and HCA in the LA group.

1465

Understanding the current FCs, FA, and HCA of LA with food allergies was the focus of this and the previous chapters. Each of these factors are closely linked with overall dietary intake and as such, provide crucial context for understanding the nutritional behaviours of this group. Therefore, the next chapter – Chapter 7, will focus on the dietary intake of LA with and without food allergies in NW England. By exploring this aspect, important insights into how LA with food allergies manage their diet within the constraints of their FCs, FA and HCA will thus be explored.

# <u>Chapter 7</u> – Dietary Intake of Late Adolescents (18-25years) With and Without Food Allergies

3

4 7.1. <u>Overview</u>

5

6 The period of late adolescence (LA) to adulthood is one characterised by significant changes 7 in independence, lifestyle and also dietary habits. Often LA will gain autonomy over their food 8 choices (FCs) as they transition to university life or start working for the first time. These 9 changes will cause a shift in FC and dietary habits, which could impact long-term health 10 outcomes. During this crucial period, habits are established and will likely persist into later life. 11 Therefore, it is important to understand the dietary intake of LA.

12

Especially in those with food allergies, the importance of understanding dietary intake is key as this group will often restrict a variety of foods and therefore nutrients, as they attempt to navigate their food allergy. Although there is a growing prevalence of food allergies, little is known about the dietary intake in this group. In particular, most research focuses on children of the adult population, leaving a significant gap in our current understating of LA with food allergies.

19

20 The aim of this chapter therefore was to provide a comparative analysis of dietary intake 21 between LA with and without food allergies. Little is known about the dietary intake and 22 therefore nutritional status of LA with food allergies. To our knowledge, this is the first study 23 to directly compare dietary intake of LA (18-25years) with and without food allergies. The 24 rationale for comparing these groups was to determine if there existed any potential 25 differences in dietary intake, owing to the presence of a food allergy. A detailed diet log was 26 collected over a period of 4 consecutive days to achieve this. Results were compared to the 27 UK dietary reference values (UK DRVs), based on the current UK DRVs set by SACN 2015 28 and COMA 1991 (Public Health England, 2016) for adults aged 19+. The findings are 29 discussed in terms of their contribution to current literature, with regard to the dietary intake of 30 LA with and without food allergies.

31

32 7.2. Methodology

- 34 **Ethical Considerations**
- 35

36 Ethical approval was obtained from the National Health Service Research Ethics Committee 37 (NHS REC) (REC Reference: 21/EE/0285, Project ID: 303224) and the University of Central 38 Lancashire's (UCLan) HEALTH ethics committee, prior to data collection. Following approval, 39 participants were provided with a participant information sheet, providing them with detailed 40 information regarding the study. The participant information sheet was accessible online via a 41 secure link and detailed the purpose and nature of the study, potential risks and benefits of 42 the research and additionally emphasised participant confidentiality and the right to withdraw 43 at any point. This ensured all participants had all relevant information at hand, allowing them 44 to decide if they would like to participate. Once participants had reviewed the participant 45 information sheet, informed consent was obtained from all those who expressed interest in 46 the study, through an online consent form. Only after consent was given, participants were 47 able to access the take part in the research.

48

# 49 Participant Recruitment

50

51 The target population for this study was 18-25 year olds with one/more existing food allergies. 52 Both food allergic and non-food allergic participants who took part in the initial food selection 53 questionnaire from Phase 1 of this study, were invited to complete a food diary. A control 54 group of non-food allergic participants, who consumed an unrestricted diet were also recruited. 55 A recruitment poster was also created and shared via social media (Facebook, Twitter, 56 LinkedIn) as means of boosting recruitment for both groups. The recruitment poster was 57 shared with members of the food allergic community and with student pages to effectively 58 reach the 18-25 year demographic. For those with food allergies, inclusion criteria included 59 clinical diagnosis of their food allergy through either a Skin Prick Test, Serum specific IgE 60 along with a detailed medical history or an oral food challenge. Participants were excluded if 61 method of diagnosis was unknown or self-diagnosed. Additionally, any participants suffering 62 from any additional health conditions that directly impacted their dietary intake e.g. diabetes, 63 were also excluded. Furthermore, any incomplete diaries were not included for data analysis. All participants were required to reside in North West (NW), England and be able to fluently 64 65 speak and understand English.

66

68

67 All data collection took place over 3 weeks:

69 22<sup>nd</sup> to 25<sup>th</sup> February 2023

70 15<sup>th</sup> to 18<sup>th</sup> March 2023

- 71 *26<sup>th</sup> to 29<sup>th</sup> April 2023*
- 72

The main reason as to why data collection was spread over three different weeks, was to meet availability of participants, thus also boosting recruitment. All participants received a £10 gift voucher via email to thank them for their time upon completion of their diet diary. This is in accordance with NIHR payment for participants and public contributors in research (NIHR, 2022).

79

### 80 Study Design

81

# 82 Client Information Profile and Survey

83

84 Each participant was asked to complete a client information profile and short survey (Appendix 85 5) prior to completing the diet diary. Reminder emails were sent to each participant if this 86 information was not completed within two weeks. Participants were asked to provide socio-87 demographic information. Lifestyle questions relating to smoking status, alcohol intake and 88 exercise and occupation activity level were also asked. Participants were additionally asked 89 to provide information regarding their dietary behaviours including type of diet, variety of diet 90 and supplement intake. Additionally, participants were asked to rate on a scale of 1-5, the 91 attention paid to healthy eating when consuming foods, with 1 being never and 5 being always. 92 Moreover, those with food allergies were asked further questions relating to their allergy. All 93 profiles were reviewed by the lead researcher (myself) and in the case of any missing 94 information, participants were contacted via email and asked to complete them.

95

## 96 Dietary Assessment Method

97

98 In order to assess habitual dietary intake, participants were asked to complete a 4-day diet 99 diary. The diet diary consisted of 4 consecutive days - three weekdays and one weekend. 100 Participants were asked to electronically document all foods and beverages consumed within 101 this time period using an application called 'Libro' (Figure 7.1). Libro is a voice assisted 102 smartphone application that has been created by Nutritics – a nutrition software. This 103 application can easily be downloaded on both iPhone and Android. Therefore, allowing 104 participants to easily record food intake wherever they may be, saving time and improving 105 accuracy. All participants were also provided with a link to a short video clip which explained 106 how to navigate through the application. Detailed instructions on how to accurately record 107 intake was provided through this video, with participants being shown how to add foods to 108 their diet log manually or alternatively by scanning the barcode of a food item. Participants 109 were also shown how to build recipes using the recipe creator function, for any home cooked

meals. Any supplements taken, were also asked to be recorded by all participants.Participants were encouraged to provide as much detail as possible when recording intake.

112



- 124
- 125 **Figure 7.1.** Screenshot of Libro app used in 4-day diet diary
- 126
- 127

# 128 Dietary Analysis Software

129

130 Dietary intake from the 4-day diet diary was analysed and interpreted using the software 131 Nutritics (Research Edition v5.88). Reasons as to why this software was chosen include the 132 Nutritics database being extremely vast, containing over 772,000 foods. Additionally, the 133 database itself includes a range of dietary supplements and 'free from' foods which was 134 particularly useful for the food-allergic group. There was also potential for participants to add 135 an unlimited number of new foods, products and supplements that were not initially part of the 136 database. The software Nutritics also uses smart portion sizes allowing clients to choose from 137 different serving sizes for both foods and recipes. Life size portions of foods were suggested 138 in the form of common household utensils (e.g. cups, spoons) and small, medium and large 139 portion sizes. These were based on various portion size resources, manufacturers data or 140 from direct weighing by trained Nutritics staff. This visual representation of different portions 141 sizes were available to participants, allowed them to accurately record intake. There was also 142 an option for participants to modify the smart portions by increasing or decreasing the quantity 143 or alternatively manually typing in any unit of measure in the box provided, when creating a 144 recipe or adding a food. The software Nutritics also provided an option for demographic portion 145 size, which took into account participants age and gender and were based on the National 146 Diet and Nutrition Survey by Wrieden et al. (2004).

The completed 4-day food log for each participant was imported directly from Libro into the software Nutritics, for analysis. Mean energy and nutrient intake were automatically calculated for each participant. DRV's were compared to the current UK DRV's set by SACN 2015 and COMA 1991 (Public Health England, 2016) for adults aged 19+ and were expressed in the form of Reference Nutrient Intakes (RNI's). Estimated Average Requirements (EAR) were used when comparing energy intake between both groups.

153

## 154 Statistical Analysis

155

156 IBM SPSS Version 29.0 was used to conduct all statistical analysis. All categorical variables 157 were expressed as numbers and percentages. Continuous variables were expressed as mean 158 and standard deviation. In order to test for the normality of distribution, the one-sample 159 Kolmogorov-Smirnov test was used. All continuous variables were found to not be normally 160 distributed and therefore, to determine any differences between macro and micronutrient 161 intake between the food allergic and non-food allergic group, the Mann Whitney U test was 162 used. Despite the data being non-normally distributed (based on the one-Kolmogorov-Smirnov 163 test), a two-way ANOVA was employed to determine the impact of food allergy status on 164 nutrient intake in participants with and without food allergies. The reason for using ANOVA is 165 that this test is robust to errors of the normality assumption. Therefore, even when data does 166 not meet the criteria for a normal distribution, ANOVA can still provide valid results.

167

## 168 **7.3.** <u>Results</u>

169

A total of 74 participants aged 18-25 years were recruited from NW, England. Of these, 33 participants were clinically diagnosed with a food allergy and 41 participants formed the control group with no food allergy. Three participants produced incomplete diaries and decided to withdraw from the study. The final sample therefore, included a total of 71 participants – 31 with food allergies and 40 without food allergies.

175

# 176 Participant Demographics

177

Table 7.1 highlights the demographic characteristics of participants, with only slight differences found between both groups. Overall, a higher number of males took part in the diet diaries (n=39, 55%) in comparison to females (n=32, 45%), with both groups averaging a similar number of males and females. The mean age for those with food allergies was 21.7  $\pm$ 1.8 years, while for those without food allergies was 23.1  $\pm$  1.6 years. BMI was computed for each individual by dividing weight (kg) by height (m)<sup>2</sup>. A difference existed between groups for BMI, with food allergic participants averaging a lower BMI (22.6  $\pm$  2.7 kg/m<sup>2</sup>) in comparison to

- 185 those without food allergies (27.2  $\pm$  9.2 kg/m<sup>2</sup>).
- 186

187 In both groups, more than half of participants were students living on campus (n=39, 55%), 188 while 30% (n=21) were students not living on campus. Only eleven (15%) participants were 189 non-students, with a greater number being from the food allergic group (n=8, 11%). 190 Occupation and activity level varied between groups, with a larger percentage of participants 191 having an increased activity level for exercise in comparison to occupation. Majority of 192 participants from both groups followed a vegetarian diet (n=37, 52%). Of the 71 participants, 193 only 17 (24%) were taking supplements. The most common supplements taken by participants 194 were Vitamin D (n=6, 35%) and Vitamin B12 (n=5, 29%) (Table 7.1).

Table 7.1. Demographic Characteristics for 18-25 year olds, with a food allergy (n=31) and
without a food allergy (n=40)

	Food Allergy (n = 31)	No Food Allergy (n = 40)
Gender (n, %)		
Male	17 (54.8)	22 (55.0)
Female	14 (45.2)	18 (45.0)
Age (n, %)		
18	0 (0)	0 (0)
19	3 (9.7)	3 (7.5)
20	7 (22.6)	0 (0)
21	5 (16.1)	1 (2.5)
22	8 (25.8)	8 (20.0)
23	2 (6.5)	12 (30.0)
24	3 (9.7)	8 (20.0)
25	3 (9.7)	8 (20.0)
BMI (द्रि, SD)	22.6 (2.7)	27.2 (9.2)
Ethnic Background (n, %)		
White British	16 (51.6)	12 (30.0)
White European	3 (10.0)	1 (2.5)
White Other	2 (6.5)	2 (5.0)
Black: British Caribbean	2 (6.5)	6 (15.0)
Black: British African	2 (6.5)	2 (5.0)
Asian: British Indian	2 (6.5)	5 (12.5)
Asian: British Pakistani	2 (6.5)	6 (15.0)
Asian: British Other	1 (3.2)	3 (7.5)
Mixed Background	1 (3.2)	1 (2.5)
Chinese	0 (0)	2 (5.0)
Living Area (n, %)		
Rural	9 (29.0)	9 (22.5)
Urban	22 (71.0)	31 (77.5)

# **Table 7.1.** Continued

	Food Allergy (n = 31)	No Food Allergy (n = 40)
Student Status (n, %)		
Student (Living on Campus)	16 (51.6)	23 (57.5)
Student (Not Living on Campus)	12 (38.7)	9 (22.5)
Non-Student	3 (9.7)	8 (20.0)
Occupation Activity Level (n, %)		
Sedentary	3 (9.7)	10 (25.0)
Lightly Active	14 (45.2)	8 (20.0)
Moderately Active	7 (22.6)	10 (25.0)
Very Active	6 (19.4)	10 (25.0)
Extremely Active	1 (3.2)	2 (5.0)
Exercise Activity Level (n, %)		
Sedentary	0 (0)	11 (27.5)
Lightly Active	4 (12.9)	7 (17.5)
Moderately Active	13 (41.9)	9 (22.5)
Very Active	12 (38.7)	8 (20.0)
Extremely Active	2 (6.5)	5 (12.5)
Type of Diet (n, %)		
Different Every Day	17 (54.8)	17 (42.5)
Different During the Week	7 (22.6)	5 (12.5)
Different During the Weekends	0 (0)	3 (7.5)
Does not Vary	7 (22.6)	15 (37.5)
Dietary Preference (n, %)		
Vegetarian	16 (51.6)	21 (52.5)
Vegan	5 (16.1)	11 (27.5)
Halal	1 (3.2)	2 (5.0)
Kosher	4 (12.9)	1 (2.5)
Other	5 (16.1)	5 (12.5)
# **Table 7.1.** Continued

	Food Allergy (n = 31)	No Food Allergy (n = 40)
How Actively Do You Try To Eat Healthily (n, %)		
Never	8 (25.8)	13 (32.5)
Rarely	6 (19.4)	4 (10.0)
Sometimes	11 (35.5)	10 (25.0)
Very Often	3 (9.7)	6 (15.0)
Always	3 (9.7)	7 (17.5)
Supplement Use (n, %)	7 (22.6)	10 (25.0)
Smoking (n, %)	5 (16.1)	17 (42.5)
Alcohol (n, %)		
Everyday	0 (0)	0 (0)
3-5times/week	0 (0)	0 (0)
Once a week	4 (12.9)	4 (10.0)
Only Weekends	3 (9.7)	4 (10.0)
Occasionally	13 (41.9)	17 (42.5)
Never	11 (35.5)	15 (37.5)

199 Table 7.2 provides further details regarding the food allergic group. Of the 31 participants who 200 were clinically diagnosed with one/more existing food allergies, 65% (n=20) were found to 201 have a single food allergy, while 35% (n=11) possessed multiple food allergies. Type of food 202 allergy varied amongst participants. Majority of participants were found to have a reaction to 203 peanuts (n=14, 45%), followed by tree nuts (n=8, 26%), egg (n=8, 26%), fish (n=6, 19%), 204 shellfish (n=5, 16%), dairy (n=5, 16%), red meat (5, 16%), poultry (n=4, 13%), oral allergy 205 syndrome (n=4, 13%), milk (n=2, 6%) and finally sesame seed (n=2, 6%). Diagnosis of food 206 allergy was confirmed through either skin prick tests, blood tests, food elimination diets or a 207 combination of tests. Food elimination diet was found to be the most common amongst 208 participants (n=22, 71%), followed by skin prick tests (n=15, 48%) and blood tests (n=7, 23%). 209



210	Table 7.2. Demographic Characteristics of Food Allergic Participants (	n=31)	)

	Male	Female
Food Allergy (n, %)	17 (54.8)	14 (45.2)
Type of Food Allergy (n, %)		
Single	8 (47.1)	12 (85.7)
Multiple	9 (52.9)	2 (14.3)
Food Causing Allergy (n, %)		
Egg	5 (29.4)	3 (21.4)
Dairy	4 (23.5)	1 (7.1)
Milk	1 (5.9)	1 (7.1)
Peanuts	7 (41.2)	7 (50.0)
Tree Nuts	4 (23.5)	4 (28.6)
Sesame Seed	1 (5.9)	1 (7.1)
Fish	4 (23.5)	2 (14.3)
Shellfish	4 (23.5)	1 (7.1)
Oral Allergy Syndrome	2 (11.8)	2 (14.3)
Poultry	3 (17.6)	1 (7.1)
Red Meat	2 (11.8)	3 (21.4)
Diagnosis (n, %)		
Skin Prick Test	9 (52.9)	6 (42.9)
Blood Test	3 (17.6)	4 (28.6)
Food Elimination Diet	12 (70.6)	10 (71.4)

#### 211 **7.3.1.** <u>Macronutrient and Micronutrient Comparison Between Groups</u>

212

213 Tables 7.3 highlights the daily macronutrient, vitamin and mineral intake for all participants 214 with and without food allergies. It was found that those with food allergies had higher intakes 215 of all macronutrients, in comparison to those without food allergies. Although differences did 216 exist in macronutrient intake between groups, the Mann Whitney U test revealed these were 217 not statistically significant differences. Similarly, there was no statistically significant 218 differences found between groups in daily vitamin intake. Daily mineral intake was found in 219 higher quantities in potassium, magnesium, phosphorus, iron, copper, zinc and iodine for 220 those with food allergies. Sodium, chloride and selenium were found in higher quantities in 221 those without food allergies than those with food allergies. From the 12 minerals included for 222 analysis, the Mann Whitney U test (Appendix 6) revealed a statistically significant difference 223 between groups in only Chloride levels (U = 432 (Z = -2.180), p = 0.029) with food allergic 224 individuals having a higher intake. The mean salt intake was also calculated by converting the 225 average sodium consumed, multiplying by 2.542 and then dividing by 1000 (D'Elia et al., 226 2019). Following conversion, it was found that those without food allergies were consuming 227 higher levels of salt (10.1  $\pm$  24.3g) compared to those with food allergies (9.1g  $\pm$  7.8g) (Table 228 7.3).

