……

FoodSensitive Study: Wave One Survey

……

September 2021

Dr Rebecca Knibb, Lily Hawkins and Professor Dan Rigby: Aston University and the University of Manchester

https://doi.org/10.46756/sci.fsa.sov133

Contents

Executive Summary

Introduction

Food hypersensitivities (FH) include food allergy, food intolerance and coeliac disease. Food allergy and coeliac disease involve an immune mediated reaction to certain foods, food intolerance is caused by a non-immune mediated reaction (such as an enzymatic or pharmacological effect). Each of these FHs result in unpleasant symptoms if the food is eaten in sufficient quantity, with food allergic reactions sometimes resulting in life-threatening symptoms. Management of FH by an individual or members of their family therefore involves constant vigilance and risk assessment to determine if a food is safe to eat. Research over the last twenty years has demonstrated that this burden, along with the unpredictable nature of FH reactions, has an impact on quality of life (QoL). QoL encompasses our emotions, physical health, the environment we live in, our social networks and day-to-day activities. FH has been shown to have an impact on many of these areas, however there are still research gaps. In particular, many studies focus on children, adolescents or parents rather than the adult population and little is known about those with food intolerances. In order to make a comprehensive characterisation and evaluation of the burden caused by living with FH, the day-to-day management of FH and associated inconveniences, the FSA has commissioned this project, led by Aston University. The project is called the FoodSensitive study and this report relates to findings for workstream one, a survey to assess the impact of FH on QoL.

Research aim

The aim of this survey was to characterise the management of FH of individuals living in the UK and evaluate the resultant impact on their QoL.

Methods

Design

This online survey is part of a longitudinal design. There will be two waves of data collection 12 months apart. This report provides the findings for the first of these two waves. Key data collected included:

- Detailed information on foods, symptoms, diagnosis, medication and hospitalisation;
- Experiences when eating out;
- Experiences with shopping and food labels;
- Sources of information for food hypersensitivity;
- Experiences of food hypersensitivity in social situations;
- General and FH specific quality of life.

The data was collected between 28th October 2020 and 4th January 2021. During this time people living in the UK experienced a range of restrictions on day-to-day living, particularly regarding eating out, due to the Covid-19 pandemic. This should be considered when considering the results.

Participants

Participants were adults with FH, parents of children with FH (aged 0 to 17 years) and children (aged 8 to 17 years) with FH, living in the UK. FH was defined as experiencing a bad or unpleasant physical reaction after consuming food. An opportunity sample (anyone who saw the study advert and was eligible to take part) was recruited through advertising via patient organisations: Allergy UK, the Anaphylaxis Campaign, the Natasha Allergy Research Foundation and Coeliac UK. The survey was also advertised on Twitter and had a study webpage with links to the surveys on the FSA site. Snowball sampling involved the participants being asked to recruit further participants through their contacts, network groups and acquaintances.

Measures

A questionnaire was developed by the project team to collect demographic data and information about food hypersensitivities, eating out, shopping, sources of information regarding FH and experiences of FH in social situations.

When asking about foods, participants were asked to first provide a list of all foods they (or their child) reacted to, and then provide more detailed information on up to three of those foods that they considered had a big impact on their lives. For each of these foods they were asked to say whether they thought their reaction was a food allergy, food intolerance or coeliac disease. Their response to this question for the first food they reported details on was used to direct them to the appropriate quality of life scale. They were also asked to say whether they thought the FH was mild, moderate or severe.

In order to measure quality of life, existing validated measures were used. In order to measure quality of life that was specific to FH we used food allergy, food intolerance and coeliac disease quality of life scales. We also measured general quality of life using the EQ-5D. This scale measures quality of life in general domains such as usual activities, pain, mobility, and anxiety. All FH specific and general quality of life scales were age-appropriate, and parents completed proxy versions for their children.

Data analysis

Participants were put into the following sub-groups for analysis:

1. Respondents with food allergy only
2. Respondents with food intolerance only
3. Respondents with coeliac disease only
4. Respondents with multiple hypersensitivities which included any two (or all three) of allergy, intolerance and coeliac disease.

Descriptive information is provided for all survey questions in the form of text, tables and graphs where appropriate. Comparisons across mean scores for groups were conducted using ANOVAs, which provide an overall F value to tell you if there is a significant difference. The effect size (np^2) was reported for all ANOVAs. Pearson's correlations were used to examine relationships between pairs of continuous variables. Correlations are used to see if two sets of data are related in some way, so for example to see if higher scores in a variable is related to higher or lower scores in another variable. Where group sizes were large enough, regression analysis was conducted to see what variables might predict QoL.

For the QoL analysis, the following comparisons were made for each group where appropriate:

- Between clinically diagnosed and self-diagnosed conditions
- By gender
- By age
- By number of foods/allergens reported

Results

A total of 930 adults with FH, 686 parents of children with FH, and 225 children with FH completed the surveys and were included in this report. Those reporting ‘other’ and ‘don’t know’ regarding the type of FH they had were excluded from the statistical analysis as we focused on the specific sub-groups listed above, however they were included when reporting descriptive information for the whole sample.

Key findings for adults

Sample characteristics

- Overall, 930 adults took part: 170 with food allergy; 216 with food intolerance; 409 with coeliac disease; 135 with multiple hypersensitivities.
- Most adult respondents were female (81%); the mean age of respondents was 50 years old, with a minimum of 18 years and a maximum of 86 years.
- 1,373 foods were reported across the whole sample to cause a bad or unpleasant physical reaction; the most common food reported was cereals containing gluten (n = 615; 45%), followed by milk (n = 149; 11%) and peanuts (n = 80; 6%).

Eating out

- Over half (61%) of adult respondents felt comfortable in asking staff for information when eating out because of a concern about experiencing a bad or unpleasant physical reaction to food.

- Over half (62%) of adult respondents felt confident that written information provided by the venue when eating out allows them to identify foods that cause a reaction. Adults were less confident in information provided verbally by staff (43% reported being very or fairly confident).
- A quarter of adult respondents (25%) reported that they had been refused service when eating out because of their FH, and around one in ten (11%) had previously been asked to sign a disclaimer when eating out.

Shopping

- The majority of adult respondents (85%) reported they check labels always or most of the time for ingredients that would cause them an adverse reaction.
- The majority of adult respondents (81%) also check labels always or most of the time for the possible presence of foods that cause a bad or unpleasant physical reaction, such as ‘may contain’ labelling.
- On a scale from 1 (Not at all) to 4 (Very confident), adult respondents were significantly less confident that the information provided by food markets or stalls allows them to identify foods that cause them a reaction, compared to in store supermarkets, online supermarkets and independent shops.
- 88% of adult respondents felt very or fairly confident that the information provided on food labelling for food sold from in store supermarkets enabled them to identify food that will cause a bad or unpleasant reaction, whereas only 51% of adults were confident in identifying foods that cause a reaction when this food is sold loose from in store supermarkets.

Sources of information

- The most helpful source of information on managing bad or unpleasant reactions to foods was patient organisations such as Allergy UK, The Anaphylaxis Campaign or Coeliac UK (40%).
- Almost a quarter of adults (25%) found the internet the most helpful source of information for their FH.

Social situations

- The majority of adult respondents reported that they were comfortable mentioning their FH in front of family (79%) and friends (61%).

- 34% of adults reported that mentioning their FH to people they did not know would not bother them; 32% said they would feel very embarrassed or uncomfortable.
- Many adults reported they feel very embarrassed or uncomfortable experiencing symptoms of a reaction in front of people they've just met (57%) or work colleagues (47%).

Quality of life

- The average scores captured on the FH specific quality of life scales indicated that adult respondents felt that their FH affected their quality of life 'moderately' to 'quite a bit'.
- Adults with FH who reacted to more than one food reported significantly poorer quality of life than those who only reacted to one food.
- Adults who self-reported mild or moderate FH reactions reported significantly better quality of life than those who reported severe reactions.
- Women with food intolerance or coeliac disease reported significantly worse quality of life than males with these conditions. There was no significant difference in quality of life between males and females with food allergy.
- Adults with food intolerance reported lower generic quality of life (scored using the EQ-5D-5L) than adults with food allergy or coeliac disease.
- Compared to the UK population distributions for the EQ-5D-5L, adults with FH had better quality of life for mobility and usual activities, but lower quality of life for pain and anxiety.
- Whilst frequency of eating out was significantly related to better quality of life, frequency of checking information at most stages of eating out was significantly related to poorer quality of life.
- Frequency of checking labels for ingredients that may cause an adverse reaction when shopping, and checking labels for the possible presence of foods that may cause an adverse reaction, were also significantly related to poorer quality of life. However, how comfortable participants were in asking staff for information when eating out, and how confident they were in the written and verbal information provided when eating out was significantly related to better quality of life.
- In regression analyses, a more severe reaction (self-reported as mild, moderate or severe) significantly predicted poorer FH specific QoL for those with food allergy, food intolerance and coeliac disease.

Key findings for parents

Sample characteristics

- Overall, 686 parents took part and reported details about FH for 932 children: 396 parents of children with food allergy; 156 with food intolerance; 39 with coeliac disease; 95 with multiple hypersensitivities.
- 69% of parent respondents were female; the mean age of respondents was 38 years (range 18 to 72 years).
- 56% of the children were male; the average age of the children was 9.5 years (range 0 to 17 years).
- Parents reported a total of 1,399 foods their children reacted to. Tree nuts (n = 256; 18%), milk (n = 204; 15%), peanuts (n = 169; 12%) and eggs (n = 167; 12%) were the most frequently reported foods.

Eating out

- Almost three quarters (73%) of parent respondents felt comfortable in asking staff for information when eating out, because of a concern about their child experiencing a bad or unpleasant physical reaction to food.
- Two thirds (65%) of parents felt confident that written information provided when eating out allows them to identify foods that will cause their child a reaction.
- Slightly fewer parents (57%) were confident in information provided verbally by staff.
- A fifth of parents (21%) reported they had been refused service when eating out because of their child’s FH, and 16% reported they had been asked to sign a disclaimer when eating out because of their child’s reactions to food.

Shopping

- The majority of parents (78%) reported they check labels always or most of the time, for ingredients that would cause their child an adverse reaction. A similar proportion (74%) check labels always or most of the time, for the possible presence of allergens, such as ‘may contain’ labelling.
- On a scale from 1 (Not at all) to 4 (Very confident), parents reported they were significantly more confident in the information provided on food labelling for food

sold from in store supermarkets than the information provided for food sold from online supermarkets, independent food shops and food markets/stalls.

- Over three quarters (77%) of parent participants felt confident that the information provided on food labelling for items sold from in store supermarkets enabled them to identify food that will cause their child a bad or unpleasant reaction. In contrast, only 49% of parents felt confident in identifying foods that cause their child a reaction when food is sold loose from in store supermarkets.

Source of information

- Respondents were divided on which sources of information for managing their child's reactions to food were most helpful, with 21% of parents finding hospital doctors most helpful, 20% finding GPs most helpful, 18% stated patient organisations and 17% stated the internet.

Social sitations

- The majority of parents (72%) were comfortable mentioning their child's FH to family, but fewer (57%) felt comfortable mentioning their child's FH to people they had just met.

Quality of life

- The average score on the FH specific quality of life scales indicated that parents felt that their child's FH affected their child's quality of life 'quite a bit' or 'very much'.
- There were no differences in quality of life based on age or gender of the child.
- Parents who self-reported that their child experienced mild or moderate reactions reported significantly better quality of life than those with children who reported experiencing severe reactions.
- Parents of children with food intolerance and multiple FHs reported significantly lower generic quality of life for their child (scored using the EQ-5D-3L) than those with food allergy or coeliac disease.
- Parents of children with FH reported their children had better quality of life for mobility and usual activities compared to parent-reported quality of life for pain and anxiety.

Key findings for children

Sample characteristics

- Overall, 225 children took part: 102 with food allergy; 100 with food intolerance; 18 with coeliac disease; 5 with multiple hypersensitivities.
- Just over half (56%) of child respondents were female; the average age of the children was 13 years (range of 8 to 17 years).
- The children reported 313 foods they reacted to. The food most commonly reported was milk (21%).

Eating out

- When eating out and before ordering food, just under half of child respondents reviewed available information always or most of the time (47%).
- Just over half (55%) of children felt comfortable asking a member of staff for information about the food when eating out, because of a concern about experiencing a bad or unpleasant physical reaction.
- Over half (56%) of children felt confident that the written information provided when eating out that allows them to identify foods that cause them a bad or unpleasant physical reaction. A higher proportion of children were confident in the information provided verbally by staff when eating out (65%).
- 18% of respondents reported they had previously been refused service when eating out because of their FH.

Shopping

- Just over half of child respondents (53%) reported that they check labels always or most of the time, for ingredients that would cause them an adverse reaction. A similar proportion (50%) reported they check labels always or most of the time, for the possible presence of allergens, such as ‘may contain’ labelling.
- It was more common for those in the 8-12 year-olds sample to report that their parents checked labels for them, for ingredients (n = 43; 40%) and for information on the possible presence of foods (n = 47; 44%), compared to the 13-17 year-olds sample (n = 22; 18% and n = 24; 20% respectively).

Sources of information

- Just over a quarter (28%) of child respondents found family and friends the most helpful source of information, followed by GPs (21%).