Table 7.3. Daily Macronutrient and Micronutrient Intake and Mann Whitney U Test for those with Food Allergies (n=31) and without Food Allergies
 (n=40)

## Mann Whitney U test

	Food Allerg	jies (n=31)	No Food Aller	rgies (n=40)	Food Allergies (n=31)	No Food Allergies (n=40)			
	Mean	SD	Mean	SD	Mean Rank	Mean Rank	u-value	z-value	p-value
Macronutrients									
Energy (kcal)	3017.2	2754.9	2153.6	1474.9	40.6	32.5	479.0	-1.635	0.102
Protein (g)	98.4	61.2	86.3	61.0	38.4	34.2	546.0	-0.858	0.391
Fat (g)	94.6	60.3	73.5	45.2	39.7	33.2	507.0	-1.310	0.190
Carbohydrate (g)	436.7	659.6	277.7	249.0	40.4	32.6	485.0	-1.565	0.118
Free Sugars (g)	238.8	655.9	84.6	67.8	38.2	34.3	551.0	-0.800	0.424
Fibre (g)	31.2	21.0	27.4	22.6	39.0	33.7	528.0	-1.067	0.286
Saturated Fat (g)	31.4	24.4	21.8	15.1	40.3	32.7	487.0	-1.542	0.123
Monounsaturated Fat (g)	23.6	20.0	17.7	14.8	39.0	32.7	496.0	-1.283	0.200
Polyunsaturated Fat (g)	10.7	8.5	8.7	7.7	39.1	32.6	492.0	-1.330	0.183
Cholesterol (mg)	261.5	379.9	159.4	173.4	37.2	32.3	490.0	-1.028	0.304
Vitamins									
Vitamin A (ug)	1035.4	1688.4	633.4	1167.5	40.0	32.9	495.0	-1.449	0.147
Vitamin C (mg)	174.4	319.2	117.4	106.8	35.6	35.5	598.5	-0.018	0.986
Vitamin D (ug)	4.6	9.1	3.0	5.7	36.9	33.5	535.0	-0.706	0.480

#### 231 **Table 7.3.** Continued

# 232

#### 233

#### Food Allergies No Food No Food Allergies (n=40) Food Allergies (n=31) (n=31) Allergies (n=40) SD SD Mean Mean Mean Mean Rank p-value u-value z-value Rank Vitamins Vitamin E (mg) 8.7 6.4 7.4 7.0 32.7 487.0 0.123 40.3 -1.542 Vitamin B1 (mg) 0.223 1.8 2.1 1.4 1.5 39.4 33.4 515.0 -1.217 1.0 0.7 0.175 503.0 Vitamin B2 (mg) 1.3 0.9 39.8 33.1 -1.356 Vitamin B3 (mg) 25.2 19.6 25.2 23.7 37.0 35.3 591.0 -0.336 0.737 Vitamin B6 (mg) 1.6 1.0 0.9 40.0 32.9 495.0 0.147 1.3 -1.449 Vitamin B12 (ug) 3.3 3.0 2.7 3.0 39.2 32.6 489.5 -1.360 0.174 Biotin (ug) 24.2 23.1 22.2 23.6 36.3 610.0 0.908 35.8 -0.116 Folate (ug) 221.6 212.6 135.1 107.0 40.5 32.5 481.0 -1.611 0.107 Minerals 3565.7 3060.7 3987.8 9550.2 41.0 32.2 466.0 0.074 Sodium (mg) -1.785 Potassium (mg) 3340.6 3248.5 2262.4 39.0 33.7 526.0 0.276 1477.6 -1.090 Calcium (mg) 701.8 737.9 601.4 448.6 36.6 35.6 602.0 -0.209 0.835 Magnesium (mg) 386.0 676.4 264.7 243.6 37.1 35.2 586.0 -0.394 0.693 Phosphorus (mg) 1026.2 0.945 1054.8 780.7 831.4 35.8 36.2 614.0 -0.070

# <u>Mann Whitney U test</u>

## 234 **Table 7.3.** Continued

# 235

## 236

#### Food Allergies (n=31) No Food Food Allergies (n=31) No Food Allergies (n=40) Allergies (n=40) SD SD Mean Mean Mean Mean Rank u-value z-value p-value Rank Minerals 11.4 9.7 33.4 517.0 0.232 Iron (mg) 7.5 7.2 39.3 -1.194 Copper (mg) 1.3 1.0 1.0 0.8 39.3 33.5 519.0 0.242 -1.171 Zinc (mg) 8.7 8.3 7.7 7.4 37.6 34.8 572.0 -0.556 0.578 Chloride (mg) 5305.4 4664.5 5949.5 14402.3 42.1 432.0 -2.180 0.029 31.3 Manganese (mg) 3.5 2.6 3.5 3.9 38.0 34.4 557.0 -0.730 0.465 Selenium (ug) 41.5 39.6 44.1 64.1 37.9 34.5 560.0 -0.696 0.487 38.2 553.0 -0.777 0.437 lodine (ug) 74.0 71.3 62.5 57.8 34.3 9.1 Salt (g) 7.8 10.1 24.3

Mann Whitney U test

#### 205

#### 237 7.3.2. Macronutrient and Micronutrient Comparison to DRV's

238

239 Daily macro and micro nutrient intake was compared to DRV's between male and female 240 participants with and without food allergies. For those with and without food allergies, 241 participants easily met the DRV's and in most cases exceeded the recommended intake. 242 Energy levels were exceeded in comparison to the EAR in males and females with food 243 allergies. In those without food allergies, male participants failed to meet EAR, while energy 244 levels in females were above recommended intake. All participants met RNI for protein intake. 245 Male participants in both groups were within recommended levels for fat intake and therefore 246 cholesterol. Surprisingly, in females with and without food allergies, fat levels, including 247 saturated fat levels were exceeded, but cholesterol levels were within range. Levels of 248 carbohydrate were exceeded by males with food allergies (63%), beyond the recommended 249 daily intake of 50% (BNF, 2021). In contrast, carbohydrate intake was below the 250 recommended DRV for males without food allergies. However based on average daily energy 251 intake for male participants in this group, carbohydrates levels were consumed in excess 252 (54%). Carbohydrate intake was met by both females with food allergies (49%) and without 253 food allergies (49%). All participants in both groups exceeded the RNI for free sugars. With 254 an average daily intake of  $37.6 \pm 21.6$ , males with food allergies were the only group to meet 255 fibre levels (Tables 7.4 and 7.5).

256

When comparing vitamin intake to RNI's, it was found that for vitamin A, vitamin C, vitamin E, vitamin B1, vitamin B3 and vitamin B12, male and female participants with food allergies exceeded recommendations in comparison to both genders without food allergies. Vitamin D levels were not met by both groups in males and females and were considerably lower in those without food allergies. Vitamin B2 and vitamin B6 levels were just met by all participants in both groups while folate levels were not met by participants without food allergies (Tables 7.4 and 7.5).

264

265 Daily mineral intake was met by participants and in most cases levels were exceeded. 266 Selenium and iodine levels were found in lower quantities when compared to RNI in all food 267 allergic participants and non-food allergic participants. Males with food allergies were easily 268 able to meet RNI for all other minerals, while males without food allergies also failed to meet 269 potassium, calcium and magnesium levels. In addition to selenium and iodine, female 270 participants with and without food allergies failed to meet RNI's for potassium. Calcium levels 271 were not met by females with food allergies. Iron levels were met by males in both groups, in 272 comparison to females in both groups who failed to meet the RNI for iron. Following

- 273 conversion, salt intake was found to be in excess of the recommended 6g/day in all
- 274 participants irrespective of food allergy status and gender (Tables 7.4 and 7.5).

- 275 **Table 7.4.** Daily Macronutrient and Micronutrient Intake for Males and Females (19-25years)
- 276 with Food Allergies (n=31) in comparison to Dietary Reference Values

		Males		Ferr		
	DRV's	Mean	SD	DRV's	Mean	SD
Macronutrient						
Energy (kcal)	2500	3498.1 ↑	3447.9	2000	2433.3 ↑	1487.5
Protein (g)	55.5	104.0 ↑	65.7	45	91.5 ↑	57.0
Fat (g)	<97	93.3	60.7	<78	99.5↓	62.1
Carbohydrate (g)	333	552.4	868.8	267	296.1	190.7
Free Sugars (g)	33	341.7 ↑	877.2	27	113.8 ↑	122.7
Fibre (g)	30	37.6	21.6	30	23.5 ↓	18.0
Saturated Fat (g)	<31	30.0	23.3	<24	37.8 ↑	26.5
Monounsaturated Fat (g)	36	23.6↓	24.0	29	23.7 ↓	14.8
Polyunsaturated Fat (g)	18	11.6↓	10.6	14	9.6↓	5.0
Cholesterol (mg)	300	261.1	470.1	300	189.1	225.1
Vitamins						
Vitamin A (ug)	700	1357.6	2158.8	600	644.2	736.3
Vitamin C (mg)	40	168.4	172.1	40	121.3	439.2
Vitamin D (ug)	10	5.1↓	10.9	10	3.9 ↓	6.5
Vitamin E (mg)*	-	10.1	7.8	-	7.0	3.8
Vitamin B1 (mg)	1	1.7	1.1	0.8	1.9	3.0
Vitamin B2 (mg)	1.3	1.3	1.0	1.4	1.6	1.0
Vitamin B3 (mg)	16.5	26.7	21.6	13.2	23.4	17.5
Vitamin B6 (mg)	1.4	1.4	1.1	1.6	1.8	0.8
Vitamin B12 (ug)	1.5	3.7	3.2	1.5	3.0	2.7
Biotin (ug)	30	31.2	27.8	105	35.6↓	15.9
Folate (ug)	200	226.6	184.4	200	235.4	249.8

277

278 \*No dietary reference values existed for vitamin E and Manganese at the time of the study

279 Red accompanied by an up  $\uparrow$  arrow indicates above the recommended limit

280 Red accompanied by a down  $\downarrow$  arrow indicates below the recommended limit

281 Green indicates within the recommended limit

- 282
- 283

		Males		Ferr		
	DRV's	Mean	SD	DRV's	Mean	SD
Minerals						
Sodium (mg)	2400	3342.1 ↑	1926.0	2400	3837.2 ↑	4112.0
Potassium (mg)	3500	3748.5	3738.6	3500	2845.4 ↓	2582.3
Calcium (mg)	700	849.8	942.5	700	521.9 ↓	315.8
Magnesium (mg)	300	486.8	894.3	270	265.5	204.9
Phosphorus (mg)	550	1154.3	898.5	550	933.9	619.8
Iron (mg)	8.7	11.5	7.5	14.8	11.1 ↓	7.7
Copper (mg)	1.2	1.3	1.0	1.2	1.3	1.1
Zinc (mg)	9.5	9.7	9.5	7.0	7.5	6.8
Chloride (mg)	2500	4728.4 ↑	2431.8	2500	6006.0 ↑	6478.2
Manganese (mg)*	-	3.8	2.9	-	3.0	2.2
Selenium (ug)	75	46.5 ↓	44.0	60	35.5 ↓	34.2
lodine (ug)	140	82.3↓	80.8	140	63.9↓	59.2
Salt (g)	6	8.5 ↑	4.9	6	9.8 ↑	10.5

286 \*No dietary reference values existed for vitamin E and Manganese at the time of the study

287 Red accompanied by an up  $\uparrow$  arrow indicates above the recommended limit

288 Red accompanied by a down  $\downarrow$  arrow indicates below the recommended limit

289 Green indicates within the recommended limit

- 302 **Table 7.5.** Daily Macronutrient and Micronutrient Intake for Males and Females (19-25years)
- 303 without Food Allergies (n=40) in comparison to Dietary Reference Values

		Males		Ferr		
	DRV's	Mean	SD	DRV's	Mean	SD
Macronutrient						
Energy (kcal)	2500	2101.1 ↓	1793.9	2000	2217.7	1003.6
Protein (g)	55.5	81.2	71.9	45	85.6	45.5
Fat (g)	<97	67.1	52.1	<78	93.6 ↑	34.8
Carbohydrate (g)	333	282.3↓	314.6	267	272.1	141.2
Free Sugars (g)	33	90.7 ↑	87.0	27	<b>77.1</b> ↑	33.0
Fibre (g)	30	27.7↓	23.3	30	27.1 ↓	22.4
Saturated Fat (g)	<31	18.1	14.0	<24	31.5 ↑	15.7
Monounsaturated Fat (g)	36	14.6↓	17.2	29	21.2↓	10.7
Polyunsaturated Fat (g)	18	8.1↓	9.8	14	9.4 ↓	4.2
Cholesterol (mg)	300	118.0	194.0	300	208.0	135.3
Vitamins						
Vitamin A (ug)	700	726.7	1540.7	600	519.3 ↓	412.2
Vitamin C (mg)	40	113.7	115.0	40	98.3	98.8
Vitamin D (ug)	10	3.8↓	7.6	10	2.2↓	2.2
Vitamin E (mg)*	-	6.4	8.4	-	8.5	4.4
Vitamin B1 (mg)	1	1.1	1.3	0.8	1.7	1.7
Vitamin B2 (mg)	1.3	1.3	0.8	1.4	1.8	0.5
Vitamin B3 (mg)	16.5	19.7	27.2	13.2	31.8	17.1
Vitamin B6 (mg)	1.4	1.4	0.9	1.6	1.7	0.8
Vitamin B12 (ug)	1.5	1.8	2.1	1.5	3.7	3.6
Biotin (ug)	30	29.4	18.9	105	30.2 ↓	27.8
Folate (ug)	200	116.1 ↓	115.3	200	158.4 ↓	93.7

304 \*No dietary reference values existed for vitamin E and Manganese at the time of the study

305 Red accompanied by an up  $\uparrow$  arrow indicates above the recommended limit

306 Red accompanied by a down  $\downarrow$  arrow indicates below the recommended limit

307 Green indicates within the recommended limit

		Males		Females		
	DRV's	Mean	SD	DRV's	Mean	SD
Minerals						
Sodium (mg)	2400	4848.4 ↑	12763.0	2400	2935.8 ↑	2426.3
Potassium (mg)	3500	1884.4 ↓	1665.4	3500	2724.4 ↓	1082.6
Calcium (mg)	700	493.1 ↓	478.4	700	733.9	381.1
Magnesium (mg)	300	224.7 ↓	204.7	270	313.5	282.4
Phosphorus (mg)	550	872.1	936.4	550	1214.5	659.1
Iron (mg)	8.7	10.6	6.2	14.8	11.2↓	8.1
Copper (mg)	1.2	1.1	0.8	1.2	1.2	0.9
Zinc (mg)	9.5	5.7↓	5.8	7.0	10.1	8.7
Chloride (mg)	2500	<b>7108.2</b> ↑	19165.0	2500	4533.3 ↑	4275.4
Manganese (mg)*	-	3.1	2.8	-	4.0	5.0
Selenium (ug)	75	41.6↓	68.6	60	47.1↓	60.0
lodine (ug)	140	40.3↓	39.5	140	89.6↓	65.5
Salt (g)	6	<b>12.3</b> ↑	32.4	6	7.5 ↑	6.2

309 \*No dietary reference values existed for vitamin E and Manganese at the time of the study

310 Red accompanied by an up  $\uparrow$  arrow indicates above the recommended limit

311 Red accompanied by a down  $\downarrow$  arrow indicates below the recommended limit

312 Green indicates within the recommended limit

Two-way ANOVA was conducted to assess the impact of gender and food allergy status on nutrient intake. Results revealed a statistically significant difference in calcium [F (1, 67) = 4.112, P = 0.047] and iodine [F (1, 67) = 5.193, p = 0.026] (Table 7.6). Simple mains effect analysis showed that no statistically significant difference existed on calcium (p = 0.321) and iodine (p=0.968) intake between genders in those with food allergies (Table 7.7). However, in those without food allergies, simple mains effect tests indicated that females had a statistically significant higher intake of calcium (p =0.034) and iodine (0.008), in comparison to males.

- **Table 7.6.** Results of Two-Way ANOVA on the impact of food allergy status and gender for
- 321 macronutrient and micronutrient intake

	df	Mean Square	F	р
Macronutrients				
Energy (kcal)	1	6036133.4	1.332	0.253
Protein (g)	1	2483.2	0.652	0.422
Fat (g)	1	551.5	0.198	0.658
Carbohydrate (g)	1	261778.9	1.172	0.283
Free Sugars (g)	1	198661.4	1.890	0.309
Fibre (g)	1	791.7	1.677	0.200
Saturated Fat (g)	1	104.0	0.267	0.607
Monounsaturated Fat (g)	1	179.1	0.594	0.444
Polyunsaturated Fat (g)	1	45.0	0.681	0.412
Cholesterol (mg)	1	206362.0	2.538	0.116
Vitamins				
Vitamin A (ug)	1	1107428.8	0.552	0.460
Vitamin C (mg)	1	92.0	0.002	0.966
Vitamin D (ug)	1	1.241	0.022	0.882
Vitamin E (mg)	1	117.1	2.637	0.109
Vitamin B1 (mg)	1	0.8	0.242	0.624
Vitamin B2 (mg)	1	1.7	2.441	0.123
Vitamin B3 (mg)	1	1016.5	2.135	0.149
Vitamin B6 (mg)	1	5.6	6.464	0.013
Vitamin B12 (ug)	1	29.4	3.4	0.070
Biotin (ug)	1	1316.3	2.429	0.124
Folate (ug)	1	12394.8	0.466	0.497

# **Table 7.6.** Continued

	df	Mean Square	F	р
Minerals				
Sodium (mg)	1	25065748.3	0.442	0.508
Potassium (mg)	1	13137655.2	2.266	0.137
Calcium (mg)	1	1398461.0	4.112	0.047
Magnesium (mg)	1	421260.2	1.812	0.183
Phosphorus (mg)	1	1370012.5	2.100	0.152
Iron (mg)	1	46.132	0.858	0.358
Copper (mg)	1	0.569	0.648	0.424
Zinc (mg)	1	183.590	3.069	0.084
Chloride (mg)	1	64175930.3	0.496	0.484
Manganese (mg)*	1	12.755	1.081	0.302
Selenium (ug)	1	1169.2	0.380	0.540
lodine (ug)	1	19814.679	5.193	0.026

Table 7.7. Results of simple main effects analysis on the impact of food allergy status and
 gender for calcium and iodine intake in those with and without food allergies

With Food Allergies	Mean Rank Male (n=17)	Mean rank Female (n=14)	df	Kruskal- Wallis H	р
Calcium (mg)	17.47	14.21	4.112	0.985	0.321
lodine	15.94	16.07	1	0.002	0.968
Without Food Allergies					
Calcium (mg)	16.95	24.83	1	4.497	0.034
lodine	16.05	25.94	1	7.098	0.008

- 326 7.4. Discussion
- 327

## 328 7.4.1. Between Groups

329

330 Often with LA, the quest for identity and purpose, the transition into university life and the 331 importance of social dynamics can lead to poor FC and therefore, poorer dietary intake 332 (Pelletier et al., 2014; Herman, 2017; Sprake et al., 2018). In addition to this, individuals with 333 food allergies will have dietary restrictions and if alternative foods that can support and 334 maintain a healthy diet are not incorporated, there is an increased risk of malnutrition (Kim et 335 al., 2013; Dilley et al., 2018; Tackett et al., 2019; Groetch and Venter, 2020). Therefore, it 336 was expected that the diet of those with food allergic participants in this study would be 337 deficient. Yet this was not highlighted in this particular research. When comparing between 338 groups, nutrient intake in those with and without food allergies was largely similar. Participants 339 with food allergies were found to consume higher quantities of all macronutrients, vitamins 340 and most minerals, with only sodium, chloride and selenium found in higher quantities in those 341 without food allergies. Analysis revealed a statistically significant difference in only one nutrient 342 between both groups - chloride levels, with higher intakes found in the food allergic group. No 343 previous research has looked at dietary intake exclusively in LA with food allergies. However, 344 one similar study which focused on early adolescence (11-18years) did report the same 345 findings as our research (Maslin et al., 2018).

- 346
- 347 7.4.2. DRV Comparison
- 348

The following section will look into the different macro and micronutrients and suggest reasons as to why participants were or were not able to meet daily guidelines. This will allow us to provide an overall picture of the dietary intake in LA with and without food allergies, in the NW of England.

353

# 354 7.4.2.1. Macronutrients

355

356 Energy

357

When comparing to DRV's, most participants in both groups met their age and gender specific recommendations for macronutrients. In order to meet the physiological demands of the body during the period of late adolescence, an increase in energy intake is necessary (Jodhun et al., 2016). Energy levels in comparison to the EAR were exceeded by all participants with food 362 allergies and female participants without food allergies. Male participants without food 363 allergies were the only group who failed to meet energy requirements, which is similar to 364 findings from a previous study (Ayogu et al., 2022). Additionally, a noticeable difference existed between groups in BMI, with food-allergic participants averaging a BMI of 22.6kg/m<sup>2</sup> 365 366 and non-food allergic participants averaging 27.2kg/m<sup>2</sup>. This difference indicates that those 367 with food allergies are within a healthy weight range, while those without food allergies are 368 considered to be overweight. These findings are dissimilar to that of a similar study (Maslin et 369 al., 2018), which found no differences between groups in BMI. Despite differences in BMI in 370 the present study, no statistically significant differences existed in the percentage of energy 371 derived from protein, fat and carbohydrates between the food-allergic and non-food allergic 372 group.

373

374 **Fat** 

375

376 Regarding fat intake, no statistically significant differences were found between those with and 377 without food allergies, however differences in gender did exist. Male participants in both 378 groups were within recommended levels of 35% and 11% of fat and saturated fat respectively 379 and therefore cholesterol. In contrast, females both with and without food allergies exceeded 380 overall fat and in particular saturated fat levels. Although these findings are consistent with 381 previous research (Nasreddine et al., 2020) they are also somewhat surprising, given that 382 literature describes women as more health conscious and having higher nutritional knowledge 383 and therefore, more inclined to meet recommendations than men (Arganini et al., 2012; 384 Jodhun et al., 2016; Munt et al., 2017; Bennett et al., 2018; Lombardo et al., 2019; Barebring 385 et al., 2020). These findings could possibly be explained by the results from previous chapters 386 in this research, where LA with food allergies experienced reduced access to healthier food 387 options and AFF. This limited availability could have caused participants, especially females 388 who may have prioritised convenience or affordability, to consume foods high in saturated 389 fats. Additionally, although saturated fat levels were exceeded in female participants, 390 cholesterol levels in this group were well within range. Thus indicating that other lifestyle and 391 dietary factors played a role in contributing to this lowered cholesterol. Additionally, genetics 392 also play a crucial role in determining cholesterol levels. Particularly, young females are 393 genetically predisposed to lower total cholesterol levels due to the increased hormonal 394 changes during this life stage (Mumford et al., 2011; Downer et al., 2014; Lephart, 2018; Nie 395 et al., 2022). Hence, this can provide a potential explanation for the results observed in female 396 cholesterol levels.

397

- 398 Carbohydrate
- 399

400 Concerning carbohydrate intake. male participants in both groups exceeded 401 recommendations of 50%, while females in both groups met these requirements. Previous 402 research has also reported a higher intake of carbohydrate in men than women (Zhao et al., 403 2020; Liu et al., 2021). Carbohydrates are a major source of energy and all participants in this 404 study either met or exceeded intakes. However, the guality of carbohydrates is undesirable 405 and a cause for concern.

406 407

#### a) Free Sugars

408

409 Firstly, all participants exceeded in their consumption of free sugars. DRV's indicate free 410 sugars should make up no more than 5% of daily energy intake (Public Health England, 2016). 411 Despite this, those in the food-allergic group had an intake of 40% and 19% of free sugars for 412 males and females respectively. Similarly, in the non-food allergic group an intake of 17% and 413 14% was found in males and females respectively. The increased sugar intake seen in food 414 allergic participants can be as a result of the inclusion of AFF in their diet. Research has found 415 that the nutritional composition of 'free from' foods is compromised, with excessive amounts 416 of fat, salt and sugar added to increase palatability (Saturni et al., 2010; Moreno et al., 2014). 417 Therefore, those with food allergies will be at a far greater risk of an imbalanced diet as 418 mirrored by these findings. However, the previous studies from this research suggest that the 419 high cost and limited availability of AFF will often pose barriers in purchasing these products. 420 There is a possibility that LA with food allergies may compensate for this high cost and limited 421 availability of AFF by consuming increased amounts of non-AFF that are cheaper, more 422 readily available, but likely less nutritious. This indicates a potential coping strategy where the 423 reduced access to AFF force individuals to consume foods of lower nutritional quality, leaving 424 them in a state of persistent unhealthy eating habits.

425

426 In addition to this, the increased overall free sugar intake in both groups is in actual fact 427 unsurprising. Much literature has found how LA consume a diet high in free sugars (Chatelan 428 et al., 2019; Livingstone et al., 2022). One reason to explain this increased sugar intake is due 429 to social norms. The search for a social identity and sense of belonging is a significant aspect 430 of development in LA. As individuals seek to form and establish their identity, they will attempt 431 to gain peer approval. This strong need for group acceptance suggests that LA are more 432 susceptible to peer norms, which will largely shape their food intake (Higgs and Thomas, 2016; 433 Stok et al., 2016; Bevelander et al., 2020). LA often contextualise energy dense, but poor 434 nutrient foods with peer and social gatherings and such foods are often an indication of meal 435 enjoyment (Qutteina et al., 2019). Poobalan et al. (2014), further supports this, showing that 436 LA were more likely to engage in poor eating behaviour when in social settings. In particular, 437 they found that eating habits of university students were more irregular and consisted of an 438 increased level of meal skipping and snack and fizzy drink consumption. Specifically, it was 439 revealed that only 40% consumed sufficient fruits and vegetables, while 60% were consuming 440 greater than 4 snacks a day which included chocolates, crisps and fizzy drinks. It was also 441 found that LA irrespective of education level or socioeconomic status were aware of what 442 constitutes a healthy and unhealthy diet and also had knowledge of the negative impacts of 443 eating poorly, yet they were unable to translate this into actual behaviour (Poobalan et al. 444 (2014). Studies have further reinforced this showing that even when individuals possessed 445 appropriate nutritional knowledge, they were still willing to choose fast foods when in social 446 environments and with peers, as it would be considered too risky to deviate from these 447 accepted norms (Brown et al., 2000; Stead et al., 2011; Pelletier et al., 2014). While much 448 literature does indicate the impact of social norms and peer influence on high sugar intake. 449 the previous studies in this piece of research indicate that LA with food allergies often avoid 450 eating out due to concerns with allergen exposure or feelings of being different. Therefore, the 451 high sugar intake observed in this study could be related to the increased consumption of 452 packaged and processed foods in certain environments where individuals feel safe. Hence, 453 the avoidance of eating in social settings does not necessarily reduce sugar consumption, but 454 instead shifts it towards different contexts where LA with food allergies feel more comfortable. 455

456 Furthermore, in contrast to our results, several studies have highlighted that women have 457 higher intake of sugar than men (Grunberg and Straub, 1992; Oliver and Wardle, 1999; 458 Wansink et al., 2003). Bennett et al. (2018), found that UK women are also more likely to 459 consume higher quantities of fruit (a natural source of sugar), which will increase total sugar 460 intake. Moreover, despite women reporting wanting to eat healthier, research has found that 461 women are more likely to consume an increased quantity of foods such as cookies, chocolate 462 and ice cream than men, all of which contribute to a higher sugar intake (Wansink et al., 2003; 463 Kanter and Caballero, 2012; Spence, 2017; Livingstone et al. 2022). Likewise, females have 464 been reported to engage in higher levels of snacking of energy dense foods (Wansink et al., 465 2003; Kanter and Caballero, 2012; Spence, 2017). Additionally, they were more likely to skip 466 more meals than men and were found to consume foods more times during the day and 467 uncontrollably too, even if they were not hungry (Lombardo et al., 2019). Meanwhile, research 468 by Mohamed et al. (2020), indicate that during times of stress (in particular during university 469 years), males are more reliant on convenience and takeaway foods, potentially explaining the 470 differences in free sugar intake seen in between genders.

471

472 **b)** *Fibre* 

#### 473

474 In this study, most participants struggled to meet dietary fibre requirements. Limited UK 475 research currently is available looking at the dietary fibre intake of LA. However, of the 476 literature which does exist, inadequate fibre levels were found to be a common occurrence in 477 this group (Chourdakis et al., 2010; Nicklas et al., 1995; Chourdakis et al., 2010; Buil-Cosiales 478 et al., 2017; Seljak et al., 2021). This can be due to many reasons. Firstly, LA will be leading 479 independent lifestyles and perhaps for the first time in their lives will be responsible for their 480 individual FCs (Hafiz et al., 2023). Previous research highlights how this reduced parental 481 supervision will lead to LA making poorer FCs, which include an increased concentration of 482 energy dense nutrient poor foods (Hebden et al., 2015; Haugland et al., 2019; Ziegler et al., 483 2021). Secondly, this group of individuals are especially vulnerable to a poor food 484 environment, making it easier to choose such foods. A high percentage of participants in this 485 study (85%) were students at university and much literature informs us that the university 486 environment is considered 'obesogenic,' making it difficult to eat healthier (Poobalan et al., 487 2014; Tanton et al., 2015; Pulz et al., 2016; Munt et al., 2017; Brennan et al., 2020; Martinez-488 Perez et al., 2021; Coyle et al., 2023). This will lead individuals to have an increased 489 consumption of processed foods high in saturated fat, salt and sugar and a diet low in fruits, 490 vegetables and whole grains (Larson et al., 2020), which consequently will contribute to their 491 reduced fibre intake. Finally, cost and time are both important predictors of FC in LA who often 492 have limited funds to spend and limited time to prepare foods. (Contento, 2011; Graziose, 493 2016; Stok et al., 2016; Hall, 2018; Sogari et al., 2018; Liem and Russell, 2019; van den 494 Bogerd et al., 2019; Monterrosa et al., 2020; Hutchesson et al., 2022). While fruits and 495 vegetables contribute to increased fibre intake, these foods are considered more expensive 496 limiting their purchase and consumption (Fricke et al., 2015; van den Bogerd et al., 2019; 497 Diamini et al., 2023). Despite their low nutritional quality, heavily processed foods, fast foods 498 and ready to eat meals, which contain little fibre will be consumed a great deal more by LA, 499 as they are both more affordable and convenient.

500

501 Dietary fibre is an essential component of a healthy diet. A high fibre diet will support digestion 502 and promote a healthy gut microbiome and additionally reduce the risk of many non-503 communicable diseases (Barber et al., 2020; McKeown et al., 2022) Consequently, these 504 findings of low fibre in this study are quite concerning. Not only do they reflect poor FCs in this 505 group of LA, which further emphasises poor dietary quality, but these individuals will naturally 506 be at an increased risk of developing a range of health issues. Despite the low levels of fibre, 507 those with food allergies did have a higher consumption than those without food allergies, 508 suggesting a greater desire to eat healthily in this group. Only male food allergic participants

509 were able to meet daily recommendations of fibre, further suggesting that these individuals 510 had better dietary choices.

511

512 An increased intake of refine carbohydrates has been associated with higher blood pressure,

513 increased weight gain, digestive issues and increased mortality (Pal et al., 2014; Dehghan et

- al., 2017, Liu et al., 2021). A diet high in free sugars and low in dietary fibre, as observed in
- 515 this study, will therefore prove problematic.
- 516

## 517 **Protein**

518

519 All participants were easily able to meet RNI for protein intake. In fact, the average protein 520 intake was almost double in both males and females with and without food allergies. No 521 statistically significant differences existed in gender or in food allergy status, which mirrors 522 findings from similar studies where nutrient intake was compared between adolescents and 523 adults of food allergies with healthy controls (Maslin et al., 2018; Skypala et al., 2018). 24% of 524 participants reported using supplements in this study, of which 65% consumed protein 525 supplements. Therefore, this could also have contributed to the increased protein intake 526 observed in both groups of participants. In the food-allergic group, many participants suffered 527 from allergies whereby exclusion of the offending allergen would naturally lead to protein 528 deficiency. However, the results from this study reveal that food-allergic participants had the 529 knowledge and ability to easily find suitable replacements and consequently meet dietary 530 protein requirements.

531

# 532 Snacking

533

534 The increased fat and carbohydrate intake in females and males respectively, the increased 535 sugar levels and reduced fibre intake observed in participants could also be attributed to 536 snacking behaviours. Snacking accounts for a large portion of LA overall diet (Wansink et al., 537 2003; Tanton et al., 2015; Larson et al., 2016; Almoraie et al., 2021). This was also through 538 the diet diaries in this study, where the raw data showed an increased consumption of junk 539 foods and energy bars. Snacking of energy dense foods, in addition to meals is a major 540 contributor to weight gain and obesity (Bellisle, 2014; Livingstone et al., 2022). Previous 541 research highlights how LA in the UK have a poorer diet quality than Europeans of the same 542 age and were on average consuming snacks more than 2.5 times per day (Llaurado et al., 543 2016). Similar results have been reported among LA in the USA (Stockton et al., 2013; Bangladesh (Goon et al., 2014), Lebanon (El-Kassas et al., 2015), Italy (Teleman et al., 2015) 544 545 and Saudi Arabia (Mohamed et al., 2020).

546

547 Snacking behaviours amongst university students has been associated with increased caloric 548 intake, lower diet quality and inevitable weight gain (Bellisle, 2014; Almoraie et al., 2021; 549 Livingstone et al., 2022). Furthermore, during the period of late adolescence, individuals will 550 be experiencing one of the most significant changes in their lives, as they move away from 551 home for the first time, while attempting to gain autonomy from their parents. During this time, 552 individuals often struggle to eat healthily and make positive FCs. As LA continue to transition 553 into a state of independence, they begin to develop their own values relating to food (Jodhun 554 et al., 2016). There will be a high preference for snacks as they are perceived to be more 555 palatable, due to their increased sugar and fat content, and require minimal time to prepare 556 (Kanarek et al., 1997).

557

558 While at university, an increase in unhealthy snacking behaviour will take place, due to an 559 increase in the exposure and use of convenience stores, vending machines (particularly on 560 campus), food delivery services, restaurants and fast food outlets (Poobalan et al., 2014; 561 Tanton et al., 2015; Jodhun et al., 2016; McGowan et al., 2017; Munt et al., 2017). All of which 562 promote and encourage unhealthy eating practices amongst individuals. Due to the increased 563 consumption of refined carbohydrates, sugar and reduced fibre indicates that perhaps 564 snacking behaviour was widespread among all participants. This further suggests LA with food 565 allergies are likely to engage in risk taking behaviour, as snacking foods often contain high 566 traces of food allergens (Maslin et al., 2018). In Chapter 6 of this research, participants 567 highlighted a reduced access to AFF on campus, which could have increased snacking 568 behaviour in this group, exposing them to potentially harmful allergens. For food-allergic 569 participants this is particularly concerning, given that an increased exposure and consumption 570 of allergenic foods can prove extremely detrimental to health and in many cases will be fatal 571 (Tackett et al., 2019; Brown et al., 2020). The limited availability of AFF on campus alongside 572 the increased snacking habits may potentially increase risky eating behaviours in this group, 573 consequently compromising their dietary quality.

574

#### 575 **7.4.2.2.** *Micronutrients*

576

577 Vitamins

578

579 The results from this study revealed that all participants were easily able to meet RNI's for 580 most vitamins and in most cases levels were exceeded. Food-allergic participants had higher 581 intakes of all vitamins in comparison to those without food allergies. 582

583 Vitamin D was considered to be an at risk nutrient for participants, with all individuals failing to 584 meet requirements. Despite not meeting requirements, those in the food-allergic group had 585 higher intakes of vitamin D than those without food allergies - findings which support previous 586 research (Maslin et al., 2018). In the general adolescent population (18-25years) vitamin D 587 deficiency is a common finding, further supporting our results (Tangprich et al., 2002; 588 Tonnesen et al., 2016; Crowe et al., 2019; Dong et al., 2021). Poor dietary choices among LA, 589 such as consuming foods low in vitamin D and also increased snacking can contribute to the 590 reduced levels of vitamin D observed in participants (Tangprich et al., 2002; Perez-Lopez et 591 al., 2010; Tonnesen et al., 2016). Research further indicates that missing breakfast, a common 592 trait in LA, can additionally contribute to vitamin D deficiency as foods consumed during this 593 meal time are an important source of vitamin D (Fagnant et al., 2022). Furthermore, in those 594 with food allergies the implementation of a restrictive diet will naturally lead to a difficulty in 595 obtaining nutrients (Steinman et al., 2010; Groetch and Venter, 2020). Skypala et al. (2021) 596 highlight low levels of many nutrients in food allergic adults, with iron, zinc, vitamin B12 and 597 vitamin D found well below the reference range. Foods such as oily fish, red meat and eggs 598 are high in vitamin D (NHS, 2020) and for those individuals in this study who were suffering 599 from these specific food allergies, vitamin D levels would naturally be reduced. These are 600 some possible reasons that explain our findings. Surprisingly, a small percentage of 601 participants in this study (n=17, 24%) were taking supplements, of which the most popular 602 was vitamin D (76%). Often LA will have low adherence of supplement intake due to reduced 603 parental supervision and therefore forgetfulness, the cost and also difficulty in swallowing pills 604 (Brorsson et al., 2020; Spetz et al., 2022). Hence, additionally providing a potential explanation 605 for the low intake seen in participants. Adequate vitamin D levels are important to ensure good 606 health. In fact, vitamin D deficiency is commonly linked with high blood pressure, heart disease 607 and an increased risked of osteoporosis (Tonnesen et al., 2016). Additionally, research has 608 also indicated that vitamin D plays an important role in cognitive function (Devere, 2014; Sultan 609 et al., 2020). For LA who are perhaps at the peak of higher education, this will have 610 unfavourable consequences.

611

#### 612 *Minerals*

613

614 Overall, the food-allergic group had higher intakes of minerals when compared to the non-615 food allergic group, further emphasising their healthier lifestyle.

616

617 All female participants in this study failed to meet iron levels. An insufficient consumption of 618 iron rich foods can further provide an explanation for the low iron levels observed in females. Moreover, this study revealed little differences in iron intake existed in those with and without food allergies, indicating that the presence of a food allergy in this group of participants did not necessarily impact iron intake. These findings are dissimilar to previous research, which highlight that those with food allergies had significantly lower intakes of iron than those without food allergies (Skypala et al., 2021).

624

625 Vitamin C is known to enhance absorption of non-heme iron (Lynch and Cook, 1980; Li et al., 626 2020). Although females in both the food allergic and non-food allergic groups exceeded the 627 RNI for vitamin C, it is possible that the uptake of iron was reduced due to the presence of 628 anti-nutrients. Anti-nutrients are compounds found in certain foods that can interfere with the 629 absorption of nutrients (Petroski and Minich, 2022). For example, antinutrients like phytic acid 630 and oxalates can bind to minerals like iron and reduce their absorption in the digestive tract. 631 This can lead to a lower bioavailability, impacting their use by the body. Anti-nutrients are often 632 found in grains and legumes, which are common components of a vegetarian and vegan diet. 633 A large number of participants in this study observed a vegetarian diet which could explain 634 their inability to meet minerals such as iron.

635

636 Regarding calcium intake, this varied in both groups. While in those with food allergies, males 637 easily met and exceeded levels, females struggled to meet dietary requirements. When 638 looking at the raw data, a greater number of females adopted a vegetarian diet and so, anti-639 nutrients could again have potentially interfered with the absorption of calcium, further 640 explaining why females were unable to meet requirements. Additionally, egg, milk and dairy 641 allergy, as reported by some food-allergic participants in this study, can all contribute to 642 calcium deficiency (Hildebrand et al., 2019; Darwin et al., 2021). Fewer females reported these 643 allergies in comparison to males, suggesting that in addition to the exclusion of these 644 allergenic foods, additional factors such as the inadequate dietary intake from calcium rich 645 foods led to calcium deficiency. These particular findings also suggest that in comparison to 646 females, males with egg, dairy and milk allergy consumed alternative foods to ensure the 647 adequate consumption of calcium. In contrast, in those without food allergies the opposite was 648 true. Male participants were unable to meet RNI requirements, while females met the intakes 649 in this group. Thus indicating that in the non-food allergic group, females had better dietary 650 choices owing to their ability to meet calcium requirements. Moreover, vitamin D levels play a 651 significant role in the absorption of calcium (Khazai et al., 2009; Veldurthy et al., 2016). 652 Research highlights that approximately a mere 10 and 15% of calcium is likely to be absorbed, 653 compared to 40% when vitamin D levels are adequate (Soliman et al., 2014). This particular 654 vitamin was found to be considerably low in participants and can further contribute to the 655 reduced calcium levels observed in this study. Especially in LA where it is necessary to ensure

the possibility of maximum skeletal growth, calcium deficiency can lead to suboptimal bone
health and therefore, the occurrence of conditions such as osteomalacia (a condition whereby
softening of the bones occur) and osteoporosis (a condition which results in the bones
becoming extremely porous and fragile) (Zadka et al., 2018; Rouf et al., 2020).

660

661 Furthermore, irrespective of gender and food allergy status, all participants failed to meet 662 selenium and iodine levels. These findings echo that of previous research (Maslin et al., 2018). 663 The challenges of meeting macro and micronutrient intakes are further exacerbated by dietary 664 lifestyle choices. One major contributing factor to explain these selenium and iodine results, 665 as well as the deficiency in many of the vitamins and minerals and even macronutrients 666 determined through this study, is the adherence to a vegan or vegetarian diet (Fallon and 667 Dillon, 2020; Bakaloudi et al., 2021), as was adopted by many in this study. Both 668 vegetarianism and veganism are common diets adopted by LA and particularly university 669 students. While this is often due to religious/cultural beliefs and moral/environmental 670 concerns, many embrace this eating behaviour as a means of restricting calorie and/or fat 671 intake, or even as a means of showing independence by adhering to a diet different to that of 672 their family (Hargreaves et al., 2021). Results from this study revealed that just over half of 673 participants (52%) were conforming to a vegetarian diet. Fewer participants observed a vegan 674 diet (23%). Overall, vegetarianism and veganism formed the most common diets chosen by 675 participants in this study. LA and adults adopting a vegetarian or vegan diet, will be at an 676 increased risk of nutrient deficiencies. In particular diets will be low in vitamin B12, vitamin D, 677 zinc, calcium, iron and fibre (Fallon and Dillon, 2020; Bakaloudi et al., 2021; Skypala et al., 678 2021).