Social situations

- The majority of child respondents (73%) reported that they were comfortable mentioning their FH to family, but only a third (34%) felt comfortable about mentioning their FH to people they had just met.
- Over half (60%) of children were not bothered about experiencing symptoms of a reaction in front of family, and 40% were not bothered about experiencing a reaction in front of friends. Only 29% of child respondents were not bothered about experiencing a reaction in front of people they had just met.

Quality of life

- The average score on the FH specific quality of life scales indicated that children felt that their FH affected their quality of life ‘moderately’ to ‘quite a bit’.
- All scores on FH specific quality of life scales were above the mean, indicating higher impairment on quality of life, apart from 8-12 year-olds with food intolerance, who scored close to the mean.
- There were no differences in quality of life based on age or gender.
- Children with self-reported mild or moderate reactions reported better quality of life than those with severe reactions.
- 8-12 year-olds with food allergy or intolerance had similar scores on the EQ-5D-3L regarding generic quality of life, but all children with FH scored worse for pain/discomfort and anxiety/depression than they scored for usual activities or mobility.
- 13-17 year-olds with food allergy had better scores on the EQ-5D-5L regarding quality of life than those with intolerance, and all respondents in this age group scored worse for pain/discomfort and anxiety/depression than they scored for usual activities or mobility.
- In regression analyses, a more severe reaction (self-reported as mild, moderate or severe) significantly predicted poorer FH specific QoL for those with food allergy and food intolerance.

Conclusions

The first wave of this UK based survey has provided a wealth of data on the impact of FH on day-to-day activities and quality of life of adults and children. Due to sufficient numbers of participants completing the survey with coeliac disease compared to other food intolerances, a more nuanced analysis of the different FHs was possible and groups with food allergy, food intolerance and coeliac disease were analysed separately. A wide variety of foods were reported, with foods containing gluten, milk, tree nuts and peanuts reported most often. Similarly, participants reported a range of symptoms, from gastrointestinal, skin reactions, breathing difficulties, swelling and anaphylaxis.

Eating out

Adults and parents reported being more confident in written information provided by staff when eating out, compared to information provided verbally. Interestingly, more child respondents reported being confident in the verbal information provided compared to written information, and their levels of confidence in verbal information was much higher than those reported by adults (65% of child respondents reported they were confident that information provided verbally by staff allows the identification of foods that cause a reaction, compared to 43% of adult respondents). Adults with food intolerance, and parents of children with food intolerance, reported being more confident in verbal information provided than those with other hypersensitivities. For example, adults with food intolerance reported being more confident in verbal information provided by staff than adults with food allergy. Similarly, parents of children with food intolerance were significantly more confident in verbal information provided by staff than parents of children with food allergy or coeliac disease.

Over half of adults and children with FH reported they felt comfortable asking a member of staff for information because of a concern about experiencing an unpleasant physical reaction. However, parent respondents reported the highest rates of comfort in asking for information (73%, compared to 61% for adults and 55% for children). Around a fifth of adult, parent and child respondents reported previously being refused service or having been asked to sign a disclaimer. It may therefore be important to investigate the ability and confidence in waiting staff in restaurants to provide suitable information for people with FH.

Shopping

Participants were asked how often they check information on food labels for ingredients that may cause them a bad or unpleasant physical reaction, in various types of shops. Most adult and parent participants reported that they checked labels always or most of the time. There were some differences across groups with parents of children with food intolerance tending to check less often and adults with coeliac disease checking more often than participants with other FHs. Children also checked less often but unsurprisingly reported that their parents tended to do this for them.

Confidence in the information provided on food labelling and about ingredients in food is important to understand. Those affected by FH need to be confident that the information provided will enable them to identify foods that cause a reaction, and therefore make the right decision regarding the safety of the food. In general, the majority of respondents expressed confidence in this information, but this varied according to the place in which the food was being sold. Adult and parent participants reported being more confident in information provided for food sold from in store supermarkets and online supermarkets, compared to independent food shops or food markets/stalls. They were also more confident in information provided for labelled food compared to food sold loose. Increasing confidence for food sold loose is therefore important for those with FHs to enable them to feel able to purchase this type of food.

Sources of information

A range of information sources were reported by participants, with patient organisations being seen as most helpful for adults with food allergy and coeliac disease. Those with food intolerance stated the internet was most helpful. Compared to other FH groups, those with food allergy also reported that a hospital doctor was the most helpful source of information. This may reflect the lack of diagnostic tests for food intolerance and higher proportion of people in this group self-diagnosing.

Similar proportions of parents rated hospital doctors, GPs, patient organisations and the internet as most helpful. Children reported family and friends to be the most helpful source of information, followed by hospital doctors and GPs. For older children (13-17-year olds), the internet was also cited as an important source of information. It is, therefore, important that family and friends are well informed about FH in order to ensure misinformation is not passed on. Likewise, it is important that people with FH are directed towards trustworthy internet sites, such as those run by patient organisations.

Social situations

Participants were asked how they felt about mentioning their food hypersensitivity or experiencing a reaction in front of others, including friends, family, work colleagues and people they've just met. Across groups, most were comfortable mentioning their FH with friends and family, and less comfortable mentioning or experiencing a reaction in front of people they had just met. Although for parents, over half reported that it would not bother them to talk about their child's FH to any group including those they had just met. Reasons for these findings need further investigation. It is unclear whether participants feel embarrassed, lack confidence or do not want to be labelled by their FH, all of which have been reported in the literature (Cummings et al., 2010; DunnGalvin et al., 2009). It may also be that reasons are different for the different participant groups and for different age groups.

Quality of life

All participants reported that their FH or their child's FH impacted their lives by 'quite a bit' or 'very much'. Self-reported or parental reported severity of FH was related to the level of quality of life as measured by the FH specific validated QoL scales. Severity also significantly predicted QoL for adults with any FH and for children with allergy or intolerance.

FH specific QoL was also related to eating out activities in meaningful ways. Being able to eat out more frequently was related to better QoL for some groups (adults and children with food allergy, adults with coeliac disease, and parents of children with food intolerance). Being more comfortable asking staff for information about food, and higher confidence in the verbal or written information provided about food when eating out, were related to better quality of life in adults. However, a greater frequency with which participants had to check information at various stages of eating out was related to poorer QoL. This was the case for adults, parents of children and children themselves with food allergy or food intolerance, but not those with coeliac disease.

Checking behaviour may create a greater burden on the individual or parent, which has an impact on QoL. For adults with food allergy and food intolerance, and parents of children with food allergy and food intolerance, greater frequency of checking labels for ingredients that cause a reaction, or the possible presence of ingredients (e.g. ‘may contain’) was related to poorer QoL. In regression models, only more frequent checking of information when eating out significantly predicted QoL, and this was in the adult FH groups only. For many of the parent and child models, a good proportion of variance in quality of life was explained, but few or no individual predictors were significant.

Adults, parents of children and children themselves with food intolerance reported poorer generic quality of life than those with food allergy or coeliac disease. It is unclear why this might be. Many of those with food intolerance said their condition was self-diagnosed, and so they may not have had the benefit of advice and support from a healthcare practitioner. Across all groups, generic quality of life related to pain, anxiety and depression was reportedly worse than other sub-domains such as usual activities, mobility or self-care. This is an interesting finding as you would not expect pain to be related to FH, as symptoms are only experienced when the food is eaten by mistake. It may be related to other long-term conditions reported by respondents and this needs further investigation.

In conclusion, self-reported severity, frequency of checking and confidence in information about ingredients in foods were the key variables associated with quality of life.

There are some limitations that should be taken into consideration:

- It is not known how representative of the UK FH population the survey is, as prevalence of different FHs are not yet known.
- There is a predominance of white British adult females completing the survey (for adult and parent surveys) which is likely to have influenced the data collected.
- The survey was carried out during the Covid-19 pandemic when there were variable restrictions on activities (such as eating out) across the devolved nations and across the time during which the survey was live.

Introduction

Background

This report presents findings from research conducted by Aston University on behalf of the Food Standards Agency (FSA). The FSA is an independent government department responsible for protecting public health and consumers' interests in relation to food across England, Wales and Northern Ireland. As part of their function to protect public health, the FSA plays an important role in ensuring that members of the public are protected from potentially life threatening food hypersensitivities, by working with consumers and the food industry to ensure consumers with food hypersensitivities can make safe and informed choices.

Food hypersensitivities (FH) include food allergy, food intolerance and coeliac disease. Eating a food you are sensitive to can result in an adverse reaction with unpleasant and sometimes life-threatening symptoms. Management of FH therefore involves constant vigilance and risk assessment to determine if a food is safe to eat. Research over the last twenty years has demonstrated that this burden, along with the unpredictable nature of FH reactions, has an impact on quality of life (Cummings et al., 2010; Morou et al., 2014). Children, adolescents, adults and parents of children with FH invest a large amount of time and resource in managing the risks associated with an adverse reaction. FH can affect social life, such as eating out; school or work life; relationships with significant others; and can cause anxiety surrounding both eating and the management of a reaction to food (DunnGalvin et al, 2009; Gallagher et al., 2011).

The FSA has a vision to improve the quality of life for people living with FH, as outlined in The FSA's Food Hypersensitivity Strategy, 2019-2025, and recently commissioned research to explore the impact of legislation which specified that information on specific allergens be provided for foods that are not prepacked (Begen et al., 2018; Begen et al., 2018). The work was led by the University of Bath and included collecting data on the quality of life of individuals with FH, and parents of children with FH regarding experiences when eating out. They reported on current eating out behaviours, satisfaction with and confidence in information provision about allergens, and preferences for information provision. Greater positivity and adventurousness when eating out was associated with better health-related quality of life (QoL), whereas greater preparation needed for eating out was associated with lower health-related QoL.

Despite the focus of research on the quality of life of those with FH, there are still significant gaps in the literature, as apart from the study conducted by the University of Bath, few studies have focused on food intolerance or adults with FH. Little is known about the factors associated with high or low QoL or how this might change over time. In order to address this, the FSA has commissioned this project to characterise and evaluate the burden caused by living with FH, the day-to-day management of FH, and associated inconveniences.

Aims of the project

The current project, called the FoodSensitive study, is being conducted across two linked workstreams. The first workstream aims to develop and test a survey to collect data on the management, and impacts of FH on daily lives, and the resultant quality of life individuals with FH experience. This information will be collected in two waves, one year apart in the first instance, to test the feasibility of retaining participants between survey waves. The second workstream aims to produce monetary valuations on the non-tangible elements of food hypersensitivities, including pain, grief and suffering, through eliciting Willingness to Pay (WTP) values (how much someone would be willing to pay to remove the anxiety and day-to-day impact related to having a FH). The sample for this work will include, but not be limited to, the sample from workstream one. In line with the FSA's statutory responsibility to protect consumer interests in food, and to enable the FSA to further understand these conditions and seek ways to reduce their burden, samples for both workstreams will be drawn from individuals living in the UK.

This report provides the findings for wave one of the survey collected for workstream one. The aim of this survey was to collect data on the management, quality of life and impact of FH on the daily lives of children and adults with FH, as well as parents of children with FH. The data was collected between 28th October 2020 and 4th January 2021.

Methods

Study design

This online survey is part of a longitudinal design where data will be collected twice, one year apart. This section summarises the research approach taken for the first of these two survey waves. More detailed information can be found in the technical report.

Participants and recruitment

Three separate groups of participants were recruited: adults with FH; parents of children with FH (aged 0-17 years); children (aged 8 to 17 years) with FH, living in the UK. FH was defined as experiencing a bad or unpleasant physical reaction after consuming food. The wording of the definition was developed to identify this population in the FSA's Food and You survey, and was based on previous work conducted by Professor Barnett and colleagues at University of Bath. The definition had also been through cognitive testing for the FSA's revised Food and You survey in Summer 2020 (Food and You 2). For recruitment purposes, we divided FH into 3 categories: food allergy, food intolerance and coeliac disease.

The FH profile of the population in the UK is unknown and so we employed non-probability opportunity sampling and snowball sampling techniques, rather than a targeted approach. The opportunity sample consisted of anyone who saw the study advert and was eligible to take part, and participants were recruited through advertising via patient organisations: Allergy UK, the Anaphylaxis Campaign, the Natasha Research Foundation and Coeliac UK. The survey was also advertised on Twitter and had a study webpage with links to the surveys on the FSA website. Snowball sampling involved the participants being asked to recruit further participants through their contacts, network groups and acquaintances. In order to reach children, advertisements were targeted at parents. The project team also advertised through their own networks including university research participation advertising. These methods enabled a rapid and cost-effective way of recruiting the desired cohort. Importantly these methods allowed the study to reach out to those with relatively milder symptoms, in particular people with food intolerance, who may not have sought medical input. It must be noted, however, that these approaches are likely to be affected by respondent biases whereby participants are more highly motivated towards FH issues, and therefore likely to take part, and are generally of a higher socio-economic status. Using an online platform restricts the survey to people who have access to the internet, and the surveys were provided in English and Welsh languages only, so those not able to understand those languages sufficiently to complete the surveys were not able to take part.