679

680 In addition to this, all participants regardless of food allergy status and gender exceeded salt 681 intake. Research indicates that FCs in LA are highly influenced by taste and there is a greater 682 preference for high salty foods (Liem and Russell, 2019; Bawajeeh et al., 2020). More than 683 half of participants were students living on campus. As individuals experience the process of 684 transition from their family diet to one of their own choice, highly processed foods make up a 685 large portion of their diet (Contento, 2011; Hebden et al., 2015; Hall, 2018; Sprake et al., 2018; 686 Liem and Russell, 2019; Larson et al., 2020; Monterrosa et al., 2020; Molenaar et al., 2021; 687 Whatnall et al., 2021). In the UK, 95% of dietary sodium is found in processed foods (Anderson 688 et al., 2010). These types of foods are convenient and readily available in and around campus 689 making them an obvious choice for many (Jiet and Soma, 2017). Therefore, it is no surprise 690 why students at university can easily exceed the daily RNI for salt intake. Moreover, multiple 691 studies have highlighted all individuals who depend on campus foods will consume higher

quantities of salt (Park et al., 2009; Rasmussen et al., 2010; Ahn et al., 2013; Faria et al.,2022).

694

695 Furthermore, constant exposure to such foods, as is the case for university students living on 696 campus, will cause individuals to develop a taste preference for foods with high salt content 697 (Faria et al., 2022). Salt intake was also found to be higher in food-allergic participants than 698 non-food allergic participants. Many free-from foods contain high levels of salt to increase 699 palatability, in comparison to their standard counterparts. A previous study conducted by 700 Consensus Action on Salt and Health (CASH), revealed how across 71 supermarkets, more 701 than half of free from products (56.3%) contained higher levels of salt than the standard 702 version with only less than a third of free from products containing low levels of salt (26.7%) 703 (Action on Salt, 2009). This is a possible explanation as to why those with food allergies were 704 consuming higher quantities of salt. Additionally, it is also important to note here that in the 705 previous studies from this research, participants reported AFF as difficult to access due to 706 their limited availability and high cost. Not all participants who took part in the previous surveys 707 and focus groups were part of the dietary intake study and so it is possible that LA who took 708 part in the diet diaries were able to access AFF despite the general trend observed, thus 709 leading to a higher salt intake amongst this group. Moreover, the increased salt intake found 710 in LA in this study may not be solely due to the consumption of AFF. Again participants who 711 struggled in accessing AFF may have compensated for this by increasing their intake of readily 712 available, highly processed foods, which were perhaps high in salt.

713

These findings illustrate the complex relationship between FA and FC, which directly influences dietary intake. This high salt intake indicates poor FCs amongst participants and may result in lower diet quality. The impact on health may also prove detrimental, with increased salt consumption associated with the development of many non-communicable diseases (Jiet and Soma, 2017; Webb et al., 2017).

719

### 720 7.5. Interventions

721

The transition from late adolescence to adulthood is a unique life stage which presents challenges in developing targeted and effective dietary interventions. Existing literature has mentioned various interventions that can improve the dietary quality of specifically LA. The role of the university environment is crucial in promoting healthy eating behaviours (Tanton et al., 2015). Previous research demonstrates that vending machines, which are prevalent across campus, can serve as a targeted means of improving the eating behaviour of LA (Grech

224

728 et al., 2015; Whatnall et al., 2020). Therefore, one approach is that universities should 729 implement interventions that can improve the availability of healthier items that are cost-730 friendly in existing vending machines. In their research, Brown et al. (2014), demonstrated the 731 simple yet effective nature of providing knowledge in vending machines. They provided 732 nutrition information, through using colour coded stickers (red = less healthy, yellow = 733 moderately healthy, green = more healthy). The use of this information intervention was 734 successful and led to the increased purchase of healthier snack items (green stickered items) 735 and a reduced purchase of red and yellow stickered food beverages. In this study, high sugar 736 and salt intake were observed amongst participants and therefore, interventions like this could 737 be especially useful in shifting dietary habits towards more healthier options. Likewise, 738 Whatnall et al. (2020), further suggest that placing educational and motivational information 739 cards/posters in or on vending machines can promote healthier food and drink choices. 740 Similarly, exposing adolescents to information suggesting how limiting unhealthy foods can 741 be beneficial to health, was found to be a successful intervention in reducing junk food 742 consumption (Robinson and Higgs, 2013). Furthermore, Kim et al. (2013), suggest the 743 importance of enhanced nutritional education for those with food allergies who will be naturally 744 adopting an elimination diet. Skypala et al. (2021) also reinforces this and further suggests the 745 need for nutritional counselling to be made available for students on campus with food 746 allergies. This will be quite useful as participants in this study, though meeting requirements 747 for many nutrients, still faced challenges with specific nutrients such as Vitamin D and 748 Calcium.

749

750 Social norms increasingly influence eating behaviours in the 18-25 age range. It is clear that 751 LA are willing to adjust eating behaviour to achieve these social goals. Much research has 752 proven how the social modelling theory can be used to impact FC and food intake behaviour 753 in LA and adults (Hermans et al., 2009; Robinson et al., 2014; Cruwys et al, 2015; Liu and 754 Higgs, 2019; Kimura et al., 2019). One example includes informing individuals of other 755 people's dietary behaviour (particularly that of peers). Croker et al. (2009) found that when 756 individuals were told 'Eighty percent of people try to eat at least 5 portions of fruit and 757 vegetable per day' this was enough to increase consumption of these types of food in a sample 758 of participants in the UK. Pelletier et al. (2014), emphasise the role of peers and have also 759 suggested targeting existing friends' groups, to modify eating behaviour positively. It is 760 important to consider here that the presence of a food allergy may often discourage LA to 761 attend social gatherings, as highlighted in the previous chapters from this research. Therefore, 762 the strategies which promote healthy eating through social influence may need to be adapted 763 for those with food allergies. One example could include accommodating for dietary restrictions in peer environments so as to not exclude LA with food allergies from the positive
 benefits of social influences in modifying eating behaviours.

766

767 Additionally, habitual consumption of certain types of foods is extremely common in this group 768 of LA and habits have been shown to be a major determinant of unhealthy snacking behaviour 769 (Verhoeven et al., 2012; De Vet et al., 2015). Social norm interventions i.e. descriptive norms 770 (what other people do) and injunctive norms (what other people approve of) have been proven 771 as powerful social norm interventions based on the social model of eating, that can break 772 unhealthy eating habits (Robinson et al., 2013; Stok et al., 2016; Suwalska and Bogdanski, 773 2021). While research in this area is still evolving, studies have revealed the benefit of such 774 interventions in promoting healthier eating/drinking behaviours (Herman et al., 2003; Pliner 775 and Mann, 2004; Hermans et al., 2009; Robinson et al., 2014; Stok et al., 2014; Cruwys et al, 776 2015; Sharps and Robinson, 2016; Smit et al., 2016; Stok et al., 2016; Liu and Higgs, 2019; 777 Kim et al., 2019; Kimura et al., 2019). Therefore, interventions based on social models can 778 and should be utilised to improve the consumption of healthy foods. Moreover, Pliner and 779 Mann. (2004), did find that it was easier to influence the consumption of palatable foods 780 through social modelling than unpalatable foods and hence, individual taste preferences 781 should also be considered when increasing healthy food intake. Although for LA with food 782 allergies, avoiding social contexts is a common practice as outlined in the previous research 783 from this study and so future research could perhaps focus on developing similar social 784 models in controlled environments where LA with food allergies feel safer, as means of 785 encouraging healthier eating.

786 A healthy lifestyle should not only be focused on promoting positive FCs, but also learning to 787 resist the temptation of healthy foods. One beneficial approach which considers this and has 788 proven successful in improving dietary choices of specifically LA, is self-regulation. Self-789 regulation strategies are a learned set of strategies that can be applied in certain situations to 790 tackle a known temptation (Vohs and Baumeister, 2011). This concept is quite fitting for LA. 791 Not only is the independence of the individual considered, but the bridge between intention 792 and behaviours will be reduced. Hence, it is no surprise why much literature has highlighted 793 the beneficial role of self-regulation strategies, in promoting a healthier diet throughout the 794 period of adolescence (Schroder et al., 2013; Tomasone et al., 2015; Kliemann et al., 2016; 795 Price et al., 2017; McClelland et al., 2017; Ling and Zahry., 2021).

Furthermore, research suggests that diet quality of LA will improve if they had more time to prepare food and greater access to healthier food (Poobalan et al., 2014; Sexton-Dhamu et al., 2021). There is a need to encourage LA to have regular meals and reduce snacking behaviours and one way to achieve this, is through improving cooking skills (Poobalan et al.,
2014). Research also indicates teaching meal preparation skills can assist in improving dietary
behaviour by reducing the reliance on convenience and takeaway foods (Thorpe et al., 2013;
Pelletier et al., 2014).

803

Many established interventions, that have proven successful to improve the dietary intake of LA, clearly exist. Yet, the present study highlights how still this group of individuals are at an increased risk of nutritional deficiencies and a poor quality diet. Especially for those with food allergies, there are additional barriers such as the limited access to AFF and social exclusion, which need to be addressed. With eating habits during this life stage likely to persist into adulthood, more must be done in order to improve the FCs and therefore diet quality of LA. Consequently, ensuring the overall long-term health of this group.

811

#### 812 **7.6.** Conclusion

813

814 To our knowledge, this is the first piece of research to provide a comparative analysis of macro 815 and micronutrient intake between LA with and without food allergies. Overall, dietary intake in 816 LA with and without food allergies was broadly similar. The results of this study did reveal that 817 participants with food allergies were on average, consuming higher quantities and easily met 818 requirements of macro and micronutrients, than non-food allergic participants. Thus, 819 suggesting a healthier lifestyle in this group. Key findings from this research highlight that 820 irrespective of food allergy status and the ability to meet requirements for many nutrients, FC 821 and hence diet quality overall in this group of participants was poor. There was an increased 822 consumption of saturated fat, refined carbohydrates, sugar and salt in all participants. A high 823 quality diet, enriched with a variety of nutrients is essential. Firstly, as a means of supporting 824 physical and mental growth and development during this critical period of late adolescence 825 and secondly, to optimise academic performance (Abraham et al., 2018; Larson et al., 2020). 826 What is quite significant, is that behaviours established during the period of late adolescence 827 are likely to persist into adulthood (Vilaro et al., 2018). Therefore, there is a clear need to alter 828 the diet quality of LA.

829

#### 830 7.7. Limitations

831

This study provided important contributions, as to our knowledge it is the first piece of research
to provide a comparative analysis of macro and micronutrient intake in LA with food allergies.

- 834 Although there are several limitations of this study that must be acknowledged.
- 835

836 A relatively small sample size of 71 participants took part in this study, which could have 837 impacted the generalisability of the findings. Again this study focused solely on LA in the NW 838 region, which means that the results may not be representative of other regions or populations. 839 Another key limitation is the reliance on self-reported dietary intake through the use of diet 840 diaries. Participants may have underreported or overreported the consumption of certain foods 841 to provide socially desirable answers, which could have influenced the accuracy of this data. 842 Also, this study employed a cross-sectional design which captured dietary intake at a single 843 point in time. Therefore, this approach did not account for any variations in food availability or 844 even consumption patterns, which could have impacted dietary intake in this group. A 845 longitudinal study could have provided a more comprehensive understanding of dietary intake 846 over a period of time. Moreover, a large number of comparisons were made between those 847 with and without food allergies. Conducting multiple statistical tests can increase the risk of 848 Type 1 errors, thereby indicating a statistically significant difference when one may not actually exist. Again despite any efforts to maintain rigor throughout the analysis process, false 849 850 positives could have occurred. Care should therefore be taken when interpreting these results. 851 In addition to this, multiple other factors which could have impacted dietary intake of the study 852 population were not considered, for instance socioeconomic status, nutrition education level 853 and access to food resources. Any differences between groups could potentially have been 854 influenced by these additional factors and this should be considered when interpreting the 855 results of this study. Further research which takes into account these limitations should 856 therefore be considered, as this may allow for a more accurate understanding of the dietary 857 intake between LA with and without food allergies. Additionally, this could help to refine 858 interventions which are specifically aimed at increasing dietary quality in this group.

859

860

861 Overall, this study has provided valuable insights into the dietary intake of the LA population 862 both with and without food allergies. Although in many instances participants easily met daily 863 nutrient requirements, there was a common finding of poor dietary quality amongst both 864 groups. These findings, along with those outlined in the previous chapters with regard to FC, 865 food access and healthcare access, nicely set the stage for the next chapter. Consequently, 866 Chapter 8 will focus on exploring possible interventions to improve FC, food access, 867 healthcare access and dietary intake in LA with food allergies, through qualitative focus 868 groups. The strategies discussed will aim to enhance the overall well-being in this group who 869 often encounter numerous challenges, as they attempt to navigate their food allergies perhaps 870 independently, thorough the critical transitional period that is LA to adulthood.

<u>Chapter 8</u> – Improving Food Choice, Food Access and Healthcare Access of
 Late Adolescents (18-25years) with Food allergies in North West, England –
 *Possible Interventions*

4

## 5 8.1. <u>Overview</u>

6

There is a growing prevalence of food allergies and for those in late adolescence (LA), the management of these allergies becomes increasingly difficult throughout the period of transition from LA to adulthood, owing to a number of additional challenges. During this time, making appropriate food choices (FCs) and accessing adequate food and healthcare is a challenge. Therefore there is an urgent need to explore strategies that can improve the current management of food allergies in this group.

13

14 In the previous chapters of this research, it was found that LA with food allergies face 15 challenges in making safe FCS, due to the limited availability and high cost of allergen free 16 foods (AFF) in the North West (NW) region, especially in the context of the university setting. 17 Gaps in healthcare were also highlighted, especially in relation to nutritional and psychological 18 support. Therefore, in this chapter from the perspectives of the food-allergic patient (FAP), 19 parent/carers (P/C) and healthcare professionals (HCPs) we suggest possible strategies to 20 improve the current FC, food access (FA) and healthcare access (HCA) of LA with food 21 allergies in the NW of England. This chapter aims to lay the groundwork for further research 22 and policy development, which can allow LA to better manage their food allergies during the 23 crucial transitional stage of LA to adulthood.

24

# 25 8.2. <u>Methodology</u>

26

For this final focus group discussion, FAP, P/C and HCPs who had participated in each of the previous focus group sessions, were invited to take part. The main findings of the preceding focus groups were shared with the participants, who then discussed their views on how to improve the current FC, FA and HCA of LA with food allergies. <u>Please refer to Chapter 6,</u> <u>section 6.2 for a detailed review of the methodology.</u>

- 32
- 33 8.3. <u>Results</u>
- 34

# 35 **Participant Demographics**

36

- 37 In this intervention focus group, a total of six participants took part two FAP, two P/C and two
- 38 HCPs. Table 8.1 highlights their demographic information. Both FAP were males between the
- 39 ages of 18 and 25 years and were suffering from multiple food allergies, which included milk,
- 40 peanut and dairy allergy. Two P/C of a child undergoing the period of transition and with
- 41 one/more existing food allergies also took part in this intervention focus group along with two
- 42 HCPs one GP and one dietitian both of whom had previous experience in providing allergy
- 43 care to LA with food allergies

Table 8.1. Demographic characteristics for food allergic patients, parents/carers and
 healthcare professionals who took part in the intervention focus group (n=6)

FOOD ALLERGIC PATIENTS	
Gender (n, %)	
Male	2 (100)
Age (n, %)	
18-25years	2 (100)
Ethnicity (n, %)	
White British	1 (50)
Black: British African	1 (50)
Type of Food Allergy	
Multiple	2 (100)
Food Causing Allergy	
Milk	2 (100)
Peanut	1 (50)
Dairy	1 (50)
PARENTS/CARERS	
Gender (n, %)	
Male	1 (50)
Female	1 (50)
Age (n, %)	
25-30years	1 (50)
45-50years	1 (50)
Ethnicity (n, %)	
White British	1 (50)
Black: British African	1 (50)
How old is your food allergic child?	
18-25years	2 (50)
Food causing allergy in your child	
Peanut	1 (50)
Egg	1 (50)
Fish	1 (50)

#### 47 **Table 8.1.** Continued

Gender (n, %)	
Male	1 (50)
Female	1 (50)
Age (n, %)	
25-30years	1 (50)
31-35years	1 (50)
Ethnicity (n, %)	
Black: British African	2 (100)

#### HEALTHCARE PROFESSIONALS

#### 48 **Thematic Maps**

- 49
- 50 Thematic analysis through the software NVivo resulted in a total of eight interventions, for the
- 51 three main domains FC, FA and HCA.



- 52 **Figure 8.1.** Developed thematic map for a series of interventions, based on the combined
- 53 perspectives of the food allergic patients, the parents/carers and the healthcare professionals.

## 54 FOOD CHOICE

55

56 Intervention 1: 'More efforts to improve labelling' 57 An agreed intervention discussed by all participants was to improve current labelling 58 standards. Participants mentioned improving the consistency of labels and making the 59 allergens more noticeable would make choosing foods easier. Clear signposting of allergens 60 on campus was also suggested. 61 62 'I think especially making it more noticeable, so putting it on the front of the packet is 63 a clear way and making sure the writing is a lot larger so it stands out, that can make it guite 64 easy for us. What would be quite good is a separate section for just the allergens and this 65 would actually help us to check quickly if the food is safe' (Parent 2, Female) 66 67 'And making sure there is clearer labelling in the cafeteria and clear signposting on 68 menus of which foods are safe to eat, because I hardly have seen that and it would really 69 help.' (FAP 1, Male, Milk and Peanut Allergy) 70 71 Intervention 2: 'Opportunities to learn more cooking skills' 72 Participants suggested the need for cooking classes to be offered on campus for food allergy 73 students. 74 75 'It's important for us to learn how to cook proper meals aswell, so when we're at 76 university it makes it easier for us. I personally have struggled with that.' (FAP 2, Male, Peanut 77 and Dairy Allergy) 78 79 'To ensure you know that they can cook when they are living on their own is really 80 really important. I think if the university provides some cooking classes for them then that can 81 be helpful because not everyone will know how to cook.' (HCP 2, Female, Dietitian) 82 83 FOOD ACCESS 84 85 Intervention 3: 'More allergen free food available on campus' 86 Participants felt that allergen free foods (AFF) were limited on campus and more options 87 needed to be provided, with particular reference to more safe, hot foods. One of the HCP (a 88 dietitian) mentioned the use of a survey to gain insight into preferable food options which could 89 help to meet food allergic students' specific dietary needs.

90 '...and the cafeteria should have like a timetable for the food they are going to be
91 serving and more options for allergy free foods, hot foods too, because right now its hardly
92 offered.' (FAP 1, Male, Milk and Peanut Allergy)

93

94 'Most of them might find it difficult to try new foods at university and more attention 95 should be given to the kind of dishes that they prefer or that might be a lot more preferable for 96 them and this is linked with the policies the universities have. Maybe some sort of survey to 97 ask them about their dietary needs and then from there what options they would like to see, I 98 think this will really give them more access to the foods and help to improve their FCs and 99 what they eat.' (HCP 2, Female, Dietitian)

100

#### 101 Intervention 4: 'We should be offered more subsidised foods'

AFF are more expensive and participants agreed that subsidies in the form of vouchers from
 healthcare services and bursaries from universities would potentially improve their access to
 AFF.

105

106 'I think maybe some coupons or vouchers or something like this for the people with
107 food allergies, so they can afford the AFF. Maybe the GP can give some sort of prescription.'
108 (Parent 1, Male)

109

110 'Food for allergic people you know is quite expensive. So yes I do agree with the
111 coupons, even the universities should provide a bursary for us students with food allergies,
112 which would make it easier.' (FAP 1, Male, Milk and Peanut Allergy)

113

#### 114 Intervention 5: 'Providing allergen free foods at food banks'

Participants further mentioned the inclusion of more AFF at food banks would be a beneficialway of improving access to these foods, particularly during times of financial need.

117

118 'Yeah I think we mentioned food banks last time. I believe you know it will definitely 119 work because it's not only some people that will be going to the food banks. We have different 120 people that will be going to the food bank and some of them will be people with allergies, so 121 more of these foods should be available. So it's very essential that food banks have arrange 122 of non-perishable foods for people with Food allergies so that people can make choices that 123 they can't always afford.' (FAP 2, Male, Peanut and Dairy Allergy)

124

125 'I think food banks are a great idea. Essentially they should kind of ideally include a 126 diverse selection of allergen friendly options, so canned foods and rice, pasta which are

127	common and are allergy free because they don't really have too many options at all. And they
128	should make an effort to include items that are specifically labelled as allergen free, a separate
129	section.' (Parent 2, Female)
130	
131	HEALTHCARE ACCESS
132	
133	Intervention 6: 'Clear policies and procedures on campus to assist in health care'
134	Participants felt the universities had an obligation to provide clearer policies and protocols to
135	improve the access to healthcare.
136	
137	'I think it's really important that there is a clear protocol for managing allergic reactions
138	at the university and including the availability of adrenaline and trained staff to administer it on
139	campus, because to consider the health of the students is part of the rules and regulations of
140	the university and sometimes things like this won't be in place.' (Parent 1, Male)
141	
142	Intervention 7: 'Greater access to nutritional and psychological support'
143	Participants discussed different ways to improve the accessibility of health care for LA with
144	food allergies. A specific focus on increasing access to dietary and psychological support was
145	discussed, including universities employing dietitians to facilitate educational workshops and
146	utilising on campus counsellors to provide relevant psychological support.
147	
148	'As a dietitian I agree that there needs to be more opportunities for us to help patients
149	with food allergies. I think for the students especially, something like an educational workshop
150	on campus every now and then could really help to improve their access to this type of support.
151	So where dietitians can come at certain times and educate the students. Maybe even an on
152	campus dietitian could be employed and they could lead this. I think exploring resources with
153	them during the workshop is something we can do, so we use Allergy cookbooks and recipes
154	that can help adolescents develop their culinary skills and we also help them to explore a
155	variety of allergen friendly meals, going over labelling and this is something which can be done
156	in the workshop, because it can be quite difficult to get appointments regularly, so I think this
157	could work quite well.' (HCP 2, Female, Dietitian)
158	
159	'Psychological support should be regularly provided on campus too, maybe regular
160	counselling with an on-campus counsellor, just making the food allergy students aware that
161	this support is there cos I can imagine them not even knowing about it. I know a lot of my
162	patients have asked for this type of support, especially dealing with mental health and we can't
163 always offer the time or even expert advice, but this could be worth exploring. (HCP 1, Male, 164 GP)

165

#### 166 Intervention 8: 'Educating the wider community – It's a network'

167 An underlying theme of education was considered to be of great importance expressed by 168 participants in the management of food allergies. TV adverts to raise awareness of food 169 allergies were proposed as a potential way of increasing the knowledge of the wider 170 community.

171

172

'It's a network and it's more about everyone in the community helping and supporting 173 people with food allergies.' (Parent 1, Male)

174

175 'I also think that you see them a lot now on tv, for raising awareness different adverts 176 for different health conditions. You don't really see this for Food allergies though I remember 177 I was in the cinema and I saw an advert raising awareness for IBS so I think something like 178 this for food allergy will be really beneficial to just educate everyone, make them more aware 179 really. They are quite useful to be honest and they do get people talking more than say a 180 pamphlet.' (FAP 1, Male, Milk and Peanut Allergy)

181

#### 182 8.4. **Discussion**

183

184 One novel aspect of this PhD research was the collaboration of FAP, PC and HCPs who came 185 together to discuss and suggest possible interventions, to improve the current FC, FA and 186 HCA of LA with food allergies. The suggested interventions were based on findings from each 187 phase of this study. The contribution of this unique group of participants, all of whom are 188 directly involved in the management of food allergies, allows for a more inclusive, patient-189 centred approach in developing solutions that address the real-world needs of individuals with 190 food allergies. It is important to note here that this study provides suggestions for interventions 191 only, based on the insights gathered from the focus groups.

192

#### 193 FOOD CHOICE

194

195 Through the focus group discussions, current food allergy labelling was a key issue raised by 196 participants, which needed improvement. Participants suggested improving the visibility, 197 readability and location of allergens in food labels, with participants agreeing front of pack 198 labelling and a dedicated section for all included allergens would help in making the allergens

199 more noticeable. These changes have all been recommended through previous research 200 (Barnett et al., 2011; Ju et al., 2015; Blom et al., 2021), yet evidently continue to remain a 201 persistent issue for the food allergic community. The need for clearer signposting of food 202 allergens across the campus cafeteria was also mentioned. While an increasing number of 203 universities are recognising the importance of addressing the needs of their food allergic 204 students, policies greatly vary across institutions and all staff may not have sufficient 205 knowledge in dealing with food allergies (Choi and Rajagopal, 2013; Dyer et al., 2018). An 206 effective labelling system is very important for the health of food allergy sufferers. Although, 207 efforts have been made and are ongoing in the improvement of food allergy labelling (FSA, 208 2022) more must be done. A whole system approach is required and collaboration between 209 allergy consumers, HCPs, the food industry, regulatory bodies and university food services is 210 key, in the hopes of achieving more clearer and consistent labelling.

211

212 In addition to improvements in food allergy labelling, participants also mentioned the need to 213 improve cooking skills. Knowledge of cooking can provide an excellent way to empower 214 students with essential skills in planning and preparing foods and existing research has 215 emphasised the benefit of this (O'Kane et al., 2021). Harper et al. (2022) further highlight how 216 the knowledge of cooking in students will not only increase FC, but will improve overall health 217 by allowing individuals to eat healthier. At present, no research has detailed the facilitation of 218 cooking classes for specifically food allergic students, who require knowledge of safe FC and 219 confidence in managing their dietary needs. Therefore, further research into this area for this 220 group should be conducted.

221

### 222 FOOD ACCESS

223

Through the focus group, participants mentioned a few different ways to improve the current access to safe, AFF. Universities have an obligation to cater for the needs of all students and more efforts must be made to expand the availability of AFF on campus.

227

In addition to this, one limiting factor in accessing AFF is their high cost. It was therefore suggested that prescription vouchers provided by healthcare services would offer a solution for food allergy sufferers, in easing the financial burden of accessing safe foods. A similar initiative for the increased access to gluten free foods for coeliac sufferers is available in certain areas (Coeliac UK, 2024). However, there is yet to be a comparable approach for those with food allergies, highlighting a gap in the support system for a community which is ever growing. Bhamra et al. (2023) found that providing families with food allergies with food 235 subsidies in the form of coupons had a positive impact. Food costs were reduced and stress 236 related to purchasing allergen friendly foods also declined in participants, showing the 237 effective nature of this concept. Implementing such a strategy should be considered, as it can 238 ensure equitable access to AFF and improve the overall well-being of food allergy patients 239 and their families. Participants further suggested that universities should also provide 240 additional bursaries for food allergic students, which would help them financially. Currently, 241 universities do offer bursaries for food insecure students (Vittozzi, 2023), however there has 242 been no record of this for students with food allergy.

243

The inclusion of AFF at food banks was also mentioned by participants, which would help to increase the access to safe foods during times of financial need. Previous research has also posited that while this is a good idea, food banks rarely accommodate for the dietary needs of those with food allergy (Minaker et al., 2014; Fong et al., 2022; Scurlock et al., 2022), something which was also acknowledged by participants in this study. Collaborating with food donors and suppliers to provide more allergen friendly foods in food banks, could serve as one means of overcoming this.

251

# 252 HEALTHCARE ACCESS

253

254 Different ways to improve the HCA of LA with food allergies on campus were also discussed. 255 To our knowledge, no UK study has explored the university campus environment and the 256 challenges food allergic students may face while transitioning to campus life. Some studies in 257 relation to this topic have been undertaken in the US, which mention how university campuses 258 are not fully equipped to deal with the needs of food allergy students (Greenhawt et al., 2009; 259 Choi and Rajagopal, 2013; Dyer et al., 2018; Bajaj et al., 2023; Wu and Wang, 2023). The 260 authors in these studies mentioned how steps need to be taken to create a safe and supportive 261 environment for students with food allergies, including the development of policies which are 262 regularly updated and reviewed, incorporating adrenaline autoinjectors on campus, training 263 staff in the case of reactions and increasing awareness of food allergies across the campus. 264 These recommendations were echoed by the participants in this study, suggesting that the 265 current UK universities are also under equipped to manage food allergy students. However, 266 more research must be done in this area to gain valuable insight into the current practices of 267 universities and challenges faced by students with food allergies. This will help to develop 268 specific interventions that can promote the well-being of students with food allergies and foster 269 a safe and inclusive environment for all.

270

271 The dietitian and psychologist offer a unique role in the management of food allergies (Daniels 272 et al., 2021; Leone et al., 2022). However, the difficulty in accessing this support is a 273 recognised challenge for FAP, as reported in Chapter 6 and previous studies (Knibb et al., 274 2019; National Allergy Strategy Group and All Party Parliamentary Group, 2021). Through the 275 focus group discussion, participants discussed ways to improve the access to this type of 276 support for students with food allergies on campus. Universities will often employ counsellors 277 and directing food allergy students to this already existing service, may prove to be a valuable 278 way to address their mental health and well-being needs. Many universities have excellent 279 services to accommodate the needs of students with food allergies, including counselling and 280 wellbeing services. Reading, Birmingham and Kent university are all excellent examples of this (Allergy UK, 2024). In comparison, NW universities are lagging behind in the support they 281 282 provide for students with food allergies, suggesting a need for more research in these 283 institutions to inform policy and practice. The recommendations discussed provide a promising 284 approach to increase the ongoing access to dietary and psychological support for students 285 managing food allergies at university. Further research should therefore assess the 286 effectiveness of these approaches.

287

288 A well-informed community is a key aspect in the management of food allergies that can 289 improve FC, FA and HCA. LA are not only reliant on their individual competence, but 290 additionally on the understanding and competence of other's. There is a sense of shared 291 responsibility between themselves, their social networks and the institutions of which they are 292 a part of (Stjerna et al., 2015; Feng and Kim, 2019; Higgs et al., 2021). Therefore, educating 293 the wider members of the community is key. This was also acknowledged by participants who 294 proposed an interesting means of achieving this. They suggested the development of more 295 TV adverts which were considered to be a powerful tool in raising awareness and educating 296 the public. Anaphylaxis UK actively raises awareness for food allergies and have produced 297 some impactful short films to that effect e.g. 'Take the Kit' and 'Leos Story'. While these are 298 powerful in nature, they may often miss reaching the broader layperson audience. Additionally, 299 although food allergies are gaining more TV and media traction, they are often misrepresented 300 which can lead to greater confusion and misunderstanding among the wider public (Opper, 301 2015). Over the last 10 years the media has drastically changed the way in which we acquire 302 and share information, in particular for the emerging adulthood demographic (Huntley et al., 303 2023). TV adverts offer a crucial means of sharing health information and working alongside 304 media experts, allergy charity bodies, FAP, HCPs and lay members of the community can 305 result in a an innovative, engaging, comprehensive and most importantly informative means 306 of raising awareness of food allergies.

307

### 308 8.5. <u>Conclusion</u>

309

310 The conceptualisation of the proposed interventions outlined by participants in this study offer 311 a unique insight into the current needs of LA with food allergies, in relation to their FC, FA and 312 HCA. Eight potential interventions under three key domains i.e., FC, FA and HCA were 313 identified. To our knowledge, this is the first study to consider the perspectives of a diverse 314 group of individuals in the development of suggested interventions that can optimise and 315 ensure success in the ongoing, daily task that is food allergy management. It is again important 316 to note here that these proposed interventions are only preliminary suggestions. Therefore, 317 pilot testing these interventions to assess their feasibility and effectiveness is important and 318 the consequent implementation of such strategies can assist in empowering LA with food 319 allergies to take effective control of their allergic disease.

320

# 321 8.6. Limitations

322

Through this study we obtained valuable insights into the perspectives of the FAP, P/C and HCPs, where potential interventions to improve the overall heath and wellbeing of LA with food allergies were outlined. Despite this, it is important to discuss the limitations associated with this study.

327

Firstly, the proposed interventions suggested by participants were largely focused on the university context, as all FAP in this study were university students. As such, the focus on the university setting may limit the generalisability of these findings to LA who do not attend university, as they may experience different challenges and have differing needs than those in an academic environment. Therefore, this study may not fully address the broader needs of the entire LA population with food allergies.

334

Secondly, there was a small sample size with only two participants representing each group (FAP, P/C and HCPs). Thus, this study may not have captured the full diversity of the experiences and perspectives within each group. Again the focus of this study was in the NW of England and so the experiences shared may not reflect that of LA with food allergies in other regions, further limiting generalisability.

340

Thirdly, the focus groups were conducted online via MS teams to suit the varying schedules of the three different groups. Although this allowed for flexibility and allowed for individuals to partake in the session, the online format may have impacted the dynamics of the group discussion. For example, non-verbal cues (as some participants did not turn on their camera)
and the natural flow of the conversation (due to lags or delays) were less apparent with this
method. Consequently, the depth of the data may have been restricted when compared to an
in-person environment.

348

Given these limitations, it is important for further research to validate and refine the proposed interventions outlined in this study. Furthermore, pilot testing these interventions will provide a means of assessing their feasibility, especially in non-university settings as this will help to potentially address the diverse needs of all LA with food allergies. In turn, this may enhance their current management of food allergies.

354

355 Overall, the findings from this study regarding possible interventions alongside the findings 356 from the previous chapters contribute to our understanding of FC, FA, HCA and dietary intake 357 of the LA population, particularly in those with food allergies. Together, these studies 358 collectively provide a comprehensive foundation for developing further interventions that can 359 help to improve the effective management of food allergies and overall health and wellbeing. 360 The final chapter – Chapter 9, will go on to provide a final conclusion which highlights the key 361 findings and implications of this research, focusing on areas for further research to 362 complement the areas that were investigated through this thesis.

- 1 Chapter 9 Overall Conclusion
- 2

### 3 9.1. <u>Overview</u>

4

5 Through the previous chapters of this research, the current food choice (FC), food access 6 (FA), healthcare access (HCA) and dietary intake of late adolescents (LA) with food allergy 7 were explored using a mixed methods approach. This final chapter aims to provide a 8 comprehensive understanding of the research carried out throughout this PhD research. This 9 section begins with a brief summary of the rationale and the principal aims of this PhD 10 research, emphasising the need to understand the unique challenges faced by LA with food 11 allergies. This is followed by a short discussion on the overall findings from each of the studies 12 which were undertaken and the implications of these findings. After this, recommendations for 13 further research are discussed to build upon the findings from this research and address the 14 ongoing challenges in the areas which were investigated. This chapter finished by mentioning 15 the overall limitations of the research followed by an overall conclusion.

- 16
- 17

# 9.2. <u>Rationale, Aims and Findings – A Summary</u>

18

The period of late adolescence to adulthood is unique and complex. There is a need for individuals to explore and experiment and this is heightened as social identity is pursued, naturally leading to much risk taking in this group. The additional task of navigating food allergies during this period is challenging. Despite this being a vulnerable time, little support is currently available to meet their specific needs and limited research currently exists looking at the management of food allergies in this group. Therefore, each study in this PhD research exclusively focused on the period of late adolescence to adulthood (18-25years).

26

27 As late adolescents (LA) transition into adulthood, shifts in food choice (FC) and eating habits 28 will occur and this will directly impact dietary intake. In those with food allergies, the 29 implementation of an avoidance diet and the limited access to safe, nutritious foods will 30 present additional difficulties. Moreover, access to comprehensive healthcare to manage food 31 allergies is vital for LA who are undergoing the unique transitional period, yet this remains a 32 challenge. Specifically this piece of research revealed that LA with food allergies struggle with 33 the balance of managing safe, nutritious FCs, while also navigating social pressures and 34 challenges to obtain autonomy. Enhancing access to guality food and healthcare are essential 35 components of successfully managing food allergies, particularly for LA, as behaviours 36 established during this period are likely to persist into later life. While some research on LA

37	FC, food access, healthcare access (HCA) and dietary intake do exist, this has seldom been
38	studied in specifically LA with food allergies. Further exploration into these areas is therefore
39	warranted and this consequently led to the development of this PhD research project. The
40	overall aim of this research was to investigate the current FC, FA, HCA and dietary intake in
41	LA with food allergies in NW England. Five objectives were set out to fill the existing research
42	gaps.
43	
44	1. To understand the various factors impacting FC behaviour in LA with and without
45	food allergies,
46	
40	2 To determine the access to healthy putritious feed and allergen free feed in LA
47	2. To determine the access to healthy, hutilitious lood and allergen hee lood in LA
40	with and without lood allergies,
49	
50	3. To explore the current HCA in LA with food allergies, from the perspective of the
51	food-allergic patient, the parent and the HCP,
52	
53	4. To determine the dietary intake of LA with and without food allergies.
54	
55	5. To suggest preventive interventions with FAP, P/C of children with food allergy and
56	healthcare practitioners who have had experience in providing care for LA with
57	food allergies.
58 59	By addressing the above aim and objectives, valuable insights into the challenges faced by
59 60	LA with food allergies in relation to food and HCA were obtained
61	LA with food allergies in relation to food and fick were obtained.
62	Four studies (Chapters 3, 4, 5 and 6) utilising mixed method approaches were undertaken to
6 <u>2</u>	explore the current EC. EA and HCA of LA with food allergies. In relation to EC, the main
64	finding which emerged was that despite the presence of food allergies food-allergic I A are
65	very similar in their determinants of FC to that of the general late adolescent population.
66	Findings from these studies further made apparent that accessing specialist foods, due to their
67	limited availability and high cost, is a struggle for LA with food allergies. Therefore, this
68	indicates that although LA with food allergies share similar decision making processes to their
69	peers, their FCs are restricted due to the need to avoid food allergens. Additionally, this piece
70	of research found gaps in accessing healthcare for LA with food allergies. While primary care
71	was more easily accessible, the allergy care provided at this level was not adequate with GPs
72	often lacking in training. Specialist support was more difficult to access, in particular

73 participants mentioned the limited access to nutritional and psychological support. Chapter 7 74 utilised food diaries to gain insights into the dietary intake of LA with and without food allergies. 75 The results highlighted how irrespective of food allergy status, dietary intake was largely 76 similar in both groups of participants. It was additionally highlighted that despite meeting 77 dietary requirements, overall diet quality was poor in both groups. This can be linked to poorer 78 FCs during a time of increasing independence and lifestyle change. Each of the studies which 79 were undertaken additionally provided a foundation for the recommendation of targeted 80 interventions (Chapter 8), to improve the current food and HCA in this group of LA and support 81 the management of their food allergies.

82

Through this PhD research we have been able to comprehensively understand the current FCs, FA, HCA and dietary intake of LA with food allergies in NW England. The insights gained from this PhD research alongside the recommended interventions can be used to inform policy and practice. This study provided several original contributions to knowledge. This is the first study to:

- 88
- explore FC, FA and HCA in LA with and without food allergies through qualitative
   and quantitative means.
- 92 geographically map the access to safe, nutritious foods and AFF in LA with and
   93 without food allergies
- 94 95

96

97

91

- provide a comparative analysis between LA with and without food allergies for dietary intake.
- e collaborate between FAPs, PC and HCP in the recommendation of evidence based interventions, to improve the current FC, FA, HCA and dietary intake of LA
   with food allergies.
- 101

# 102 9.3. Implications of Findings

103

Overall, the findings from this research contribute to our understanding of FC, FA, HCA and
dietary intake in LA with food allergies. There are several implications of this research which
are outlined below.

107

108 Firstly, this piece of research advances our current knowledge of the complex interplay 109 between food allergies, dietary behaviour and healthcare needs during the period of LA. 110 Through identifying challenges LA face when making FCs, especially in the university context 111 and the difficulties in accessing appropriate healthcare, this study fills an important gap in the 112 existing literature. Not only do these findings provide us with a broader understanding of the 113 different factors influencing food and HCA in this group, but it further enhances our 114 understanding of the unique needs of LA with food allergies, a group which is often 115 underrepresented in research.

116

117 Secondly, the findings of this study contribute to our knowledge of theoretical frameworks in 118 the field of health, nutrition and the management of food allergies for LA. For instance, it was 119 found that traditional models of improving FC may need to be adapted for LA, who often avoid 120 or restrict eating in social contexts to effectively manage their food allergy. Future models 121 should therefore consider the food safety and accessibility of those with food allergies as 122 research indicates that social identity and peer influence can shape eating behaviour. The 123 gaps in healthcare also found in this study illustrate the need for nutritional and psychological 124 support to be better integrated within healthcare systems, so as to improve the effective 125 management of food allergies in this group.