Recruitment rates and the profile of those responding were closely monitored to minimise the risk of under-recruitment in any one group. Initially the numbers of adults, parents and children responding against the overall target numbers for these groups were monitored. The number of respondents reporting food allergy, food intolerance and coeliac disease were then also monitored within each of these groups. Recruitment was supplemented where needed with the use of online survey panels through Qualtrics to meet the target numbers in each group, and to try and ensure an equal spread of allergy, intolerance and coeliac disease. Qualtrics^{XM} is a worldwide company that offers a secure online survey system and the ability to recruit participants with specific inclusion and exclusion criteria to online studies. Qualtrics were used as Aston University had a license for the online survey and the project team were experienced in using this and recruiting using Qualtrics' participant panels. Qualtrics advertised the study to their UK panel and also advertised to parents in order to recruit children with food hypersensitivities.

Screening questions at the start of the survey asked individuals if they lived in the UK and had a bad or unpleasant reaction to food. For each survey there was also a specific screening question regarding age or if they were a parent. All participants had to complete the screening questions at the start of the survey to ensure they were eligible for this study. In order to establish a participant panel that could be drawn on for wave two of the survey, participants were asked for their consent to be contacted to complete the survey again. Participants were asked to supply a unique code made up of memorable information (date of the month of their birthday and their initials), to facilitate the matching of data between successive waves.

Measures

In order to capture the data needed for this study, a combination of bespoke questions and a suite of validated psychometric scales were used. The bespoke questions were required to meet the additional evidence needs of the FSA that weren’t captured by the psychometric scales. This included demographic and FH information as well as questions designed to measure the day-to-day management and impact of food hypersensitivity for each age group and for parents.

Respondents were asked to list all foods they reacted to; then provide further details of up to three foods that they perceived had a big impact on their life. Parents were asked to provide details of up to three children and up to three foods per child. This enabled data to be captured on the complexity of FH while not overburdening respondents. For each of the three foods, respondents were asked about specific symptoms, self-reported severity, method of diagnosis, medication and hospitalisation. Respondents were asked to indicate if they thought their reaction to each of these three foods was due to food allergy, food intolerance or coeliac disease. Respondents could also choose to report a different reaction, or if they didn’t know. They were then classified in line with what they assessed themselves as being. This ensured that the FH specific QoL scale they were directed to had face validity, as the scale matched with the participant’s belief regarding their own reaction. It also allows for an exploration of misunderstandings regarding food allergy, intolerance of coeliac disease in the sample, based on a comparison with their responses to other questions regarding type of food, symptoms and timing of reactions.

For each of the three foods, respondents were asked to say whether they thought their FH was mild, moderate or severe. This type of self-reported rating of severity has been used in previous published studies (Acaster et al., 2020a; Acaster et al., 2020b) and has been shown to significantly correlate with QoL ratings.

Questionnaire drafts were sent to the patient organisations participating in the study Project Advisory Group for comments and feedback. They were also sent to an independent peer reviewer for comments. Changes to the questionnaire wording, particularly in simplifying wording for child respondents, were made as a result of the feedback received.

Key data collected included:

- Detailed information on foods, symptoms, diagnosis, medication and hospitalisation;
- Experiences when eating out;

- Experiences with shopping and food labels;
- Sources of information for food hypersensitivity;
- Experiences of food hypersensitivity in social situations;
- Quality of life (measured by valid and reliable questionnaires).

Validated psychometric scales were used to measure FH specific and generic quality of life. A full list of all scales used can be found in the technical report. The specific psychometric quality of life questionnaire respondents completed was based on their own answer to the question regarding the type of FH they perceived they suffered from. For adults, this was for the first food they told us details about. Adults reporting food allergy completed the Food Allergy Quality of Life Questionnaire for Adults (FAQLQ-A) and those reporting food intolerance completed the FIQLQ-A. Adults reporting coeliac disease completed the Coeliac Disease Quality of Life scale for adults (CDQOL).

For parents, the specific quality of life questionnaire they completed was based on their answer regarding the type of FH for the first food of the first child they told us about. For food allergy, parents completed the FAQLQ-Parent proxy for children or for teens, and food intolerance they completed the FIQLQ-Parent proxy for children and teens. Those reporting coeliac disease in their child completed the Coeliac Disease quality of life scale parent-proxy (CDDUX).

Children aged 8-12 years reporting food allergy completed the FAQLQ for children; those aged 13-17 completed the FAQLQ for teens. There was no available validated scale for children or teens with food intolerance, so we adapted the FAQLQ for children and teens using the same methodology that had been used previously to adapt the other FAQLQs for food intolerance. Children reporting coeliac disease completed the Coeliac Disease quality of life scale for child self-report (CDDUX).

A generic quality of life scale - the EQ5D - was used to enable direct comparison across respondent subgroups. The EQ5D is a generic, preference-based health status measure. Participants report their current health on dimensions such as mobility, self-care, pain and discomfort, usual activities, anxiety and depression. Responses are converted into a single index value that can be used in cost-effectiveness analyses, where a score of 1 represents full health and a score of 0 represents dead. Participants were also asked to rate their current health on a 0 to 100 visual analogue scale (VAS) with higher scores representing better QoL. The EQ5D is a widely used well-validated scale to measure quality of life in healthy participants and participants with various health conditions. It has also recently been used to measure quality of life in children with peanut allergy (Acaster et al., 2020a; Acaster et al., 2020b) and has been used by the FSA in previous research on foodborne diseases. Adults completed a self-report version, parents completed a parent proxy for their children, and children and teens completed the child version, the EQ5D-Y.

Further information on sampling, the survey measures and the survey methodology can be found in the technical report.

Data analysis and reporting conventions

Sub-groups used within the analysis and reporting were:

1. Respondents with food allergy only;
2. Respondents with food intolerance only;
3. Respondents with coeliac disease only;
4. Respondents with multiple hypersensitivities which included any two (or all three) of allergy, intolerance and coeliac disease.

Participants reporting ‘Other’ or ‘Don’t know’ are not reported on as a subgroup as the key interest in this research was the three main food hypersensitivities. The total number of participants who completed the survey and who were therefore included in the analysis for this report can be found in Table 1. The main data is reported separately for adults with FH, parents of children with FH, and children aged 8-17 years with FH. Descriptive information is provided for all survey questions in the form of text, tables and graphs where appropriate. Comparisons across mean scores for groups were conducted using ANOVAs, which provide an overall F value to tell you if there is a significant difference. The effect size (np^2) was also reported for all ANOVAs. Pearson’s correlations were used to examine relationships between pairs of continuous variables. Correlations are used to see if two sets of data are related in some way, so for example to see if higher scores in a variable is related to higher or lower scores in another variable. Where group sizes were big enough regression analysis was then conducted to see what variables might predict QoL.

For the QoL measures, the following comparisons were made for each group where appropriate:

- Between clinically diagnosed[1] and self-diagnosed;
- By gender;
- By age;
- By number of foods/allergens reported.

Results were reported as significant if $p<0.05$. This indicates that we can be 95% confident that the results did not come about by chance. Where there were multiple comparisons a Bonferroni correction was applied to them, to reduce the risk of stating a difference was significant when it was not. Where this was applied, a corrected α level was used to determine significance (0.5 divided by the number of comparisons). All tests were two-tailed. Effect sizes were reported for all analyses. Findings were not weighted due to the lack of available food hypersensitivity population information.

---

[1] Clinical diagnosis included a health care professional making a diagnosis based on a clinical history, skin prick tests, blood tests and/or food challenge.

Table 1: Number of participants included in the analysis

Participant group	Adults N (%)	Parents of children N (%)	Children N (%)
Respondents with food allergy only	170 (16.7)	396 (49.9)	102 (38.2)
Respondents with intolerance only	216 (21.2)	156 (19.7)	100 (37.5)
Respondents with coeliac only	409 (40.1)	39 (4.9)	18 (6.7)
Respondents with multiple hypersensitivities	135 (13.2)	95 (12.0)	5 (1.9)
Respondent reporting ‘Other’ or ‘Don’t know’	89 (8.7)	107 (13.5)	42 (15.7)
Total	1,019 (100)	793 (100)	267 (100)

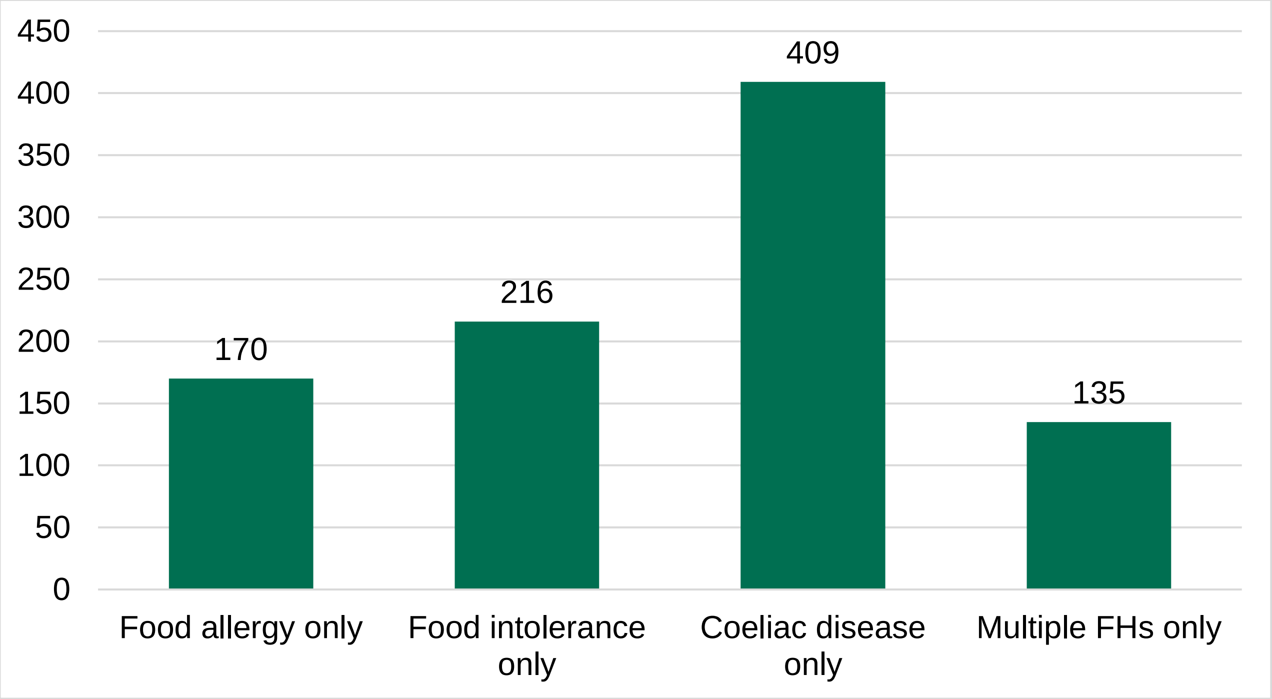
Part 1 - Adults with FH

A total of 1,019 adults with FH completed the survey, which included 89 reporting ‘other’ conditions or ‘don’t know’ when asked to describe their reaction to food. These participants are not reported on as a subgroup but are included in the ‘all adults’ figures.

Prevalence of food hypersensitivities

A large proportion of the adult sample was made up of those with coeliac disease (44%). The next most reported hypersensitivity was food intolerance (23%) and then food allergy (18%).

Figure 1: Prevalence of adults within the sample with each food hypersensitivity



Base: All adults excluding ‘other’ and ‘don’t know’ (930).

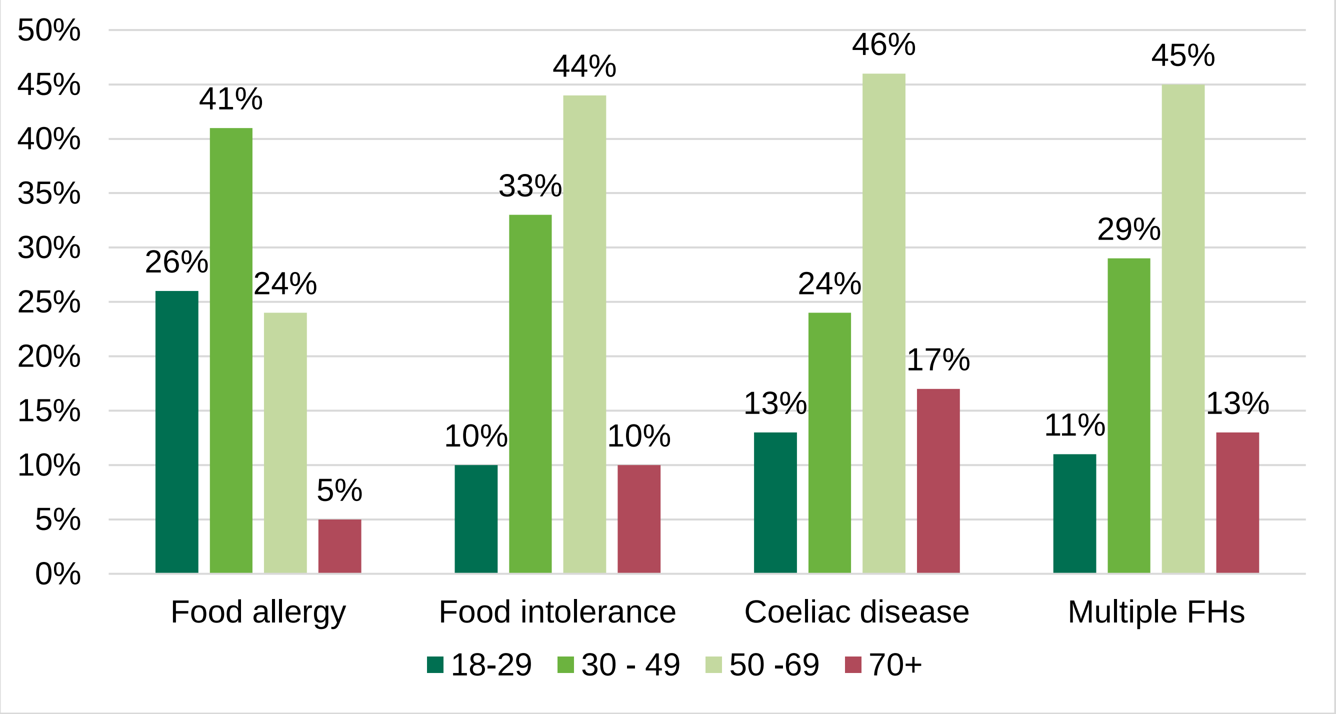
Profile of adult participants

Key demographics

From a total of 1,019 adults, 81% (n = 820) of those reporting a food hypersensitivity were women (19%; n = 191 were men). The mean age of all participants was 50 years old (SD = 16.6), with a range from 18 to 86 years old. The majority of adults were of White British ethnicity (n = 961; 95%). (See Annex A: Table 4).