126

127 Finally, the practical implications of this research are profound. It was found that an increased 128 access to AFF which are affordable is needed, particularly in the university environment 129 options are currently limited and where LA spend large amounts of time. Additionally, gaps in 130 healthcare were identified and the research indicated a need to provide more adequate care 131 at the primary level and provide increased nutritional and psychological support. A holistic 132 approach to food allergy management is needed and therefore healthcare practices may need 133 to be revised to incorporate strategies that not only focus on the physical aspects of managing 134 food allergy, but also the emotional and mental well-being of patients.

135

Overall, this piece of research provided key insights into the current FCs, FA, HCA and dietary
 intake of LA with food allergies. These findings point to several areas for future research which
 are outlines in the subsequent section.

139

# 140 9.4. <u>Recommendations</u>

141

Following the implications of this study, several important recommendations are mentioned to quide future research. 144

145 One unique aspect of this study was the intervention phase, which involved food-allergic 146 patients, parents/carers and HCPs. The first-hand experiences and thoughts of this group are 147 highly valuable and led to the development of interventions that are tailored to the specific 148 needs, concerns and preferences of the target population. The implementation of these 149 interventions will increase the likelihood of success, leading to positive outcomes in this group. 150 Therefore, it is recommended that these interventions are pilot tested to assess their feasibility 151 in a real-world setting and determine any potential drawbacks, allowing for any necessary 152 changes to be made.

153

154 LA between the ages of 18 and 25 years undergo a transitional phase marked by increasing 155 independence and decision-making, which present unique challenges in the management of 156 their food allergy. However, this group is often neglected in research. Therefore, more 157 research focusing on this critical period of late adolescence to adulthood is needed in relation 158 to food and HCA. Exploring how beliefs and attitudes change throughout this period of 159 independence will also prove insightful and this can be achieved through longitudinal studies. 160 This information can then be used to prepare LA in the effective management of their food 161 allergies during this crucial period of development. A comparison between those in early 162 adolescence and adulthood should also be considered, as this can provide insight into the 163 management of food allergy and how it may evolve through the different life stages. This will 164 prove particularly valuable for HCA, where understanding the challenges and opportunities 165 faced by individuals in pediatric allergy care, adult allergy care and while transitioning between 166 the health services can lead to the development of interventions, which can enhance the 167 overall healthcare experience for all those managing food allergies. Such studies would 168 benefit from a mixed methods approach, where using both cross-sectional and longitudinal 169 methodology alongside interviews and focus groups can effectively capture the depth of 170 experiences, attitudes and behaviour. Thus providing a more comprehensive understanding 171 of how different factors influence the management of food allergies.

172

173 In addition to this, little research currently exists which has measured the food insecurity of LA 174 with food allergies. Food insecurity can hinder the ability for this group to access safe, 175 nutritious foods, which can influence educational attainment impacting long-term financial 176 stability. Moreover, the period of late adolescence is one of increased growth and 177 development and food insecurity can negatively impact nutritional choices and dietary 178 patterns. The NW of England has a large number of neighbourhoods with high levels of 179 socioeconomic deprivation. Focusing research in these specific areas can help to identify food 180 deserts and uncover specific factors that contribute to the increased vulnerability of FA in this group. Additionally, accessing AFF are difficult due to cost and limited availability. Therefore,
conducting further research on the availability and variety of AFF in food banks is important
for addressing the needs of LA with food allergies.

184

185 At present, there is a paucity of research looking at the management of food allergies in the 186 university setting. The university environment presents unique challenges for individuals with 187 food allergies and addressing this gap in knowledge is crucial. Research should focus on 188 effective strategies to navigate these difficulties faced by LA with food allergy during this time. 189 As the presence of food allergies will affect attendance, academic performance and overall 190 health, future studies should also explore the impact of food allergies on the academic 191 performance of food-allergic students. The effectiveness of existing university policies which 192 have been designed to support food-allergic students during their time at university, should 193 additionally be investigated. This can inform the need for any improvements in protocols which 194 can benefit the food-allergic student population. In the same way, a closer look at the 195 knowledge, attitudes and practices of staff at the university, in particular dining services, will 196 prove beneficial in determining the level of allergy preparedness and identify any training gaps. 197 Both surveys and interviews with students and university staff can help to assess the level of 198 allergy preparedness in the university context and identify any gaps in training and policy. The 199 research findings from these proposed studies can serve as a basis to encourage policy 200 change allowing universities to adopt evidence-based practices, thus creating an inclusive and 201 supportive environment, one which prioritises the safety and the well-being of all students with 202 food allergies.

203

204 Furthermore, additional research could focus on exploring the economic burden of food 205 allergies in LA and their families. A specific focus in the context of university life for LA who 206 are students could potentially be considered. There is a significant financial strain associated 207 with higher education and this coupled with the management of food allergies during this time 208 can create additional challenges for this group. Investigating how these pressures of university 209 life directly impact the management of food allergies can provide valuable insights into the 210 need for financial support such as bursaries and subsidies that are specifically tailored for 211 students with food allergies. Quantitative surveys with food allergy students and their families 212 can provide initial insights. Employing qualitative methodology such as semi-structured 213 interviews and focus groups can further add to this data providing more depth. Additionally, 214 using longitudinal study methods can also provide an understanding of how financial 215 pressures and the management of food allergies may evolve over time and influence 216 academic outcomes. These combined approaches can provide a greater, more

comprehensive understanding of the economic challenges faced by LA with food allergies inthe university environment, which could ultimately inform future interventions and polices.

219

## 220 9.5. Overall Limitations

221

A mixed methods approach was utilised for this PhD research. This combination of both quantitative and qualitative methodologies allowed for a more comprehensive understanding of the research questions. While this study has made useful contributions, it is also essential to recognise, discuss and reflect upon the limitations that existed in this research, which may have impacted the interpretation and generalisability of the results.

227

228 For phase one of this research, online questionnaires were used to initially collect data for the 229 FC, FA and HCA of LA. While this allowed for a quick and easy manner of gathering a large 230 amount of data, without a researcher present, participants may have misinterpreted some 231 questions - although a pilot study was conducted to overcome this. For the first questionnaire 232 directed toward LA with and without food allergies, the term 'healthy, nutritious food' was not 233 defined. This could have led to different interpretations based on individual beliefs, culture and 234 nutritional knowledge. This subjectivity may have resulted in varied responses, making it 235 challenging to draw clear conclusions and generalise the results.

236

237 One primary limitation of this study is the reliance on self-reporting. Participants may not have 238 provided accurate and/or truthful information when completing the online questionnaires. This 239 is especially true for the food diaries where participants were asked to share information 240 relating to their personal diet. It is often the case that adolescents are reluctant to truthfully 241 share about their diet due to fear of judgement and in many cases will report what they 242 perceive to be as socially acceptable, as opposed to actual dietary habits (Jones et al., 2021). 243 Memory bias could have also played a part in the potential for inaccurate responses in the 244 participants who completed the food diaries. Despite the software Libro being employed to 245 ease recording of food consumption, some participants may have struggled to remember all 246 the foods and beverages consumed over the four days, especially if they did not record this 247 information immediately after consumption. Moreover, recording all foods and beverages over 248 a period of 4-days may prove burdensome for some participants, which may have also led to 249 inaccurate recordings. One additional factor to be considered as a limitation, is the period of 250 time in which the diet diary responses were collected. To allow for a larger number of 251 participants to take part, three separate weeks were used for data collection. The different 252 time periods could have captured variations in the eating habits of the participants due to social and environmental factors e.g. assignment or exam stress which is known to alter
 dietary habits (Hafiz et al., 2023), making it difficult to draw reliable and consistent conclusions
 regarding the overall dietary intake of the group.

256

257 One strength of the qualitative focus groups was the unique insight into the lived experiences 258 of food-allergic patients, parents and HCPs. However, there is also an element of social 259 desirability with this method where participants may have provided responses influenced by 260 perceived societal expectations, thus impacting the validity of the results. In addition to this, 261 all focus groups were conducted online via MS Teams due to time constraints and scheduling 262 challenges due to the diverse nature of the participants group (food-allergic patients, parents 263 and HCPs). This presented some challenges. For example, some participants experienced 264 technical difficulties causing them to miss parts of the session, which disrupted the flow of the 265 focus group. Additionally, although participants were encouraged to turn on their cameras to 266 mirror an 'in person' focus group setting, not everyone complied making it difficult to interpret 267 body language and facial expressions. Many participants also faced distractions in their 268 home/work environment, as was evident through background noise, which could have affected 269 their focus and impacted the quality of their contributions. There was also an unequal 270 participation from participants in each focus group. Perhaps the nature of the online setting 271 discouraged some participants to actively engage, despite efforts from myself. Furthermore, 272 saturation of focus groups, where the emergence of new themes and information reaches a 273 standstill, allows for a comprehensive understanding of the research questions. However, due 274 to limited time, it was only managed to conduct two focus groups for the food-allergic patients 275 and one for parents/carers and HCP. Thus, there may be new themes that remain unexplored. 276

277 Across each of the studies, sample size could have posed potential issues, which could have 278 affected the generalisability of the results to the broader population. Time constraints of course 279 played a part in this. In particular, recruiting HCP was challenging due to their limited 280 availability and accessibility, with a considerably smaller number of this group taking part in 281 the initial questionnaires (n=42). Similarly, despite data collection for the diet diaries spread 282 over three weeks, a small number of participants (n=72) were included in the final sample for 283 this study. This could be attributed to the burdensome nature of recording food and beverage 284 intake or possibly the limited time constraints experienced by LA owing to the balance of 285 education, work and social activities.

286

In addition to this, the sample of food-allergic LA in this study while providing valuable insights,
had limitations in terms of representation. Most participants were LA from university settings.
There is a lack of representation as the experiences of food-allergic LA who do not attend

university were not captured. Future research should therefore include a more diverseparticipant pool, ensuring a broader representation of the food-allergic population.

292

293 Despite the limitations mentioned above, this piece of research does add to the existing 294 literature and additionally contributes new insights in relation to the FC, FA, HCA and dietary 295 intake of LA with food allergies. Future studies should aim to consider these limitations through 296 refining methodologies, while also employing more diverse methods, which can help to 297 provide a more comprehensive understanding of the complex interplay between FC, FA, HCA 298 and dietary intake of LA with food allergies.

299

# 300 9.6. Overall Conclusion

301

302 In conclusion, this PhD research endeavoured to gain insights into the current FC, FA, HCA 303 and dietary intake of LA with food allergies. The recommendations and the limitations outlined 304 above are designed to inform future research in the areas studied that will lead to the 305 development of practical, targeted interventions, in the hopes of improving the management 306 of food allergies in LA and their overall quality of life. This piece of research stands as a 307 stepping stone toward a deeper understanding of the challenges faced by LA with food 308 allergies. Ongoing collaboration and efforts between food-allergic patients and their families, 309 HCPs, allergy charity bodies, key stakeholders and researchers is required, to enhance the 310 experiences and outcomes of this too often neglected yet critical life stage.

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### **Appendices**

Appendix 1 - Food Choice Questionnaire

# **Food Choice Behaviour**

Page 1

An Investigation into the Current Food Choice Behaviour of Late Adolescents with and without Food Allergies

### Page 2: Consent

#### Project Background:

Individuals between 18 and 25 years will be in a state of transition from late adolescence to adulthood. This period of transition presents a challenging developmental stage, due to factors such as increased peer pressure and heightened emotions, which can lead to poor food choice. Food insecurity has been defined as the inability to acquire sufficient food to meet nutritional requirements, due to financial or resource constraints. Food insecurity can negatively impact all populations. However, individuals with a food allergy undergoing this crucial period of transition from late adolescence to adulthood, are the most vulnerable. Poor food selection behaviour is prevalent in this group of individuals and is associated with adverse physical and mental health effects.

Furthermore, an under recognition of food allergies exists in those with a lower socioeconomic status. These individuals have poorer access to food and once diagnosed, cost of medication and continued support (e.g. travelling long distances for safe quality food and health care) presents an economic burden.

Late adolescents with food allergies who are subject to reduced food access, are more likely to engage in unhealthy behaviours. For instance, skipping breakfast, inadequate sleep, consuming alcohol, smoking cigarettes, substance abuse and binge-eating, are all common practices prevalent amongst late adolescents experiencing food insecurity. This can have devastating effects for future health status, as behaviours established during late adolescence are likely to persist into adulthood. Therefore, promoting positive change during this life stage is critical.

Limited research is currently available investigating the food choice for those with food allergies, undergoing the period of transition from late adolescence to adulthood.

#### Aim:

The research aims at understanding the impacts of food allergy and socioeconomic status on food access, nutritional status and health care access in late adolescents with and without food allergies.

#### Participant Criteria:

You have been invited to take part in this study because you fulfill the following participant inclusion criteria:

- Between the ages of 18 and 25
- Diagnosed with a food allergy OR Do not suffer from any food allergy

1. If you agree to participate in this research, please select 'I agree' \* Required

- I agree
- I disagree

## Page 3: Section One - About You

2. What is your Age? \* Required

O 18			
C 19			
C 20			
C 21			
C 22			
C 23			
C 24			
C 25			

#### 3. What is your Gender? \* Required

- Male
- Female
- Transgender
- Prefer not to say

4. What is your Height (cm)? \* Required

5. What is your Weight (kg)? \* Required

#### 6. What is your Postcode? \* Required

#### 7. What is your Ethnicity? **\*** Required

- O White British
- White European
- O White Other
- O Black: British Caribbean
- O Black: British African
- O Black: British Other
- O Asian: British Indian
- O Asian: British Pakistani
- O Asian: British Other
- O Mixed Background
- Chinese
- Other

7.a. If you selected Other, please specify:

8. What is your highest level of Education? \* Required

O None

- C GCSE (or equivalent qualification)
- A-Level (or equivalent qualification)
- O Bachelors Degree
- C Post Graduate Degree
- Other

8.a. If you selected Other, please specify:

- 9. What is your current Occupational Status? \* Required
  - O Part-time Student
  - Full-time Student
  - Self-employed
  - O Part-time employed
  - Full-time employed
  - Unemployed
  - O Other

9.a. If you selected Other, please specify:

9.b. If 'student' was selected, do you currently live on campus?

YesNo

10. How many individuals including yourself live in your household? \* Required

1
2
3
4
Other

**10.a.** If you selected Other, please specify:

11. Which of the following best describes the area in which you live? \* Required

- City
- Town
- Countryside
- Village
- Other

**11.a.** If you selected Other, please specify:

## Page 4: Section Two: About your Diet/Diet Quality

**12.** Which type of diet do you currently follow? **\*** Required

- O Vegan
- Vegetarian
- $\ensuremath{\mathbb{C}}$   $\ensuremath{\mathsf{Mainly}}$  animal based foods, with some plant based foods
- O Mainly plant based foods, with some animal based foods
- O Other

**12.a.** If you selected Other, please specify:

13. How would you best describe your overall diet? \* Required

- Different everyday
- C Different only during the week
- Different only during the weekends
- Not much variation

14. Do you currently take any supplements? \* Required

- O Yes
- O No

14.a. If Yes, which one/s?

**15.** Have you been told by a medical practitioner to alter your diet due to medical conditions other than food allergy, such as diabetes, obesity, Crohn's disease, ulcerative colitis?' **\*** *Required* 

○ Yes○ No

15.a. If Yes, which one/s?



16. Do you currently take any medication? \* Required

- O Yes
- O No

16.a. If Yes, which one/s?



# Page 5: Section Three: About your Lifestyle

17. Do you currently smoke? \* Required

O Yes

O No

17.a. If Yes, how many per day?

17.b. If No, have you previously smoked on a regular basis?

O Yes

O No

18. How often do you consume alcohol? \* Required

- Everyday
- 3-5 times/week
- Once a week
- Only on weekends
- Other
- N/A I do not consume alcohol

**18.a.** If you selected Other, please specify:

19. How many days/week do you perform exercise? \* Required

- Everyday
- 3-5 times/week
- 2-3 times/week
- Once a week
- Less than once a week

# Page 6: Section Four: About your Food and Health Care Access/Availability

20. Do you currently possess a driving license? \* Required

0	Yes
0	No

21. Do you currently own your own vehicle? \* Required

0	Yes
C	No

22. If No to Questions 18 and 19, what is your most frequent mode of transport when accessing food and/or health care? **\*** *Required* 

- O Bike
- Car (Passenger)
- Bus
- O Train
- C Taxi
- Walking
- Other

22.a. If you selected Other, please specify:

23. How many miles from where you live, do you need to travel to the nearest store to purchase healthy, nutritious food? **\*** *Required* 

- $\bigcirc$  < 1 mile
- 1 to 2 miles
- 2 to 4 miles
- 4 to 6 miles
- 6 to 8 miles
- 8 to 10 miles
- $\odot$  > 10 miles

24. How many miles from where you live, do you need to travel to your nearest GP or health centre? **\*** *Required* 

- $\odot$  < 1 mile
- 1 to 2 miles
- 2 to 4 miles
- 4 to 6 miles
- 6 to 8 miles
- O 8 to 10 miles
- $\odot$  > 10 miles

**25.** How many miles from where you live, do you need to travel to your nearest hospital? **\*** *Required* 

- <1 mile
- 1 to 2 miles
- 2 to 4 miles
- 4 to 6 miles

- 6 to 8 miles
- 8 to 10 miles
- $\bigcirc$  > 10 miles

26. In the last 12 months, has there been any occasion when you were in need of the following - Medication, Specialist Care, Follow-up Care - but due to FINANCIAL constraints you were unable to do so? **\*** *Required* 

YesNo

26.a. If Yes, which one/s were you unable to access? Optional

- MedicationSpecialist Care
- Follow-up Care

*26.b.* If Yes, has the Covid-19 pandemic influenced your financial ability to access Medication/Specialist Care/Follow-up Care?

⊙ Yes ⊙ No

27. In the last 12 months, has there been any occasion when you were in need of the following - Medication, Specialist Care, Follow-up Care - but due to TRAVEL constraints you were unable to do so? **\*** *Required* 

YesNo

27.a. If Yes, which one/s were you unable to access?

- ☐ Medication
- □ Specialist Care
- □ Follow-up Care

27.b. If Yes, has the Covid-19 pandemic influenced your travel ability to access Medication/Specialist Care/Follow-up Care?

C Yes

C No

### Page 7: Section Five: About your Food Choice

Food choice is a complex and multifactorial process. Below is a list of different determinants of food choice, which have each been placed into different categories. Using the 5-point Likert scale, rate how influential each of the following items within each category are, with respect to your food choice.

#### 28. Sensory Aspects of Food Choice \* Required

Please don't select more than 1 answer(s) per row.

Please select at least 5 answer(s).

	Not Influential	Slightly Influential	Moderately Influential	Very Influential	Extremely Influential
Taste	Γ	Γ	Γ	Γ	Γ
Smell	Γ	Γ	Γ	Γ	Γ
Appearance	Γ	Γ	Γ	Γ	Γ
Texture	Γ	Γ	Γ	Γ	Γ
Hunger	Γ	Γ	Γ	Γ	Γ

29. Convenience and Food Choice **\*** *Required* 

Please don't select more than 1 answer(s) per row.

Please select at least 3 answer(s).

	Not influential at all	Slightly Influential	Moderately Influential	Very Influential	Extremely Influential
Ease of Access	Γ	Γ	Γ	Γ	Г
Cooking Skills	Г	Γ	Г	Γ	Г
Time taken to	F	F	F	F	F
---------------	---	---	---	---	---
prepare					

#### 30. Social Aspects of Food Choice \* Required

Please don't select more than 1 answer(s) per row.

Please select at least 3 answer(s).

	Not influential at all	Slightly Influential	Moderately Influential	Very Influential	Extremely Influential
Family	Γ	Γ	Γ	Γ	Г
Peers	Γ	Г	Г	Γ	Г
Culture	Г	Г	Г	Г	Г

#### 31. Psychological Aspects of Food Choice \* Required

Please don't select more than 1 answer(s) per row.

Please select at least 2 answer(s).

	Not influential at all	Slightly Influential	Moderately Influential	Very Influential	Extremely Influential
Emotion	Γ	Γ	Γ	Γ	Γ
Stress	Γ	Γ	Γ	Γ	Г

32. Economic Aspects of Food Choice \* Required

Please don't select more than 1 answer(s) per row.

Please select at least 2 answer(s).