Participants with a food allergy were typically younger (mean age: 41.4 years old; SD = 15.1) than those reporting a food intolerance (mean age: 50.6 years old; SD = 15.4), coeliac disease (mean age: 53.0; SD = 16.9) or multiple hypersensitivities (mean age: 52.2; SD = 15.7; Figure 2 for age distribution).

Figure 2: Age distribution, by hypersensitivity



Base: all adults (excluding ‘other’ and ‘don’t know’) 912; Food allergy (163); Food intolerance (209); Coeliac disease (408); Multiple FHs (132).

More women also reported each of the hypersensitivities than men, reflecting the large proportion of women who responded to the survey. Similar to the overall sample average, across hypersensitivities, the majority of adults were from a White British background (see Annex A Table 4 for a full breakdown).

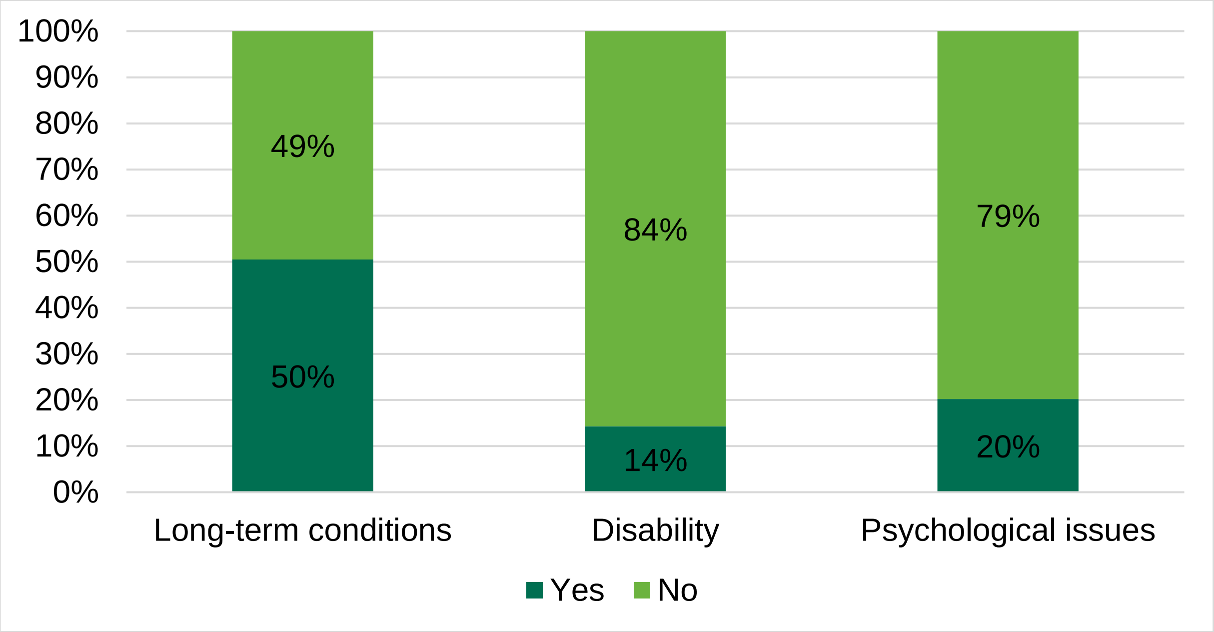
The most common region for adult respondents living with a food hypersensitivity was the South East of England (n = 185, 18%; see Annex A Table 5). Sixty-seven percent of the whole sample was married, in a civil partnership, or living with a partner (n = 670) and 21% (n = 212) were single. Approximately a third (n = 327, 32%) had an undergraduate degree.

Thirty-four percent (n = 348) of the sample were in full-time employment, 27% (n = 273) were retired and 15% (n = 154) were working part-time. Only 3% (n = 31) were unemployed (see Annex A Table 6 for a full breakdown). Across the hypersensitivities, those with food allergy (44%, n = 73) and food intolerance (n = 71; 33%) had the highest percentage in full-time employment, whilst those with coeliac disease (36%) and multiple hypersensitivities (30%) were most likely to be retired.

Other long-term conditions

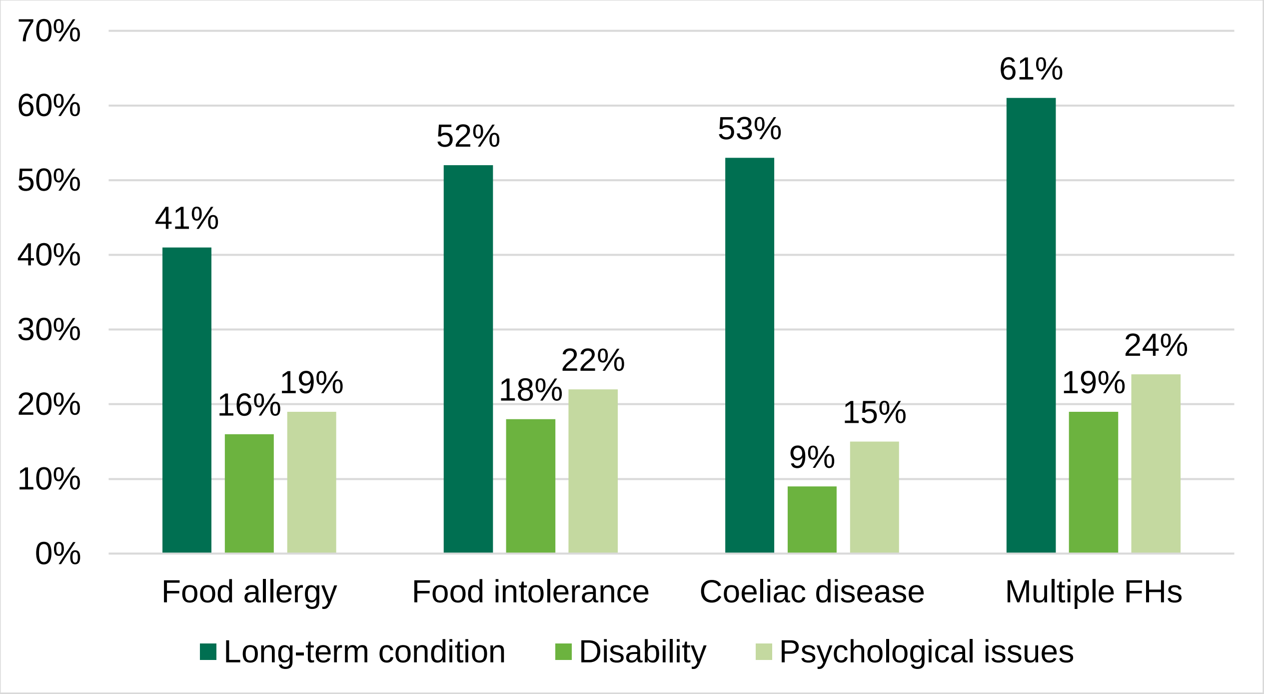
Other long-term conditions included diabetes, heart disease and arthritis. Fifty percent of the whole sample reported a long-term condition (n = 508), 14% (n =138) reported having a disability and 20% (n = 198) were receiving treatment for psychological issues such as anxiety and depression. Participants with multiple hypersensitivities had the highest proportions of those reporting another long-term condition (62%), having a disability (19%) and those in psychological therapy (24%).

Figure 3: Other long-term conditions



Base (all adults): Long term condition (1,014); Disability (1,012); Psychological issues (1,014)

Figure 4: Other long-term conditions by hypersensitivity



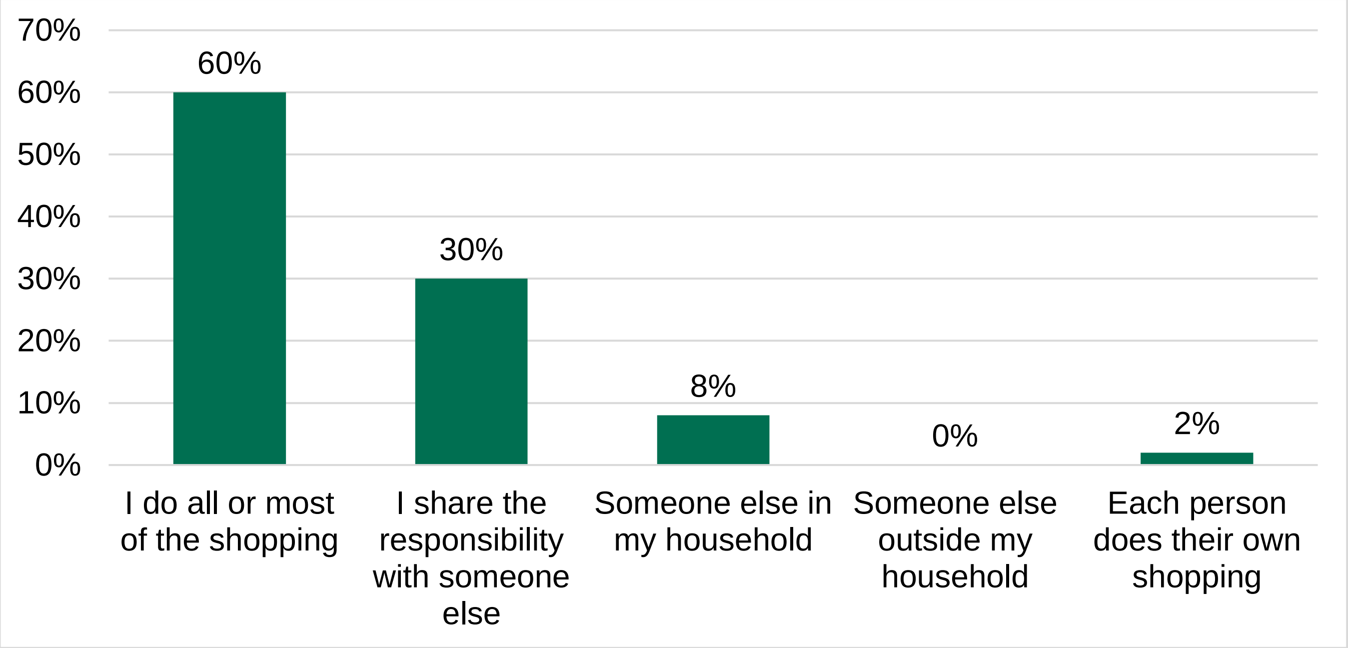
Base: all adults (excluding ‘other and ‘don’t know’) 926; Food allergy (168); Food intolerance (215); Coeliac disease (408); Multiple FHs (135)

Excluding foods and food preparation

Participants were asked if they excluded foods from their diet for any other reasons, apart from their food hypersensitivity (e.g. religious reasons, vegetarian/vegan diets, to lose weight). While the majority of participants did not exclude foods (68%, n = 695), the most common reasons across all hypersensitivities for doing so was because of following a vegetarian, pescetarian or vegan diet (11%; n = 116; Annex A Table 7).

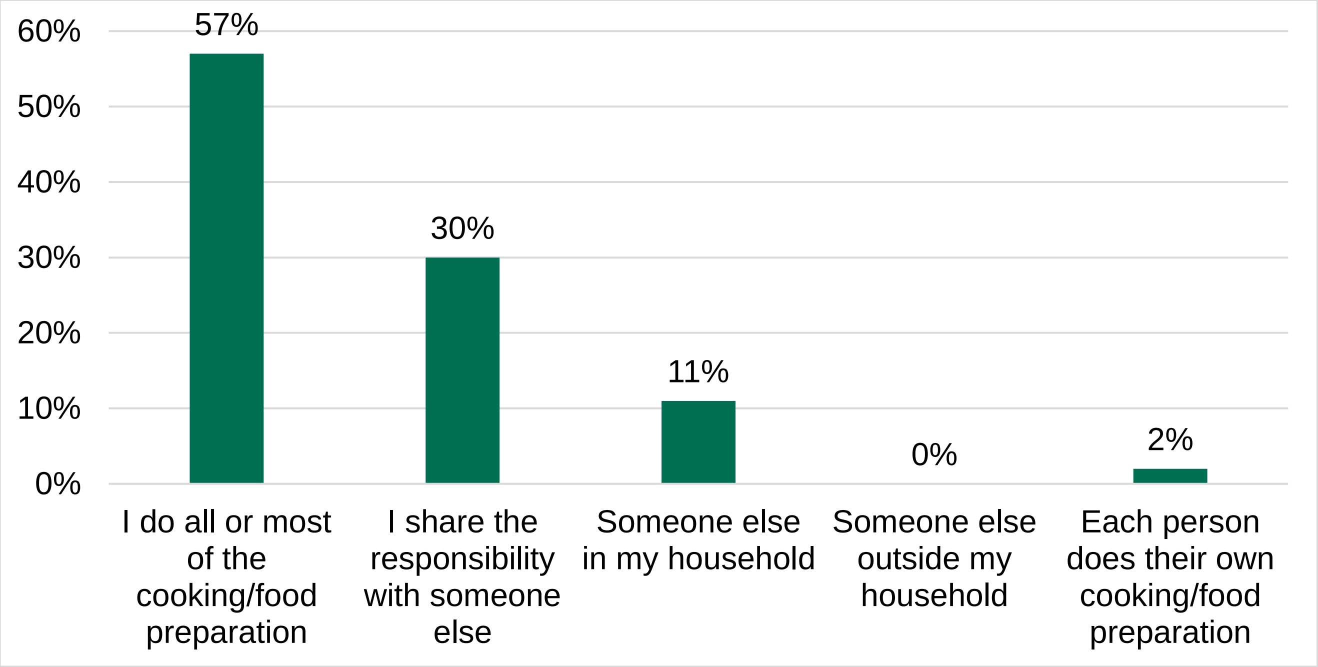
Data was collected on different aspects of food preparation, such as who did the shopping and cooking in each participants' household (Figures 5 and 6). The majority of all participants did the shopping (60%) and cooking themselves (57%).

Figure 5: Responsibility for food shopping



Base: All adults (1,013).

Figure 6: Responsibility for food preparation and cooking



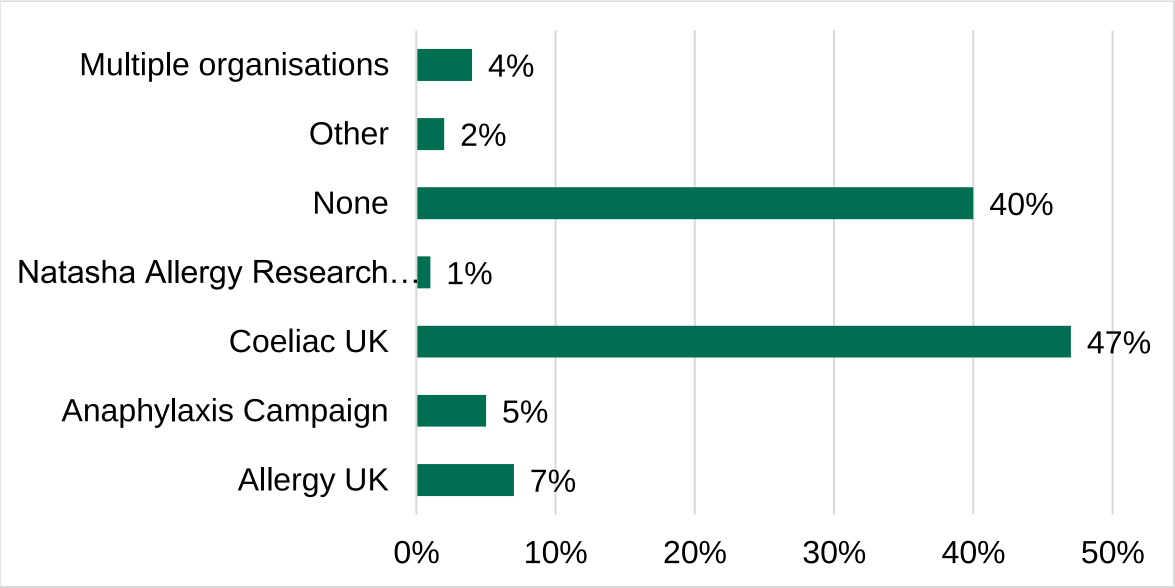
Base: All adults (1,009).

These proportions were also similar for each of the food hypersensitivities, with the majority of participants shopping and cooking for their own food or sharing the responsibility with someone else.

Patient organisation membership

Participants were asked to report on whether they were a member of any patient organisations. As one of the primary recruitment methods to the study was through patient organisations, many adults were members of established organisations supporting those with food hypersensitivities, especially Coeliac UK (47%) (see Figure 7). ‘Other’ support groups included groups on social media (such as Facebook support groups; Mast Cell Action groups; National Eczema Society; IBS Network and other doctor-patient support groups; FODMAP UK; Diabetes UK and Finnish Coeliac Society).

Figure 7: Membership of patient organisation groups (%)



Base: All adults (1019)

Membership differed according to hypersensitivity; the majority of adults with food allergy (52%) and food intolerance (80%) were not members of a patient organisation, whereas the majority of those with coeliac disease (91%) and multiple hypersensitivities (75%) were members.

Reactions to food

Initially, participants were provided with a list of foods and asked to select all foods they experienced a bad or unpleasant physical reaction to, and there was no limit on the number of foods that could be reported here. Cereals, milk, fruit and vegetables were the most frequently reported foods, as well as ‘Other’ foods, which included meats, fish, herbs and spices (e.g. chilli), cheese, pulses, chocolate, condiments (e.g. mayonnaise), maize, coconut, colourings, artificial sweeteners/flavourings, and tea/coffee. Please see Table 8 (Annex A) for a full breakdown of frequencies of foods reported by hypersensitivity.

Participants were then asked to report the foods they experienced reactions to that had a big impact on their lives. Participants could report up to three individual foods, and the reactions they experience in relation to these, in more detail. Most respondents only reported experiencing an adverse reaction to one food (n = 769, 76%), however, 149 (15%) participants reported a second food and 101 (10%) reported three foods.

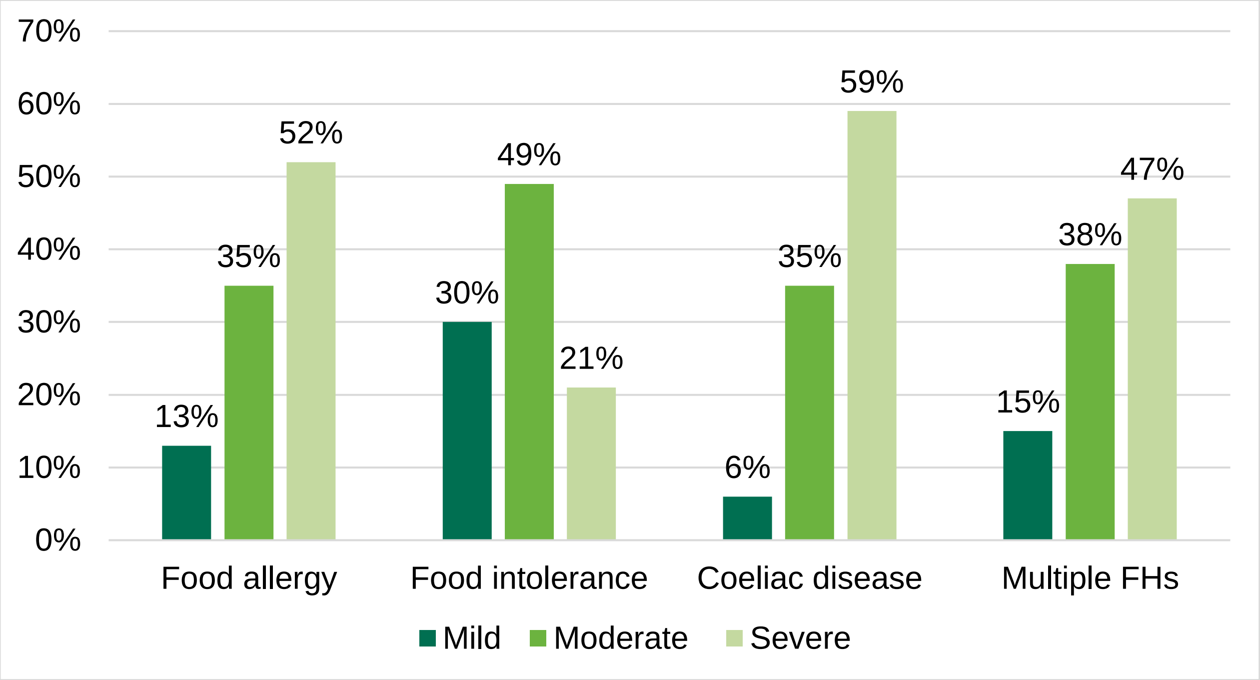
Foods with adverse reactions

A total of 1,373 foods were reported individually. The most common food reported was cereals containing gluten (n = 615; 45%), and 95% of those with coeliac disease reported this as their only allergen. However, there were some other foods that those self-identifying as having coeliac disease also reported, which may not strictly result in a coeliac reaction (e.g. molluscs).

Milk (n = 149; 11%), peanuts (n = 80; 6%) and 'other' (n = 145; 11%) foods were also common sources of adverse reactions. 'Other' foods reported included herbs/spices, cheese, meat, condiments, legumes and pulses, colourings, additives, chocolate and corn/maize. The majority of those reporting a reaction to peanuts were participants with food allergy (22%; n = 57), whereas milk was most commonly reported by those with multiple hypersensitivities (21%; n = 70), and 'other' foods were most commonly reported by those with food intolerance (18%; n = 48). For a full breakdown of foods by hypersensitivity please see Annex A, Table 9.

Respondents were asked to report whether they thought their reaction to the stated food was mild, moderate, or severe, as part of the self-report questionnaire. No definitions were given of what was classed as severe, moderate, and mild and this was left to the interpretation of respondents. Most reactions to food were self-reported as severe or moderate (44%, n= 608 and 38%, n= 527 respectively). Only 17% (n = 233) of these reactions were categorised by respondents as mild (Figure 8). For food allergy, coeliac disease and multiple hypersensitivities, more participants reported their reactions as severe compared to mild and moderate. For those with food intolerance, the majority reported this as moderate (Figure 8).

Figure 8: Severity of reaction to all foods reported, by hypersensitivity



Base: All foods reported by adults with hypersensitivities (excluding ‘other’ and ‘don’t know’; 1,277); Food allergy (252); Food intolerance (269); Coeliac disease (425); Multiple FHs (331).

Symptoms

Participants reported a wide range of symptoms, which were grouped into breathing (e.g. coughing/sneezing, wheezing, breathless), skin (rash, itchy, dry skin, swelling of face, eczema), gastrointestinal (e.g. abdominal pain, sickness/vomiting/diarrhoea, loss of weight), mouth/throat/ ear symptoms (e.g. tingling/itching, tight throat, tongue swelling) and other reactions (e.g. anaphylaxis, incontinence, collapse or seizure). Participants could choose all symptoms relevant to their reactions, so numbers reflect how many times each symptom type was chosen by respondents.

Across all three foods respondents could report, the majority of symptoms typically experienced were gastrointestinal (54%; n = 4,202), for those with food intolerance (68%; n = 771), coeliac disease (81%; 1779) and multiple hypersensitivities (50%; 1013). However, for food allergy, the most common symptoms reported were breathing (26%; n = 564) and skin symptoms (26%; 567; see Annex A Tables 10-12 for a full breakdown)

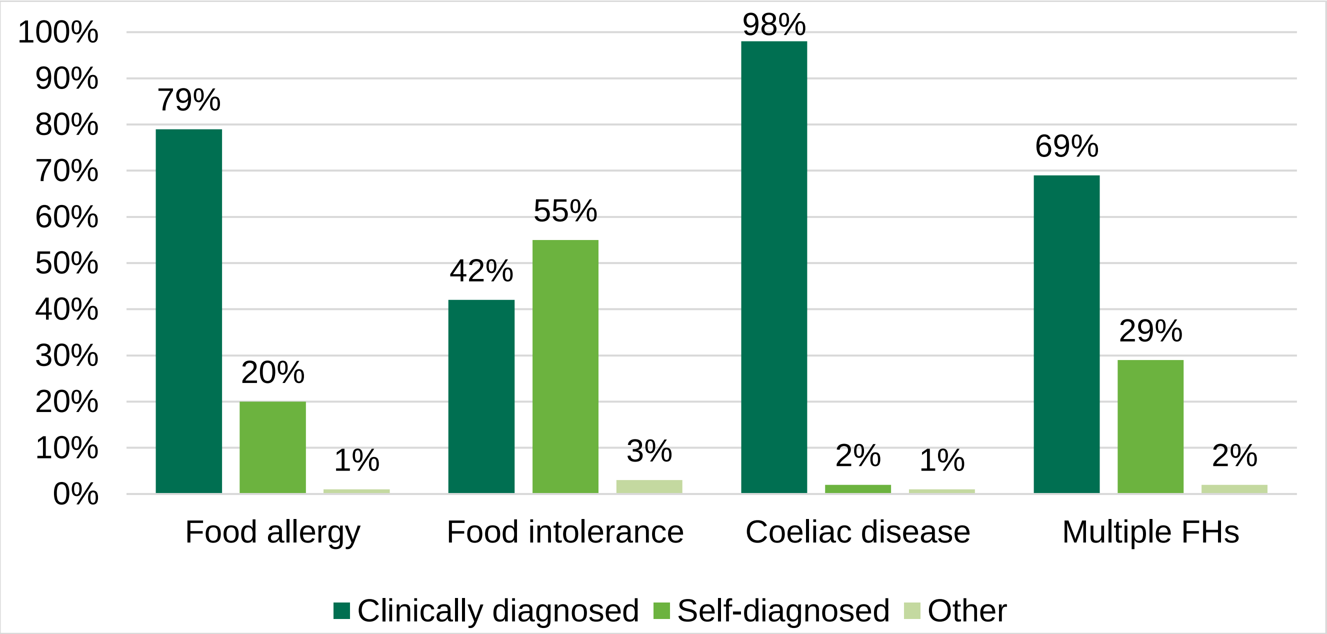
When asked to report the most severe symptoms they had experienced to the foods they reported, for adults with food intolerance (72%; n = 500), coeliac disease (83%; n = 1088) and multiple hypersensitivities (52%; n = 622) gastrointestinal symptoms were reported as the most common severe symptoms. For adults with allergy, however, the most common severe symptom type was skin symptoms (25%; n = 366; Annex A Table 13).