	Not influential at all	Slightly Influential	Moderately Influential	Very Influential	Extremely Influential
Cost	Γ	Γ	Γ	Γ	Γ
Income	Γ	Γ	Γ	Γ	Γ

#### 33. Advertising and Food Choice \* *Required*

Please don't select more than 1 answer(s) per row.

Please select at least 2 answer(s).

	Not influential at all	Slightly Influential	Moderately Influential	Very Influential	Extremely Influential
Social Media	Γ	Γ	Γ	Γ	Γ
TV Adverts	Γ	Γ	Γ	Γ	Γ

#### 34. University and Food Choice \* Required

Please don't select more than 1 answer(s) per row.

Please select at least 3 answer(s).

	Not influential at all	Slightly Influential	Moderately Influential	Very Influential	Extremely Influential
The University Environment (living on campus)	Г	Г	Г	Г	Г
Student Life	Γ	Γ	Γ	Γ	Γ
Exams	Γ	Γ	Γ	Γ	Γ

35.	Familiarity and Food Choice	* Required
		18 / 31

Please don't select more than 1 answer(s) per row.

Please select at least 2 answer(s).

	Not influential at all	Slightly Influential	Moderately Influential	Very Influential	Extremely Influential
Previous Experience (It is familiar)	Г	Г	Г	Г	Г
Habit (It is usually what I eat)	Г	Г	Г	Г	Г

#### 36. Health Aspects of Food Choice \* Required

Please don't select more than 1 answer(s) per row.

Please select at least 9 answer(s).

	Not influential at all	Slightly Influential	Moderately Influential	Very Influential	Extremely Influential
The number of vitamins and minerals it contains	Г	Г	Г	Г	Г
How fresh it is	Γ	Γ	Γ	Г	Γ
Ability to help control weight	Г	Г	Г	Г	Г
Energy Balance	Γ	Γ	Γ	Γ	Γ
If it contains only natural ingredients	Г	Г	Г	Г	Г
High Fibre	Γ	Γ	Γ	Г	Γ
Low fat	Γ	Γ	Γ	Γ	Γ
Low salt	Γ	Γ	Γ	Γ	Γ
Low sugar	Γ	Γ	Γ	Γ	Γ

## 37. Labelling and Food Choice \* Required

Please don't select more than 1 answer(s) per row.

Please select at least 2 answer(s).

	Never	Rarely	Sometimes	Often	Always
l read the food label	Г	Г	Г	Г	Г
I can easily understand the food label	Г	Г	Г	Г	Г

## Page 8: Section Six: About Your Food Allergy

The following section is only to be completed by those participants who possess one or more food allergies.

#### 38. Do you have a Food Allergy?

O Yes

O No

39. Which food/s are you allergic to?

- Celery
  Gluten
  Gluten
  Crustaceans
  Egg
  Fish
  Lupin
  Milk
  Molluscs
  Mustard
  Tree Nuts
  Peanuts
  Sulphur Dioxide
  Soya
  Sesame Seeds
- Jesame Se
- □ Other

39.a. If you selected Other, please specify:

40. How were you diagnosed with your food allergy? \* Required

- Skin prick test
- □ Blood test
- Food elimination diet
- □ Self-Diagnosed
- □ Other

40.a. If you selected Other, please specify:

41. Have you been prescribed any medication for your food allergy? \* Required

- O Yes
- No

41.a. If Yes, which medications have you been prescribed? Optional



*41.b.* If Yes, do you always take your prescribed medication with you wherever you go? *Optional* 

○ Yes

#### 41.b.i. If No, why not?



42. Do you currently live with anyone who also possesses a food allergy?

○ Yes○ No

42.a. If Yes, what is your relationship with this individual?

43. When was the last time you experienced an allergic reaction?

- In the last year
- In the last 2 years
- In the last 5 years
- In the last 10 years
- More than 10 years
- N/A I have never had an allergic reaction

44. Was your last allergic reaction accidental?

O Yes

O No

Unsure

○ N/A - I have never had an allergic reaction

45. How would you rate the severity of your most recent allergic reaction?

- O MILD (Redness of the skin, runny nose/sneezing, slight cough)
- O MODERATE (Hives, eczema, itchy mouth, stomach pain, odd taste in the mouth)

• SEVERE/LIFE THREATENING (obstructive swelling of the lips, tongue, and/or throat, trouble swallowing, shortness of breath, turning blue, drop in blood pressure, loss of consciousness, chest pain, weak pulse)

C N/A - I have never had an allergic reaction

46. How much does your food allergy influence your diet?

- O Not influential at all
- Slightly Influential
- O Moderately Influential
- Very Influential
- C Extremely Influential

47. How often do you avoid the food/s you are allergic to

- Never
- Rarely

- Sometimes
- Often
- Always

48. What precautions do you take to avoid the food/s you are allergic to?

- Reading food labels
- Contacting food companies
- Asking cooks/chefs when eating out
- □ Asking waiters/service staff when eating out
- □ Checking menus/websites
- Asking friends about food they have prepared
- Carrying an adrenaline auto-injector
- □ Wearing a medical ID
- □ Other

48.a. If you selected Other, please specify:

#### 49. Have you used an adrenaline auto-injector before?

- Yes
- No
- Unsure

50. Do you know how to accurately administer an adrenaline auto-injector?

○ Yes

- O No
- Unsure

51. How often do you carry an adrenaline auto-injector with you?

- Never
- C Rarely
- Sometimes
- O Often
- Always

52. Do you feel your food allergy does impact or has previously impacted your quality of life?

O Yes

O No

52.a. If Yes, provide details as to how you have been affected

53. How many miles do you need to travel to the nearest store to purchase allergen free food?

- $\odot$  < 1 mile
- 1 to 2 miles
- 2 to 4 miles
- 4 to 6 miles
- 6 to 8 miles
- 8 to 10 miles
- $\odot$  > 10 miles

54. How many miles do you need to travel to receive health care for your food allergy?

< 1 mile</li>
1 to 2 miles
2 to 4 miles
4 to 6 miles
6 to 8 miles
8 to 10 miles
> 10 miles

55. Do you regularly attend your health care centre to seek or receive treatment for your food allergy?

C YesC No

55.a. If No, why not?

1	·	

**56.** Do you currently have access to transition care at your local GP clinic or hospital, to support the management of your food allergy? (*Transition care can be defined as the process of providing the necessary support - medical, psychosocial and educational needs - to those in late adolescence, as they prepare to move from paediatric allergy services to adult allergy services*)

- O Yes
- O No
- ⊂ Unsure

56.a. If Yes, what resources are available? (Tick all that apply)

- Designated phone hotline
- □ Appointments with a designated health care professional
- E-resources
- Webinars
- □ Workshops
- □ N/A no specific resources
- □ Unsure
- □ Other

56.a.i. If you selected Other, please specify:

57. Which Healthcare Professional/s do you feel have helped you the most throughout your food allergy? (*Tick all that apply*)

□ Allergy Specialist
Allergy Nurses
□ GP
□ Pharmacists
☐ Dietitians
□ Speech and Language Therapist
☐ Psychologists
□ Other

57.a. If you selected Other, please specify:

58. Have you been seen by an allergy specialist before? \* Required

C Yes

O No

58.a. If Yes, for how long?

58.a.i. Has your experience/s with an allergy specialist been useful?

- C Yes
- O No

59. Do you feel you could be better supported in managing your food allergy? \* *Required* 

○ Yes○ No

59.a. If Yes, please provide details as to how.

60. Do you feel there is adequate support for the mental health of those with food allergies? **\*** *Required* 

O Yes

O No

*60.a.* If No, what would you like to see improved with regards to quality and access of mental health care?

## Page 9: Final page

Thank you for taking the time to complete this survey. The findings will help to further our understanding of the current food choice for late adolescents with food allergies.

**Appendix 2** - Distance travelled of 8 to 10 miles and > 10 miles by food allergic participants by postcode region

HEALTHY NUTRITOUS FOOD	
8 TO 10 MILES	>10 MILES
BB2	PR2
BB3	LA9
BB7	LA13
PR1	BL5
LA11	BL9
FY5	L12
BL1	L17
BL5	L19
M4	L23
M12	L34
M50	CH36
WN6	CH65
L15	CW10
L16 CW10	
ALLERGEN FREE FOOD	
8 TO 10 MILES	>10 MILES
BB3	PR2
PR7	PR4
LA9	M9
FY8	WN3
BL3	WN4
BL5	L12
M6	CH32
M7	CW10
WN2	
L23	
L27	
CH28	

PRIMARY CARE		
8 TO 10 MILES	>10 MILES	
BB2	PR2	
M6	PR4	
M11	BL3	
L16	BL6	
	BL8	
	L12	
	CH61	
SECONDARY/TERTIARY CARE		
8 TO 10 MILES	>10 MILES	
BB9	BB2	
	BB3	
	BB8	
	FY5	
	PR1	
	PR2	
	PR4	
	PR7	
	LA9	
	LA14	
	LA17	
	BL5	
	BL6	
	BL8	
	M6	
	M7	
	M9	
	M12	
	WN6	
	L12	
	L19	
	L23	

SECONDARY/TERTIARY CARE	
8 TO 10 MILES	>10 MILES
	L27
	L34
	CH28
	CH65
	CH70
	CW10

# Health Care Access

## Page 1

An Investigation into the Current Health Care Access for Late Adolescents with Food Allergies

## Page 2: Consent

#### Project Background:

The period of transition from late adolescence to adulthood (18 to 25 years) is a challenging developmental stage. It is a time of physical, cognitive, psychological and social development. This coupled with responsibility of self-management of a food allergy, makes it an extremely stressful and significant period.

Access to adequate healthcare is a basic requirement for all those suffering from food allergies. It is imperative that late adolescents with food allergies have the means to obtain sufficient knowledge, skills and confidence, allowing them to gain independence and enhance individual self-management abilities. Despite this, allergy service provision across the UK is severely lacking, with a shortage of allergy clinics and specialists available, who can provide the necessary advice and treatment.

Furthermore, an under recognition of food allergies exists in those with a lower socioeconomic status. These individuals have poorer access to health care and once diagnosed, cost of medication and continued support (e.g. travelling long distances for safe quality food and health care) presents an economic burden.

Limited research is currently available investigating the current health care access for those with food allergies, undergoing this period of transition from late adolescence to adulthood.

#### Aim:

The research aims at understanding the impacts of food allergy and socioeconomic status on food access, nutritional status and health care access in late adolescents with and without food allergies.

#### Participant Criteria:

You have been invited to take part in this study because you are a health care professional, who has worked with or currently works with 18 to 25 year olds with one or more existing food allergies.

1. If you agree to participate in this research, please select 'I agree' \* Required

○ I agree

○ I disagree

## Page 3: Questions

2. What is your Age? \* Required

- 0 20-29
- O 30-39
- O 40-49
- O 50-59
- 60+

3. What is your Gender? \* Required

- Male
- Female
- Transgender
- Prefer not to say

4. What is the postcode of the place in which you currently work? \* Required

5.	Which of the following best describes where the patients you see live? (Tick all that
арр	ly) 🛊 Required

- □ City
- □ Town
- □ Countryside

□ Village

□ Other

5.a. If you selected Other, please specify:

6. What is your current profession? \* Required

- Doctor
- Nurse
- O Pharmacist
- Dietitian
- C Speech and Language Therapist
- Psychologist
- O Health Care Assistant
- O Other

6.a. If you selected Other, please specify:

7. Which of the following fields do you currently specialise in at the place in which you work? (*Tick all that apply*) **\*** *Required* 

- Primary Care
- □ Paediatrics
- □ Adult Medicine

□ Allergy

□ N/A - I do not specialise in any field

□ Other

7.a. If you selected Other, please specify:

8. In which setting do you currently work? (Tick all that apply) \* Required

- □ Primary Care (e.g. health centre/walk-in clinic)
- Secondary Care (e.g. hospital setting with a specialist)
- □ Tertiary Care (e.g. hospital setting providing highly specialised services)
- □ Private Practice
- □ Other

8.a. If you selected Other, please specify:

9. Which age ranges does your service cover? (Tick all that apply) \* Required

□ All ages
□ 0-14
□ 15-17
□ 18-24
□ 25+
□ Other

9.a. If you selected Other, please specify:

*10.* How many years has your current work involved seeing 18 to 25 year olds with one or more existing food allergies? **\*** *Required* 

- 0-5 years
- 6-10 years
- 11-20 years
- 20+ years

**11.** Have you had any specific training in how to care for 18 to 25 year olds with one or more existing food allergies? **\*** *Required* 

O Yes

- O NO
- Unsure

11.a. If Yes, provide details

**12.** In the last year, how many patients between the ages of 18 and 25 years with one or more existing food allergies did you see? (*Note: This could be for any reason relating* 

to their food allergy). \* Required

0-5
6-10
11-15
16-20
20-25
26+

13. How many patients between the ages of 18 and 25 years with one or more existing food allergies, regularly attend their appointments at the place in which you currently work? **\*** *Required* 

- 0-10%
- 11-25%
- 26-50%
- 51-75%
- C 76-100%
- Unsure

**14.** Will irregular attendance by 18 to 25 year olds with one or more existing food allergies, at the place in which you currently work, lead to them being discharged from your services or lead to the removal of their name from the GP practice list? **\*** *Required* 

- Yes
- O No
- Sometimes
- Unsure

**15.** How confident are you in providing tailored advice for 18 to 25 year olds with one or more existing food allergies? **\*** *Required* 

- O Not confident at all
- O Somewhat confident
- Fairly confident
- Completely confident

**16.** What resources does the place in which you currently work have, that are tailored to meet the needs of 18 to 25 year olds with one or more existing food allergies? (*Tick all that apply*) **\*** *Required* 

Г	Designated	phone	hotline
	Designated	prioric	nounic

- Appointments with the designated practice/service lead
- E-resources
- ☐ Webinars
- □ Workshops
- □ Transition guidelines for health care professionals
- □ Transition assessment tools
- □ N/A no specific resources
- □ Other

16.a. If you selected Other, please specify:



**17.** In your current place of work, who is responsible for deciding when patients should transfer from paediatric to adult allergy services? (*Tick all that apply*) **\*** *Required* 

Γ	Allergy	Consu	ltant
---	---------	-------	-------

Allergy Nurse

□ GP

- Patient
- □ Other
- □ Unsure

**17.a.** If you selected Other, please specify:

18. At what age do you believe that transition care should begin? \* Required

- O 10-14 years
- © 15-17 years
- O 18-25 years
- O 26+
- Other

18.a. If you selected Other, please specify:

**19.** At what age does transition care for individuals with one or more food allergies begin, at the place in which your currently you work? **\*** *Required* 

10-14 years15-17 years

- 18-25 years
- 0 26+
- Other
- N/A There is currently no transition care

19.a. If you selected Other, please specify:

20. How important do you believe transition care is for 18 to 25 years olds with one or more existing food allergies? **\*** *Required* 

- O Not important at all
- Slightly Important
- Important
- Fairly Important
- Extremely Important

**(21.)** How would you rate the communication regarding your patients (18 to 25 year olds with one or more existing food allergies), between the local allergy clinics and their primary care providers? **\*** *Required* 

- Very Poor
- O Poor
- Average
- Good
- Excellent

22. Please use the space below to provide any additional thoughts you may have, about the transition process for 18 to 25 year olds with one or more existing food allergies.



## Page 4: Final page

Thank you for taking the time to complete this survey. The findings will help to further our understanding of the current health care access for late adolescents with food allergies

## Appendix 4 - Topic guides

Food Allergic Patients





## <u>Transitioning to Independence: Late Adolescents Access to Food and Health</u> <u>Care and Self-Management of Food Allergies</u>

## <u>Topic Guide</u>

#### Introduction:

Hi everyone, thank you all for attending today. My name is Zainab Laheri and I am a PhD student at the University of Central Lancashire. I will be facilitating todays focus group. With me is my colleague (name of colleague...). He/she will observe the procedure, take notes and record the session.

#### Purpose and Guideline:

We are here today to explore how your food allergy influences your attitudes, behaviours, beliefs and experiences when it comes to choosing food. We have a list of pre-determined factors of food choice that will be used to initially prompt the discussion. However, these are not extensive and if you would like to discuss any additional determinants of food choice not mentioned, please feel free to do so. There are no right or wrong answers. You can agree or disagree with each other and you may change your mind at any time during the session. This is an open space and I would like you to feel comfortable speaking your mind and sharing your views. You will not be judged on what you say. Your participation is voluntary and if at any point you feel uncomfortable, you may leave.

During the session, my colleague will be taking notes and tape-recording the session, to ensure nothing is missed. Please speak one at a time and speak clearly. Show respect to others when they are speaking and sharing their views. If possible, please turn off your phones before the session begins to ensure there are no disruptions. Everything you say will of course be confidential. You will not be able to be identified from what you say during this discussion. For the sake of analysis, each participant will be assigned a code to ensure anonymity. However, to illustrate certain points, direct quotes will be included within the final thesis.

Before we begin does anyone have any questions?

## Focus Group Discussion

## Food Choice

- Social aspects family, peers, culture, eating out
- University Environment *living on campus, student life, exams*

Prompt individuals – Why do certain factors influence you more? Do you actively try to eat healthily? What challenges do you face when trying to eat healthily - particularly on campus during your time at university. Is there a difference between your diet at home in comparison to your diet when you are at university?

## Food Allergy

- Do you feel you are more restricted in your food choices because of your food allergy?
- Do you feel you have enough access to allergen free foods?
- Do you regularly read food labels? If not, why?
- Are there any barriers when eating out? If yes, what are they?
- Do you openly discuss your food allergy with your peers/individuals at university/colleagues? Have you had to compromise eating healthily, in order to stay safe and not risk an allergic reaction?
- Do you feel you are able to eat more healthy whilst keeping safe at home?
- How often do you use food banks? Do you feel that food banks include enough options for allergen free foods?

Are there any factors that impact your food choice that have not been discussed? If so, what are they? To what extent do these influence your food choice?

## **Health Care Access**

- Do you feel you are being provided sufficient care for your food allergy?
- Have you experienced any challenges when trying to access care for your food allergy? If so, what are they? Online access of Health Care? Self-Help?
- GP's Sufficient care being provided?
- Typically how long do you travel to access secondary or tertiary care for your food allergy?
- How do you feel about the current mental health support that is being provided by health care professionals? Psychological impact of food allergies?

### Is there anything else that you would like to discuss?

Thank you for taking the time to explore your current food choice, food access and health care access. Everything discussed has been extremely helpful.

Once you have left, if you have anything further to add or you forgot to mention anything during this session, please feel free to email me (contact information can be found on the participant information sheet). Thank you once again for your participation. You will receive your £25 gift voucher via email in the next week.

#### Parents/Carers





## <u>Transitioning to Independence: Late Adolescents Access to Food and Health</u> <u>Care and Self-Management of Food Allergies</u>

## <u>Topic Guide</u>

#### Introduction:

Hi everyone, thank you all for attending today. My name is Zainab Laheri and I am a PhD student at the University of Central Lancashire. I will be facilitating todays focus group. With me is my colleague (name of colleague...). He/she will observe the procedure, take notes and record the session.

#### Purpose and Guideline:

We are here today to explore your childs diet in relation to their food allergy and health care access.

There are no right or wrong answers. You can agree or disagree with each other and you may change your mind at any time during the session. This is an open space and I would like you to feel comfortable speaking your mind and sharing your views. You will not be judged on what you say. Your participation is voluntary and if at any point you feel uncomfortable, you may leave.

During the session, my colleague will be taking notes and tape-recording the session, to ensure nothing is missed. Please speak one at a time and speak clearly. Show respect to others when they are speaking and sharing their views. If possible, please turn off your phones before the session begins to ensure there are no disruptions. Everything you say will of course be confidential. You will not be able to be identified from what you say during this discussion. For the sake of analysis, each participant will be assigned a code to ensure anonymity. However, to illustrate certain points, direct quotes will be included within the final thesis.

Before we begin does anyone have any questions?

## Focus Group Discussion

### Food Allergy and Diet

- What challenges do you as parent/carers face when trying to ensure that your child is able to eat healthily with a food allergy.
- Do you feel as though your child is having to compromise the nutritional quality of their diet, because of their food allergy?
- How often do you read food labels? Do you find the current food labelling challenging to interpret?
- How do you prepare your child to manage their food allergy and diet when they are moving away from home for the first time.