Participants reported that their symptoms most frequently started between 5 to 30 minutes (n = 371; 28%) after ingesting the stated food. For those with food intolerance (n = 127; 48%), coeliac disease (n = 249; 61%) and multiple hypersensitivities (n = 139, 43%) symptoms more frequently occurred after 30 minutes. However, for those with food allergy, the majority of symptoms started within 5 minutes (n = 125, 50%; Annex A Table 14).

Diagnosis

Across all three foods reported, the majority of respondents with food allergy (77%) or coeliac disease (98%) reported their reactions as clinically diagnosed. Whereas, the majority of those with food intolerance reported that their reactions were self-diagnosed (n = 137, 55%; Figure 9). A small number of adults across the hypersensitivities reported that they had been diagnosed by an alternative therapist (n = 18; 1%) which was classed as ‘other’.

Figure 9: Diagnosis by hypersensitivity



Base: All foods reported by adults with hypersensitivities (1215); Food allergy (245); Food intolerance (248); Coeliac disease (417); Multiple FHs (305).

The majority of all reactions reported by all adults were diagnosed by a hospital doctor, GP, or nurse (n = 784 combined, 64%). The most common method of diagnosis for all reactions reported by all adults was a blood test for coeliac disease (n = 345, 21%; reflecting the large proportion of the sample with coeliac disease) or Other (n = 343, 21%), which included other diagnostic tests, such as endoscopy, biopsy and various symptoms experienced (see Annex A Tables 15 and 16 for a breakdown of ‘Other’ responses). Nineteen percent (n = 323) reported that they had noticed symptoms themselves as a diagnosis method, of which 14% (n = 46) were those who reported also getting a clinical diagnosis. This is likely explained by the fact that participants could choose multiple options for diagnosis method, which may have included a clinical method such as blood tests in addition to reporting that they had noticed the symptoms themselves.

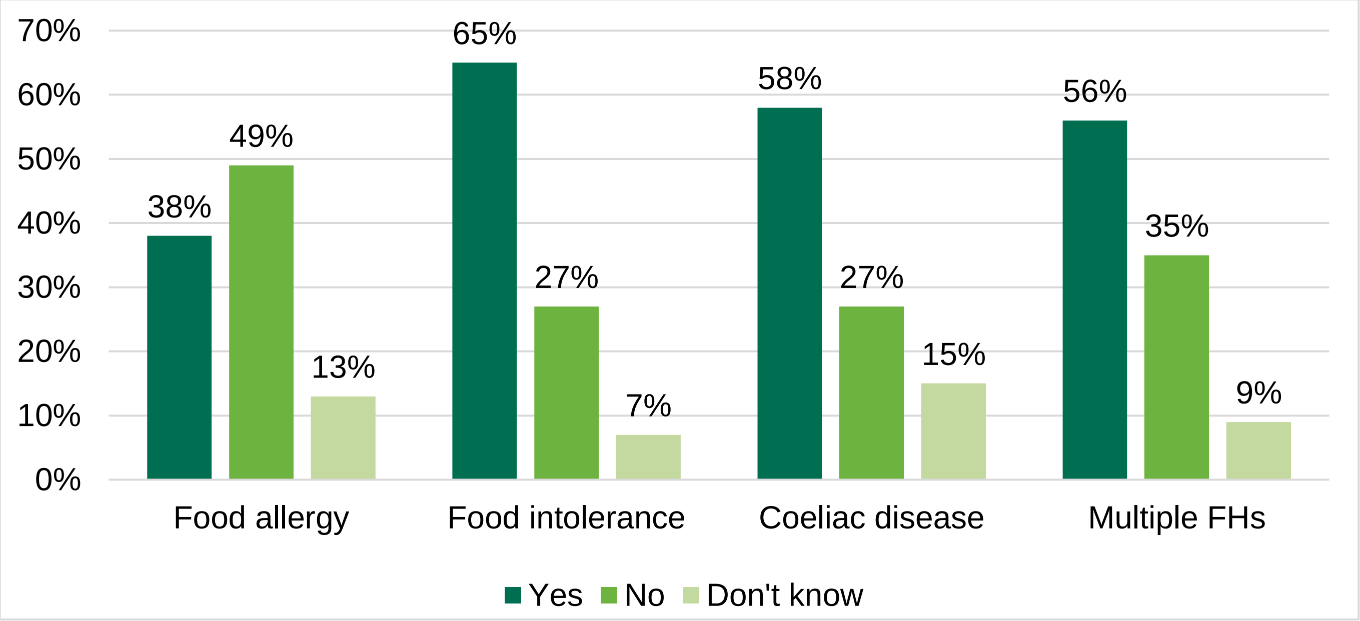
By hypersensitivity, those with food allergy most often reported being diagnosed by skin prick test (n = 98; 28%). For those with coeliac disease, it was by blood test (n = 273; 51%). For participants with food intolerance (n = 132; 46%) and multiple hypersensitivities (n = 105; 26%), self-diagnosis was the most common diagnosis method reported.

Mean age for diagnosis was 35.8 years old (SD = 17.7). When looking at the first food that adults had the most significant reaction to. Significance testing was completed only for first foods reported as sample sizes were too small to enable comparisons for second and third foods. Respondents with food allergy were, on average (mean = 22.4, SD = 16.3), diagnosed significantly younger than respondents with other hypersensitivities (food intolerance mean = 38.1, SD = 15.8; coeliac disease mean = 40.5, SD = 17.5; multiple hypersensitivities mean = 36.7; SD = 17.7) $F(3) = 42.7$, $p < .001$, $\eta p^2 = 13$ (all comparisons, $p < .001$).

About their reaction

Participants were asked whether they had ever been able to eat the stated food without having a reaction to it, as well as how many times they had reacted to the food in the previous 12 months. Across all foods reported, over half the sample (n = 707; 55%) reported having been able to previously eat their stated food without experiencing a reaction. This was also reflected across each of the hypersensitivities, except for reactions reported by those in the food allergy group, with 49% of this sample unable to previously consume their stated food without experiencing a reaction (Figure 10).

Figure 10: Participants able to eat stated food previously



Base: all foods reported by adults with hypersensitivity (1205); Food allergy (243); Food intolerance (255); Coeliac disease (411); Multiple FHs (296)

Thirty two percent (n = 425) of the sample reported that they had not reacted to the first food they reported in the previous 12 months, however 17% had reacted between 3 and 6 times, and 15% (n = 204) had reacted more than 10 times. Participants with food intolerance reported they had reacted to food more often in the last 12 months (mean = 4.1, SD = 1.9) compared to the other hypersensitivities. Significance testing was completed only for first foods reported as sample sizes were too small to enable comparisons for second and third foods. Those with food allergy reacted significantly less often (mean = 2.5, SD = 1.9), on average reporting they had experienced only one or two reactions in the previous 12 months, compared to those reporting coeliac disease (mean = 3.2, SD = 2.0) and multiple food hypersensitivities (mean = 3.2; SD = 2.1; all *p*s<.008; Annex A Table 17).

Anaphylaxis

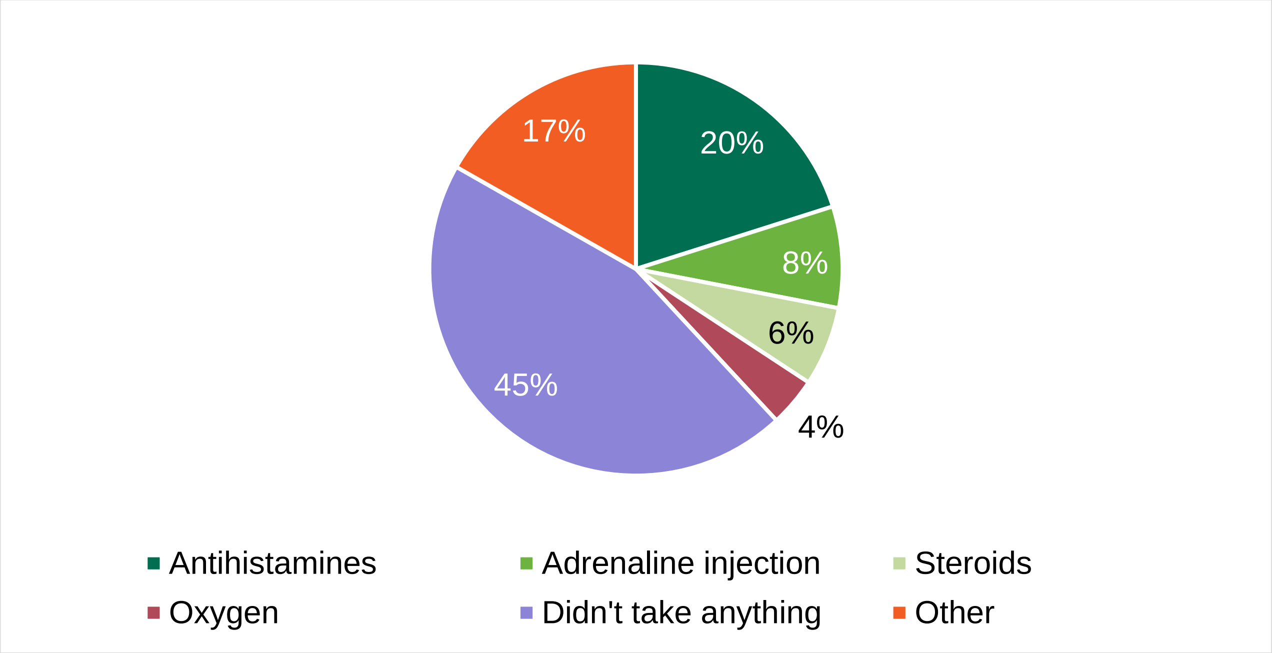
The total number of participants with experience of anaphylaxis was 172 (13%), of which 64% (n = 110) were those with food allergy and 23% (n = 39) were those with multiple food hypersensitivities. Anaphylaxis was defined to respondents as ‘You might have had an anaphylactic reaction if you had breathing difficulties and/or a drop in blood pressure quite suddenly after eating food. You may also have had a rash or stomach symptoms such as vomiting at the same time’. A further 9% (n = 15) reporting this had coeliac disease and 3% (n = 6) were those with food intolerance, indicating those with food allergy in this sample were most at risk of anaphylaxis. However, given that anaphylaxis is not a typical reaction for coeliac disease or food intolerance, some respondents may have incorrectly reported this reaction, or possibly misunderstood the question, despite being given a definition.

Furthermore, for 15% (n = 203) of all foods reported, participants had been prescribed an adrenaline auto-injector. This was mostly reported by participants with food allergy (71%, n = 144), though it was also reported by almost a quarter of respondents with multiple food hypersensitivities (23%, n= 47).

Treatment

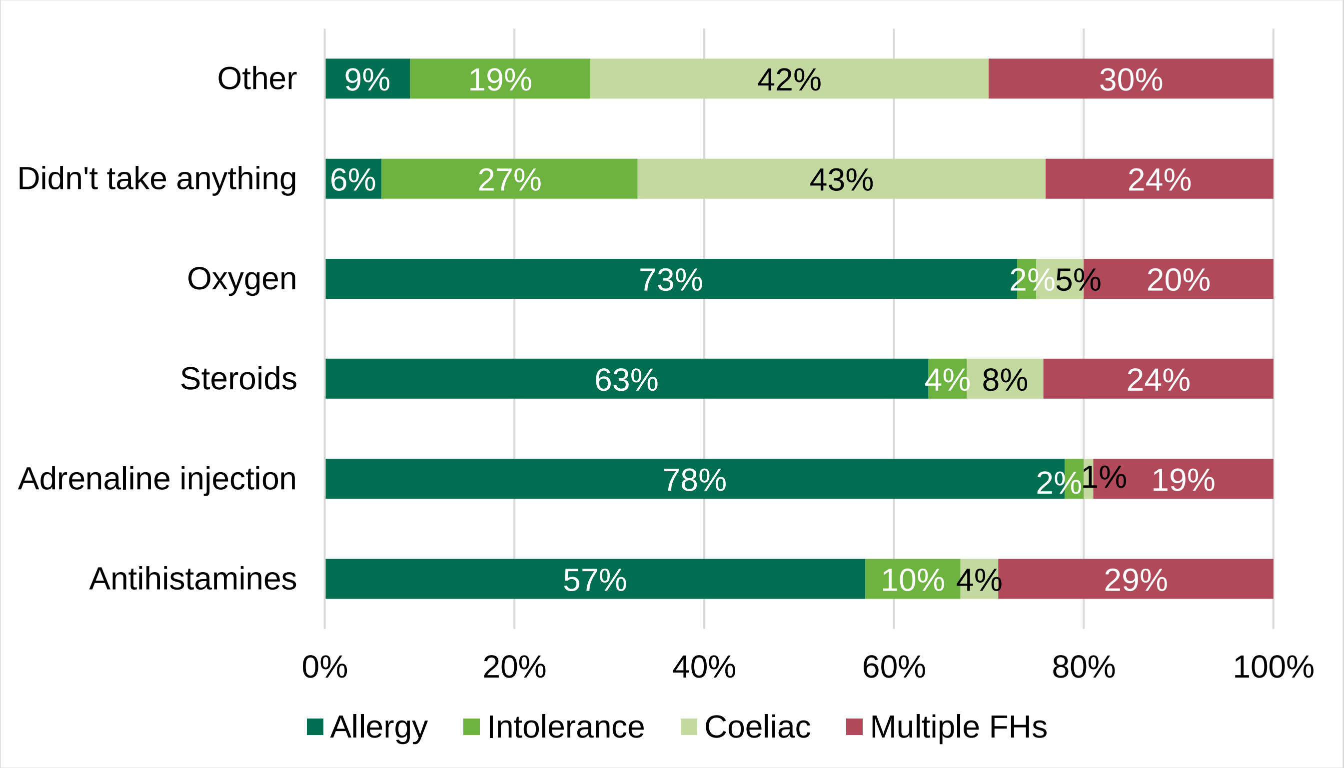
Participants could select all applicable treatments for their stated food hypersensitivities. Just under half (45%, n=705) reported not taking anything. The most common treatment reported across all foods was antihistamines (n = 314; 20%). Treatments were most commonly reported by those in the food allergy group (n = 375; 87%; see Figures 11 and 12).

Figure 11: Treatments for reaction to all foods reported



Base: All foods reported by all adults (1,562)

Figure 12: Treatments for all foods reported by food hypersensitivity



Base: All foods reported by all adults (1,479)

Hospital admission

For the majority of foods reported (92%, n = 1,202) participants had never had to call an ambulance, and two thirds (67%, n = 897) had never been admitted to hospital as an emergency for their reactions to their stated food. For those that had been admitted to hospital (n = 155, 12%), nearly half (48%) were admitted the first time that they reacted to their stated food and 68 (44%) were admitted just once. Adults with food allergy were the most likely to be admitted to hospital for their reactions to their stated food (n = 82; 35% of those with food allergy and 53% of all those admitted), as well as those with coeliac disease (n = 35; 9% of respondents with coeliac disease and 23% of all those admitted) and multiple hypersensitivities (n = 26; 8% of respondents with multiple FH and 17% of all those admitted). Those with food intolerance were least likely to be admitted (n = 8; 3%).

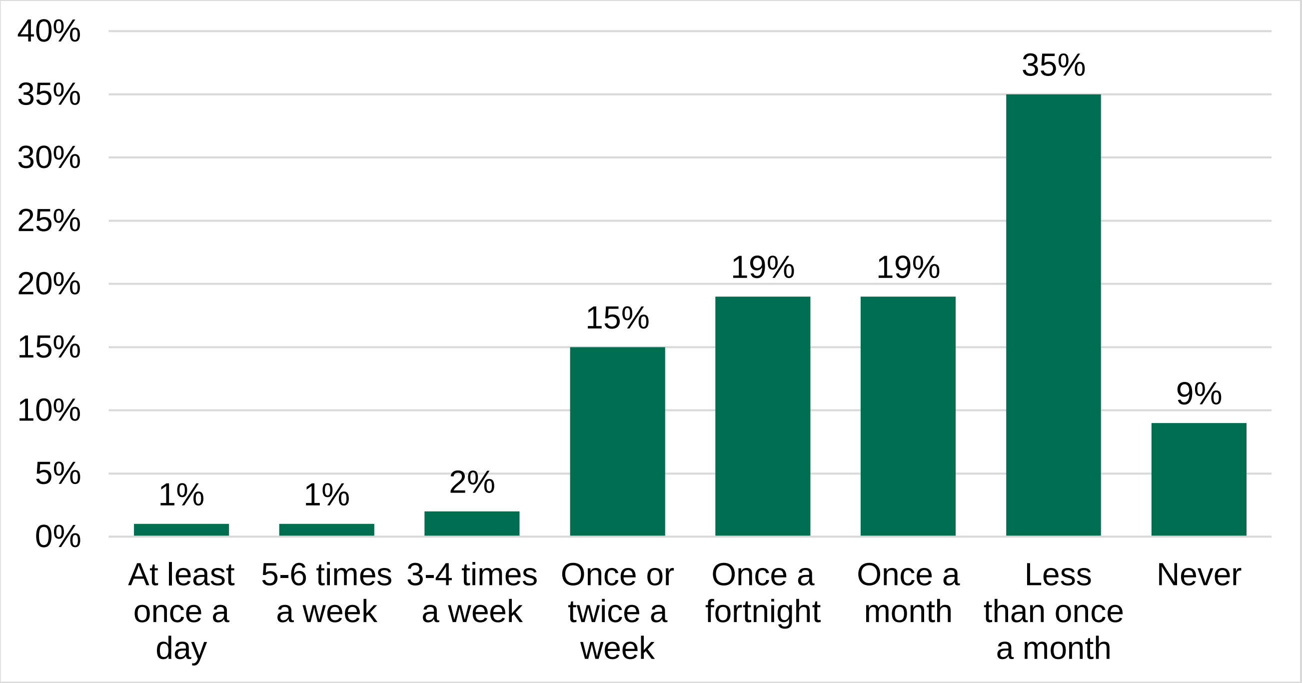
For all groups, the majority of participants who had been admitted to hospital, had been admitted between once and 3 to 6 times, but for those with allergy it was more common that they had been admitted either twice or between 3 to 6 times compared to other groups (n = 43; 53%; see Annex A Table 18 for full breakdown). Those from the food allergy group were most likely to be admitted the first time they reacted to their stated food (n = 49, 66%), compared to those with food intolerance (n = 3, 38%), coeliac disease (n = 9, 32%) or multiple hypersensitivities (n = 11, 48%).

Eating out

Participants were asked how often they eat out, and how comfortable they feel with various aspects of eating out, such as asking for information from a member of staff. Respondents were asked about their current eating out behaviour, however this survey was open during the COVID-19 pandemic when restrictions on eating out were variable across the UK, so this context should be considered when interpreting the results reported.

A third of participants reported that they eat out or get food to take away from a restaurant or other food outlet less than once a month (n = 338, 35%), but over half of the overall sample reported they eat out more frequently than this (n = 549; 55%; Figure 13).

Figure 13: How often participants eat out or get food to take away

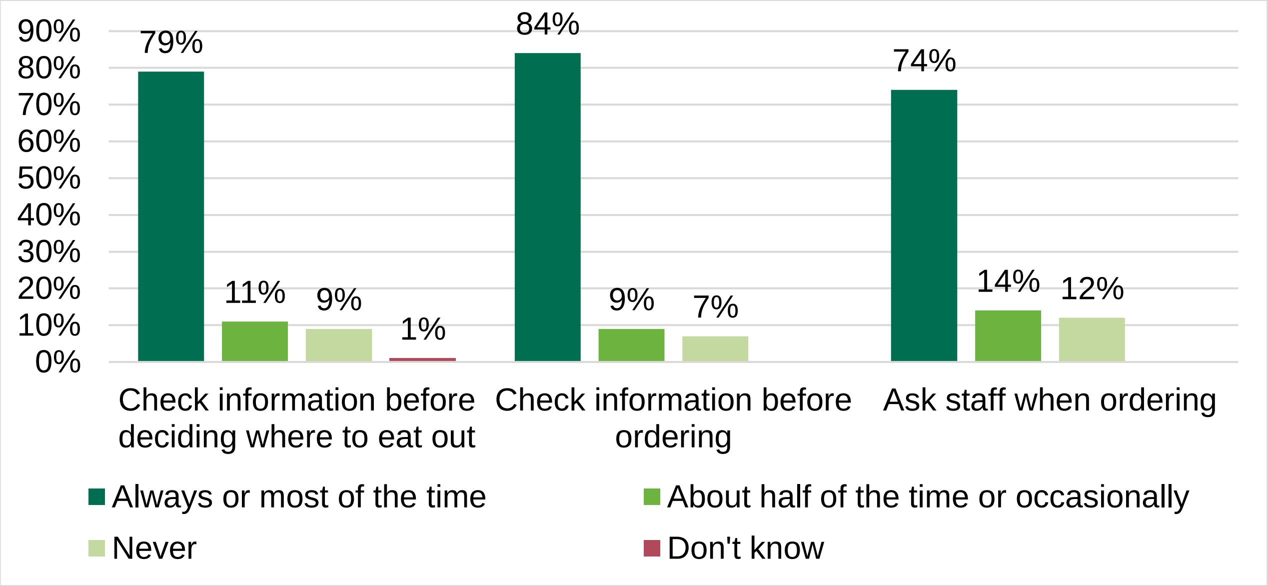


Base: All adults (932). ‘At least once a day’ and ‘5-6 times a week’ = <0.5% each.

However, there were significant differences in how often adults with different hypersensitivities eat out, *F*(3) = 5.41, *p* =.001, ηp^2 = .02. On a scale of 1 (Never) to 8 (at least once a day), those with food allergy reported eating out once a month or fortnight, and this was significantly more often (mean = 3.4, SD = 1.5) than those with food intolerance (mean = 3.0, SD =1.3), those with coeliac disease (mean = 2.9, SD = 1.2) and those with multiple hypersensitivities (mean = 3.0, SD = 1.5; all *ps* <.008), who on average ate out around once a month (see Annex A Table 19).

Participants reported almost always reviewing information at each stage of eating out (see Figure 14).

Figure 14: How often participants review information when eating out



Base: All adults answering each question; Check information before choosing where to eat out (885); Check information before ordering (882); Ask staff for information when ordering (886).

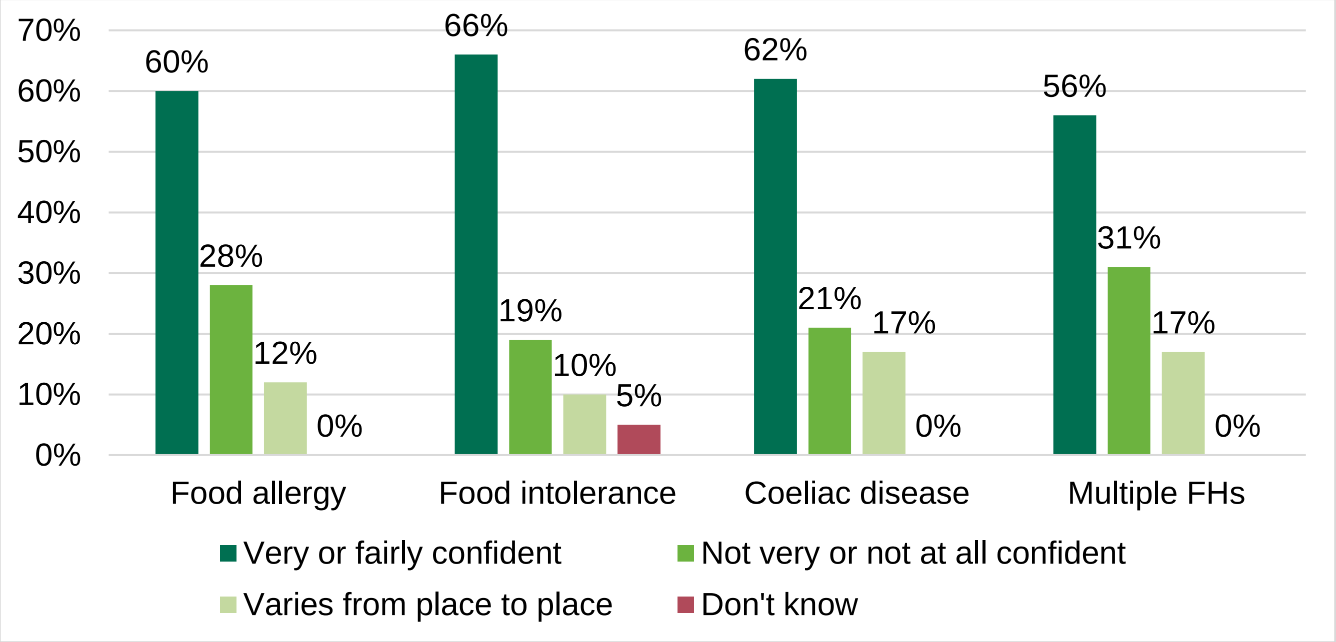
Within each hypersensitivity group, most adults reported they always or most of the time check and review any available information that allows them to identify foods that will cause a bad or unpleasant physical reaction. However, on a scale of 1 (Never) to 5 (Always) there were significant differences between hypersensitivity groups. Adults with multiple hypersensitivities (mean = 4.6, SD = 0.9) and coeliac disease (mean = 4.8, SD = 0.6) check if this information is available when deciding where to eat out significantly more often than those with food allergy (mean = 4.2, SD = 1.3) or food intolerance (mean = 3.3, SD = 1.6; all *ps*<.008), on average reporting that they always check this.