## Health Care Access

- Have you faced any challenges when accessing health care for your child?
- What sort of guidance and support have you been exposed to so far, when accessing health care for your child.
- Do you feel you have enough guidance and support to make informed decisions about your child's healthcare, with regard to their food allergy?
- At what age do you think transition care between paediatric and adult health care services should start? Why do you think this?
- What additional healthcare support do you feel would benefit your child?

### Is there anything else that you would like to discuss?

Thank you for taking the time to explore your child's impact of food allergy on their diet and their health care access. Everything discussed has been extremely helpful.

Once you have left, if you have anything further to add or you forgot to mention anything during this session, please feel free to email me (contact information can be found on the participant information sheet). Thank you once again for your participation. You will receive your £25 gift voucher via email in the next week.
# Health Care Professionals





# <u>Transitioning to Independence: Late Adolescents Access to Food and Health</u> <u>Care and Self-Management of Food Allergies</u>

# <u>Topic Guide</u>

# Introduction:

Hi everyone, thank you all for attending today. My name is Zainab Laheri and I am a PhD student at the University of Central Lancashire. I will be facilitating todays focus group. With me is my colleague (name of moderator). He/she will observe the procedure, take notes and record the session.

# Purpose and Guideline:

We are here today to explore the current health care access available for late adolescents (18-25years) with food allergies. We will also discuss any barriers or facilitators you may have experienced when providing care for these individuals. There are no right or wrong answers. You can agree or disagree with each other and you may change your mind at any time during the session. This is an open space and I would like you to feel comfortable speaking your mind and sharing your views. You will not be judged on what you say. Your participation is voluntary and if at any point you feel uncomfortable, you may leave.

During the session, my colleague will be taking notes and tape-recording the session, to ensure nothing is missed. Please speak one at a time and speak clearly. Show respect to others when they are speaking and sharing their views. If possible, please turn off your phones before the session begins to ensure there are no disruptions. Everything you say will of course be confidential. You will not be able to be identified from what you say during this discussion. For the sake of analysis, each participant will be assigned a code to ensure anonymity. However, to illustrate certain points, direct quotes will be included within the final thesis.

Before we begin does anyone have any questions?

# Focus Group Discussion

# **Health Care Access**

- What support is currently available in your practice?
- How important do you feel transition care is? Is it necessary for late adolescents with food allergies? Will it be of benefit to them?
- At what age do you feel transition care should start? Why is this?
- What sort of training have you received to improve the care you provide for late adolescents with food allergies? Is there any of you who have not received any training? Why not? What training do you feel would benefit you?
- Do you think the place in which you work will benefit from a transition guideline?
- What resources are already in place at your practice?
- What additional resources do you think late adolescents with food allergies will benefit from?
- Have you found anything in particular that has allowed you to provide better care for late adolescents with food allergies? Would you recommend this to other practices?
- What barriers have you experienced when providing care for late adolescents with food allergies?
- What is your current stance on mental health and food allergies? Is there enough support being provided for late adolescents? What about specialist psychological support? Is this available for this group of individuals?

# Is there anything else that you would like to discuss?

Thank you for taking the time to explore the current health care access for late adolescents with food allergies. Everything discussed has been extremely helpful.

Once you have left, if you have anything further to add or you forgot to mention anything during this session, please feel free to email me (contact information can be found on the participant information sheet). Thank you once again for your participation. You will receive your £25 gift voucher via email in the next week.

# Interventions





# <u>Transitioning to Independence: Late Adolescents Access to Food and Health</u> <u>Care and Self-Management of Food Allergies</u>

# <u>Topic Guide</u>

# Introduction:

Hi everyone, thank you all for attending today. My name is Zainab Laheri and I am a PhD student at the University of Central Lancashire. I will be facilitating todays focus group. With me is my colleague (name of moderator). He/she will observe the procedure, take notes and record the session.

# Purpose and Guideline:

We are here today to discuss how we can improve the current food and health care access available for late adolescents with food allergies. The aim is to conceptualise and co-develop one or more preventive interventions that will provide the necessary support for this group of individuals to successfully self-manage their food allergy.

There are no right or wrong answers. You can agree or disagree with each other and you may change your mind at any time during the session. This is an open space and I would like you to feel comfortable speaking your mind and sharing your views. You will not be judged on what you say. Your participation is voluntary and if at any point you feel uncomfortable, you may leave.

During the session, my colleague will be taking notes and tape-recording the session, to ensure nothing is missed. Please speak one at a time and speak clearly. Show respect to others when they are speaking and sharing their views. If possible, please turn off your phones before the session begins to ensure there are no disruptions. Everything you say will of course be confidential. You will not be able to be identified from what you say during this discussion. For the sake of analysis, each participant will be assigned a code to ensure anonymity. However, to illustrate certain points, direct quotes will be included within the final thesis.

Before we begin does anyone have any questions?

# Focus Group Discussion

The findings from the questionnaire and previous focus group indicate that ... were the most influential factors of food choice. This suggests that ... What are your thoughts? How can we improve this?

With regard to the current health care access, the questionnaire and previous focus group indicate that ... These were the barriers mentioned .... And these were the facilitators ... These are the up to date resources proposed by EAACI for the most effective transition for this group. What are your thoughts? How can we improve?

In terms of the nutritional status of late adolescents with food allergies, we found... How do you propose we can improve the diet for this group, particularly in the university setting?

What potential interventions based on these findings would seem appropriate and beneficial? How can we improve the current food choice, food access and health care access for 18-25year olds with food allergies?

Is there anything else that you would like to discuss?

Thank you for taking the time to provide your knowledge, thoughts and expertise in the codevelopment of the intervention/s. Everything discussed has been extremely helpful. Once implemented, the intervention/s will undoubtedly prove useful – to firstly empower late adolescents with food allergies to make better food choices and secondly, to allow them to easily access the necessary support from health services, to assist in the successful selfmanagement of their food allergy.

Once you have left, if you have anything further to add or you forgot to mention anything during this session, please feel free to email me (contact information can be found on the participant information sheet). Thank you once again for your participation. You will receive your £25 gift voucher via email in the next week.

<u>Appendix 5</u> – Nutrition Client Information Survey

# **Nutrition Client Information**

# Page 1: Nutrition Client Information Survey

# 1. First Name

2. Surname

# 3. Date of Birth



# 4. Gender



5. Weight (kg)

# 6. Height (m)



# 7. Postcode



# 8. Occupation Activity Level

- Sedentary
- Lightly Active
- Moderately Active
- Very Active
- Extremely Active
- 9. Exercise Activity Level
  - Sedentary
  - Lightly Active
  - Moderately Active
  - Very Active
  - Extremely Active

# 10. Dietary Preference

- Vegetarian
- O Vegan
- Halal
- C Kosher

**11.** Please list all existing food allergies that have been clinically confirmed. If you don't have any food allergy please write N/A

# Page 2: Thank you for your participation

# Appendix 6 – Mann Whitney U Tests

# Macronutrient Between Groups

Test Statistics <sup>a</sup>						
	Protein		Carbohydrate	Energy		
	(g)	Fat (g)	(g)	(Kcal)	Fibre (g)	
Mann-Whitney U	546.000	507.000	485.000	479.000	528.000	
Wilcoxon W	1366.000	1327.000	1305.000	1299.000	1348.000	
Z	858	-1.310	-1.565	-1.635	-1.067	
Asymp. Sig. (2- tailed)	.391	.190	.118	.102	.286	

Test Statistics <sup>a</sup>						
	Saturated Fat	Monounsatura	Polyunsaturat	Cholesterol		
	(g)	ted Fat (g)	ed Fat (g)	(mg)	Sugars(g)	
Mann-Whitney U	487.000	496.000	492.000	490.000	551.000	
Wilcoxon W	1307.000	1276.000	1272.000	1193.000	1371.000	
Z	-1.542	-1.283	-1.330	-1.028	800	
Asymp. Sig. (2- tailed)	.123	.200	.183	.304	.424	

# a. Grouping Variable: Food Allergy

# Vitamins Between Groups

Test Statistics <sup>a</sup>						
	Vitamin A	Vitamin D	Vitamin E	Thiamin	Riboflavin	
	(ug)	(ug)	(mg)	(mg)	(mg)	
Mann-Whitney U	495.000	530.500	487.000	515.000	503.000	
Wilcoxon W	1315.000	1271.500	1307.000	1335.000	1323.000	
Z	-1.449	706	-1.542	-1.217	-1.356	
Asymp. Sig. (2- tailed)	.147	.480	.123	.223	.175	

# **Test Statistics**<sup>a</sup>

	Niacin (mg)	Vitamin B6 (mg)	Biotin (ua)	Folate (ug)	Vitamin B12 (ug)
Mann-Whitney U	591.000	495.000	610.000	481.000	489.500
Wilcoxon W	1411.000	1315.000	1430.000	1301.000	1269.500
Z	336	-1.449	116	-1.611	-1.360
Asymp. Sig. (2- tailed)	.737	.147	.908	.107	.174

# **Test Statistics**<sup>a</sup>

	Vitamin C
	(mg)
Mann-Whitney U	598.500
Wilcoxon W	1418.500
Z	018
Asymp. Sig. (2-	.986
tailed)	

a. Grouping Variable: Food Allergy

# Minerals Between Groups

Test Statistics <sup>a</sup>					
	Sodium	Potassium	Calcium	Magnesium	Phosphurus
	(mg)	(mg)	(mg)	(mg)	(mg)
Mann-Whitney U	466.000	526.000	602.000	586.000	614.000
Wilcoxon W	1286.000	1346.000	1422.000	1406.000	1110.000
Z	-1.785	-1.090	209	394	070
Asymp. Sig. (2- tailed)	.074	.276	.835	.693	.945

# **Test Statistics**<sup>a</sup>

		Copper		Chloride	Manganese
	Iron (mg)	(mg)	Zinc (mg)	(mg)	(mg)
Mann-Whitney U	517.000	519.000	572.000	432.000	557.000
Wilcoxon W	1337.000	1339.000	1392.000	1252.000	1377.000
Z	-1.194	-1.171	556	-2.180	730
Asymp. Sig. (2- tailed)	.232	.242	.578	.029	.465

# **Test Statistics**<sup>a</sup>

	Selenium	
	(ug)	lodine (ug)
Mann-Whitney U	560.000	553.000
Wilcoxon W	1380.000	1373.000
Z	696	777
Asymp. Sig. (2- tailed)	.487	.437

a. Grouping Variable: Food Allergy

# <u>Appendix 7</u> – Extra Quotes from Focus Groups

# FOOD ALLERGY PATIENTS (Section 6.3.1)

#### Theme 1: The Social Challenges in Food Choice

'My social life is definitely affected, you know its different than before but I do still go out. If there's food involved, I just don't eat. I'll stick to drinks really. That's the best way' (FAP 1, Male, Milk, Egg and Peanut Allergy).

'I do still go out socially, but I am selective about which gatherings I go to because not everyone understands. You can tell that the staff there, they don't really know much so for me I definitely don't eat because well I just don't like to risk it.' (FAP 8, Female, Peanut and Milk Allergy)

'When I'm with my family it's okay because my family they know the kind of food I can eat and most of them are careful in what they serve me so it has been helpful. I feel more relaxed with them' (FAP 8, Female, Peanut and Milk Allergy)

'I eat so much better with my family. Like my mum she'll always prepare a variety of stuff and its everything that I can eat which is really good.' (FAP 6, Male, Soy and Egg Allergy)

'Sometime it gives my friends a sense of unacceptance. Like I'm trying to dissociate myself from them. So if I reject the kind of things they eat, it makes them feel like I'm not of their standard. Like I'm way higher than their standard. So that actually makes it very difficult to eat when I'm with them.' (FAP 1, Male, Milk, Egg and Peanut Allergy).

### Theme 2: The Impact of the University Environment on Food Choice

'I don't eat at university, because there is limited allergen free options. Maybe once a week they have something in the university cafeteria but that's it.' (FAP 13, Male, Milk and Soy Allergy)

'There are lots of fast food places outside campus which is close and not too expensive so I eat a lot there' (FAP 3, Female, Fish Allergy)

'I think that the healthier stuff is actually more expensive. So I just stick with the cheaper stuff because money well sometimes you know financially it can be difficult.' (FAP 16, Male, Shellfish, Milk, Soy Allergy)

'I just need to plan ahead when I'm at university... I have my steady lunch box that I use to make sure that I have all my supplies, all my food supplies for the day are available in my backpack that way I'm not tempted to, you know, eat in the cafeteria. Yeah. So that's how I've been trying to survive.' (FAP 17, Male, Milk, Egg, Wheat and Soy Allergy) 'During exam weeks and deadlines I have to rely on convenience foods because there is not much time to prepare foods.' (FAP 15, Male, Egg, Fish and Milk Allergy)

#### Theme 3: 'Labelling makes it hard'

'And plus the labelling really confuses me. Sometimes it says its got no peanuts in but then it will also say that it might have this or it might have that and then it just gets really frustrating and it stresses me out. I don't really trust a lot of the foods now.' (FAP 9, Male, Soy, Mil, Peanut and Tree Nut Allergy)

#### Theme 4: Barriers in Accessing Allergen Free Foods

'Yes I think being at uni, it is hard financially. There are quite a few expenses already. And then with food especially allergy free food cos it's just too expensive I'll try and wait for offers and shop in bulk when I have vouchers.' (FAP 3, Female, Fish Allergy)

'The supermarkets I think are really expensive but I'll just try and go to the convenience stores, it's cheaper and quicker especially during the weekdays when I'm still on campus, but I think definitely I do struggle with getting allergy free food there. They might have the odd one thing but I just stick to the same foods really.' (FAP 12, Male, Milk, Egg and Egg Allergy)

'I don't always have time to get it because it's is quite a long way out. Cos for me I normally just go to the Tesco express down from the where I live and they do have some stuff but to be honest they don't have many choices and I have well multiple allergies so it means for me there really isn't too many options.' (FAP 17, Female, Milk, Egg, Soy and Peanut Allergy)

#### Theme 5: 'Allergen Free Doesn't Mean It's Safe'

'Sometimes when I've got allergen free food, once I remember on the back it said that it was egg free but I still had a reaction and it did get bad.' (FAP 15, Male, Egg, Fish and Milk Allergy)

'Twice now I've still ended up having a reaction after eating free from foods. I don't get it because it clearly said on the packaging that it didn't have milk or egg but then it still affected me. Now I make sure I don't get that brand anymore.' (FAP 2, Male, Milk Allergy)

#### Theme 6: 'My Diet Is Affected.'

'A lot of my meals are not well prepared, because I can't use a lot of ingredients and its actually really quite difficult to find like proper alternatives that meet all the nutrients.' (FAP 19, Male, Egg, Peanut, Soy and Wheat Allergy)

#### Theme 7: Challenges in Accessing Adequate Healthcare – GPs and Specialist Care

'I've had a lot of bad experiences when trying to get support for my food allergy. Like once first they said that I was allergic to this food and then that food and then it kept changing so I was avoiding a lot to begin with. It can be quite taxing when you have to go for tests and the results takes ages. The whole process just took too long and my weight dropped a lot in that time. By the time they referred me to the allergist I was in quite a bad state. It wasn't good at all. I don't even understand why it took them that long and all of it the whole process has just put me off. Now I don't even bother going to my GP, I'll try and just manage it myself really' (FAP 11, Male, Shellfish and Fish Allergy)

'So first at the beginning when they gave me the epi-pen it was a bit confusing the information they gave on how to use it. I tried to ring up to ask but the GP was really busy I didn't even get through. It was taking ages so I just went online and then watched a video. That was so much easier for me now I'll first just check online without asking.' (FAP 3, Female, Fish Allergy)

'OK, yeah for me, it's not always that easy because although we have like the insurance, but there are still like some out of pocket costs including like the coping and then prescription medications. Its difficult, sometimes I don't know what to do.' (FAP 1, Male, Milk, Egg and Peanut Allergy).

# Theme 8: 'The Best Option Is To Manage It Myself'

'I just get prescriptions myself and do what I have to do. I feel like I'm fine doing it myself cos I know what works and what doesn't. I'll use online websites and stuff and they've really helped me and I've been managing it myself for quite a while now.' FAP 11, Male, Shellfish and Fish Allergy)

'Most importantly you just need a proper diagnosis, after this yeah its fine to manage it yourself. It's the better option really cos everything's online now. (FAP 17, Female, Milk, Egg, Soy and Peanut Allergy)

#### PARENTS/CARERS (Section 6.3.2.)

#### Theme 1: 'It's challenging to make sure my child has a balanced diet'

'Dealing with allergy has been hard both for me and my child. There was a period when he wasn't growing properly but we weren't offered any support on how to deal with this. We need more contributions by the HCP. Because it's a problem. Some guidance at the beginning would really make a difference. We need to make sure our child actually eats a balanced diet irrespective of the allergies and the foods they react to negatively.' (P/C 2, Male)

### Theme 2: 'Labelling Is Challenging and Limits Food Choice'

'The labelling has been quite difficult. I feel like now I'm getting more used to the different phrases but it's hard cos sometimes we'll buy something and then there's still a reaction and the shopping, yeah I have to factor in more time now, sometimes its hard.' (FC 8, Male)

# Theme 3: 'It is Difficult To Access Allergen Free Foods Because of the Limited Availability'

'It is expensive, yeah I do find that it is. But at the end of the day my child needs it, it's up to me right now to make sure they can have proper foods and some of the AFF have been quite good, I mean the taste, it's not the same as every normal food but it has been better than just avoiding everything altogether.' (P/C 9, Female)

# Theme 4: 'Good Allergy Health Care Is a Challenge'

'When we went for an appointment the GP centre didn't have all the equipment to do the testing there and we had to wait a while before we were called again, it was quite odd. And then because my child she has not just one but multiple food allergies, there was no help on which foods to avoid and good replacements.' (PC 3, Male)

# Theme 5: 'Managing My Child's Food Allergy Has Psychologically Impacted Me'

'I worry a lot when my son goes away at uni. It's hard because I know how difficult it is and now he has to do it himself and there's this constant worry and fear.' (P/C 5, Female)

'And it would be great to have healthcare providers who showed genuine empathy and understanding towards my concerns and worries about my child's health, so having health care providers that will take time to listen and provide reassurance and other personalised care to make a significant difference. Because in my personal experience, there really isn't hardly any care like this.' (P/C 1, Female)

#### **HEALTHCARE PROFESSIONALS (Section 6.3.3.)**

#### Theme 1: Challenges with Patient Engagement

'In the past a lot of the time the patient he/she won't actually come to the appointments so just even getting them here is hard. It's that age and when I have asked sometimes financially they find it difficult.' (HCP, Dietitian)

### Theme 2: Challenges with Providing Psychological Support

'It's really hard to provide the patients with this support in the hospital, we don't really have much but it is very, very important and very, very necessary for people having food allergy, you know, there are some situations where they go through some kind of stress and other mental issues. So in this kind of situation, it's very necessary to provide them with a qualified mental health provider who would be able to take them through this stage.' (HCP 5, Dietitian)

'Also being able to direct patients to counselling and therapy. This is not always available for them and these services can help patients cope with the emotional and psychological impact of food allergy. Because you know the food allergy is more like a chronic disease, you may not suffer from the pain every day but every time you eat you may be afraid something bad might happen. So all those thoughts might make you have some kind of anxiety, which could actually develop into something worse if it isn't treated.' (HCP 6, Dietitian)

### Theme 3: Issues with the Referral System

'As a dietitian I do work with the allergist and sometimes the patients have been wrongly referred, that can take up more time which isn't really helpful.' (HCP 5, Dietitian)

'A lot of the time what happens is the patient will get referred to the specialist, but the advice they require could have easily been dealt with earlier by the GP if they had the correct knowledge and the right training and this could have also saved a lot of time and I think this does frustrate the patient and I can understand why.' (HCP 4, Nurse)

# Theme 4: Inconsistent Use of Transition Guidelines

'So my hospital where I work, there's a guideline. Yes. But I don't know if, I don't think that everyone will actually use them because sometimes we just know they are ready to move so then they will go to the adult allergy clinic.' (HCP 8, GP)

# Theme 5: Ongoing Professional Development

'I have completed a certificate program in pediatric and adult immunology. I have also completed courses on diagnosis and management of FA and this has all helped me when I am treating my patients.' (HCP 4, Nurse)

### Theme 6: Support Networks

'We have a list of community resources available for our patients, such as local allergy support groups and allergy-friendly restaurants and the patients will come back and say that this has helped them navigate their allergies a little better.' (HCP 7, Dietitian)