When asked how often participants review any available information before ordering food, adults with food intolerance (mean = 3.6, SD = 1.6) review this information significantly less often (about half or most of the time) than adults with other hypersensitivities (all *ps* <.001), who review this either always or most of the time. Finally, adults with coeliac disease (mean = 4.7, SD = 0.7) and multiple hypersensitivities (mean = 4.5, SD = 1.0) on average reported asking a member of staff for information that enables them to identify foods that cause a bad or unpleasant reaction significantly more often than those with food allergy (mean = 3.9, SD = 1.4) or food intolerance (mean = 2.9, SD = 1.6; all *ps* <.001).

As well as asking how often participants check available information when they eat out, they were also asked how comfortable they felt doing so, and how confident they were that the information provided would allow them to identify foods that cause bad or unpleasant physical reactions. Over half of all participants were comfortable in asking staff for information when eating out because of a concern about experiencing a reaction (n = 542; 61% were very or fairly comfortable). Across hypersensitivities, most adults were comfortable asking for information (63% of the food allergy, 64% of the food intolerance and 61% of the coeliac disease groups respectively, and 59% of the multiple hypersensitivities group reported being very or fairly comfortable asking for information; see Annex A Table 20).

Adults were mostly confident that the written information provided when eating out allows them to identify foods that cause a reaction (n = 545; 62% were very or fairly confident). However, there were some differences in how confident adults with different hypersensitivities were in written information $F(3) = 3.85$, $p = .01$, $\eta p^2 = .01$. On a scale from 1 (Not at all confident) to 4 (Very confident) those with food intolerance (mean = 2.9, SD = 0.7) were significantly more confident in written information than those with multiple hypersensitivities (mean = 2.6, SD = 0.8; $p<.008$). All other differences were non-significant (all ps>.008; Annex A Table 21 and Figure 15).

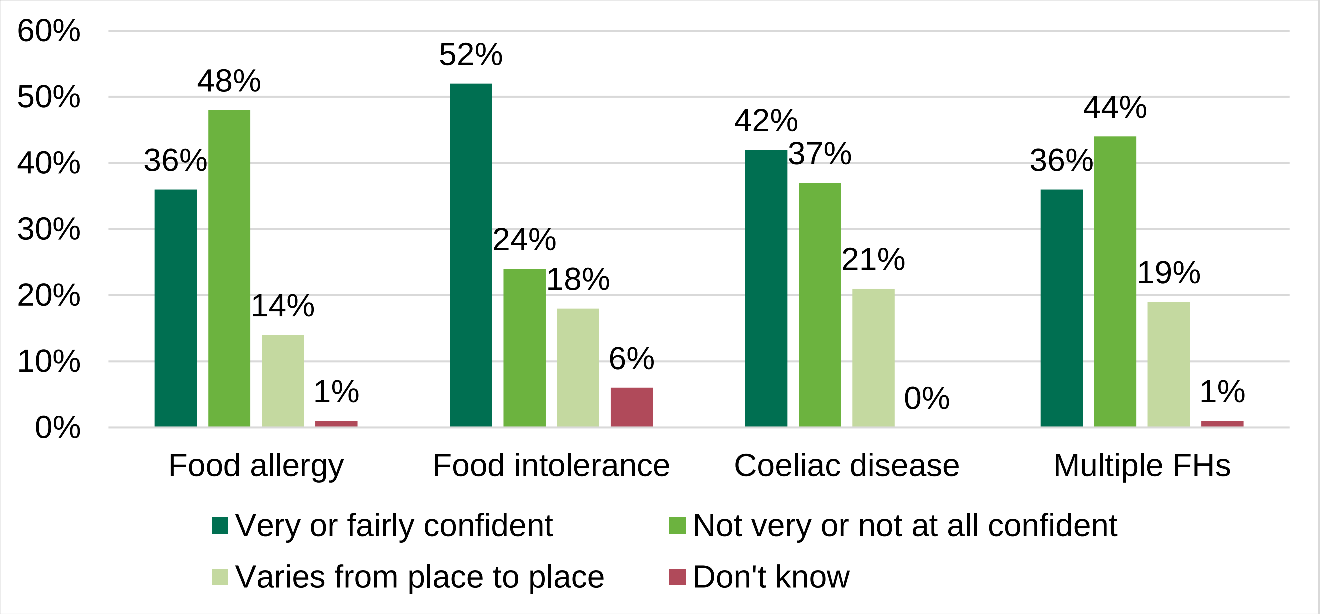
Figure 15: Confidence in written information, by hypersensitivity



Base: All adults with hypersensitivities (809); Food allergy (146); Food intolerance (184); Coeliac disease (363); Multiple FHs (116)

Participants were more divided in opinion on how confident they were that the information provided verbally by staff when eating out allows them to identify foods that cause a reaction, with 43% (n = 384) very or fairly confident in information provided, but 36% (n = 321) not very or not at all confident. There were significant differences across the different hypersensitivities, *F*(3) = 6.52, *p* <.001, ηp^2 = .03. Those with food intolerance (mean = 2.7, SD = 0.8) were significantly more confident in verbal information provided by staff compared to participants with food allergy (2.4, SD = 0.9), coeliac disease (mean = 2.5, SD = 0.8) or multiple hypersensitivities (mean = 2.3, SD = 0.8; all *p*s <.008; Figure 16).

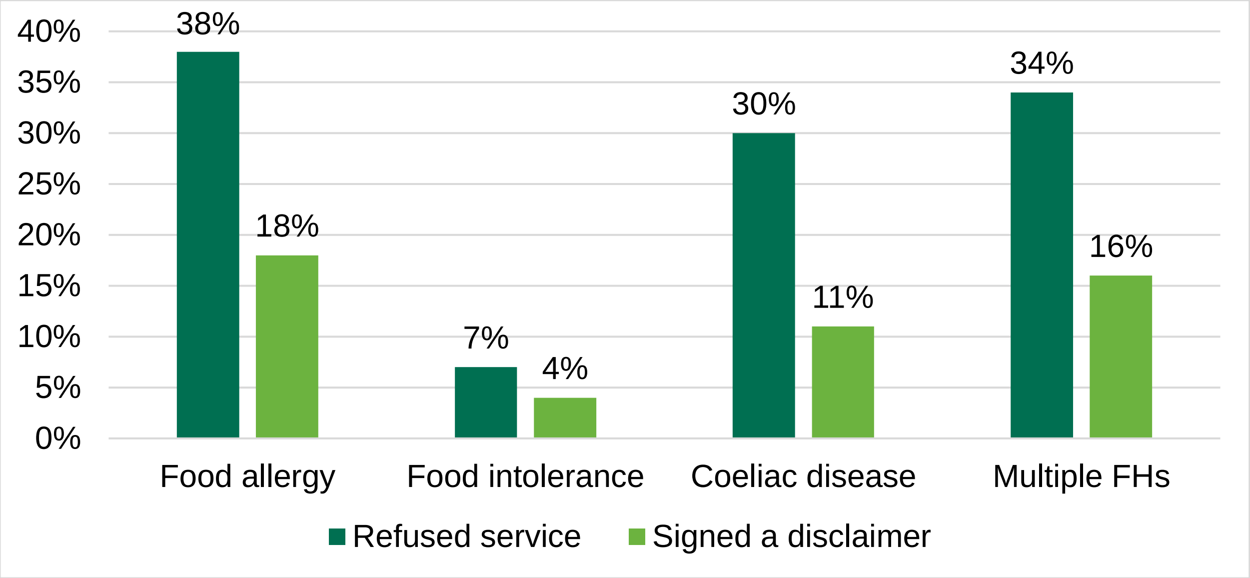
Figure 16: Confidence in verbal information by hypersensitivity



Base: All adults with hypersensitivities (809); Food allergy (146); Food intolerance (184); Coeliac disease (363); Multiple FHs (116)

One in four (25%, n = 217) participants reported they had previously been refused service because of their hypersensitivity, and one in ten (11%, n = 95) reported that they had been previously asked to sign a disclaimer when eating out. Those with food allergy reported the highest percentages of being refused service (38%, n = 54) and being asked to sign a disclaimer (18%, n = 26), whilst those with intolerance reported the lowest percentages of being refused service (7%, n = 12) and asked to sign a disclaimer (4%, n = 8) as a result of their conditions. See Figure 17 for percentages reported by hypersensitivity.

Figure 17: Proportion of adult respondents refused service and asked to sign a disclaimer when eating out, by hypersensitivity



Base: Adults with hypersensitivities (Refused service (RS): 799; Signed disclaimer (SD): 803); Food allergy (RS: 143; SD: 146); Food intolerance (RS: 181; SD: 182); Coeliac disease (RS: 359; SD: 359); Multiple FHs (RS: 116;SD: 116).

Shopping

Participants were asked how often they check information on food labels for ingredients that may cause them a bad or unpleasant physical reaction, in various types of shops. It was common for participants to check labels for ingredients that would cause an adverse reaction always or most of the time (n = 824; 85%), as well as check labels for information about the possible presence of these foods (e.g. ‘may contain; n = 780; 81%). While the majority of those with each hypersensitivity reported they check labels for the possible presence of foods that could cause an adverse reaction ‘always or most of the time’, those with food intolerance had the lowest percentage of those checking labels for the possible presence of foods always or most of the time (61%; n = 124; see Annex A Table 22 and 23).

On a scale from 1 (Never) to 5 (Always), there were significant differences in how often adults check labels for ingredients, $F(3) = 61.4$, $p < .001$, $\eta p^2 = 17$. Adults with coeliac disease check labels for ingredients significantly more often (mean = 4.8, SD = 0.5) than those with food allergy (mean = 4.4, SD = 1.0) or food intolerance (mean = 3.8, SD = 1.4; all ps <.001).

Participants with food intolerance (mean = 3.6, SD = 1.5) check labels for information about the possible presence of foods (e.g. may contain) significantly less often than adults with food allergy (mean = 4.2, SD = 1.2), coeliac disease (mean = 4.8, SD = 0.6) and multiple hypersensitivities (mean = 4.6, SD = 0.8), *F*(3) = 66.5, *p* <.001, ηp² = 19 (all comparisons p<.001). Further, those with coeliac disease and multiple hypersensitivities also check labels for information on the possible presence of foods significantly more often than adults with food allergy (both *p*s <.001).

Data was also collected on how confident participants were that the information provided on labels allowed them to identify foods that will cause a bad or unpleasant physical reaction when buying foods from different types of food businesses. On a scale from 1 (Not at all) to 4 (Very confident), participants were significantly less confident in the information provided on labels at food markets or stalls (mean = 2.1, SD = 0.8) compared to in store supermarkets (mean = 3.3, SD = 0.7), online supermarkets (mean = 3.1, SD = 0.8) and independent shops (mean = 2.9, SD = 0.8 ; all *ps* <.001; Figure 18). Confidence in information provided on labels by independent shops (mean = 2.9, SD = 0.8) was also significantly lower than for in store supermarkets (mean = 3.3, SD = 0.7) and online supermarkets (3.1, SD = 0.8, both *ps* <.001; Annex Tables 24-27).

Figure 18: Confidence in the information provided on food labelling in different food outlets

Base: All adults (answering for each food business type); Supermarkets (966); Online supermarkets (950); Independent shops (952); Food markets (954)

Adult participants were also less confident that they could identify foods that cause them a bad or unpleasant physical reaction when buying food sold loose compared to labelled food. For example, 88% of participants felt very or fairly confident in identifying foods that cause a reaction using the information on food labelling for items sold from in store supermarkets, whereas this was true for only 51% of adults when asked about identifying food sold loose from in store supermarkets. This was also similar for online supermarkets, with 66% feeling confident about identifying labelled items that cause a reaction, compared to 42% feeling confident identifying loose food items (see Figure 19).

On a scale from 1 (Not at all) to 4 (Very confident), participants were significantly more confident they could identify foods that would cause them a bad or unpleasant reaction when buying food sold loose from in store supermarkets (mean = 2.7, SD = 1.0) compared to independent shops (mean = 2.5, SD = 0.9) and food markets (mean = 2.2, SD = 0.9; all *ps* <.001). Participants were also significantly more confident they could identify foods that would cause them a bad or unpleasant reaction when buying food sold loose from online supermarkets (mean = 2.6, SD = 1.0) than independent shops (mean = 2.5, SD = 0.9) and food markets (mean = 2.2, SD = 0.9; all *ps* <.001). See Annex Tables 28-31.

Figure 19: Confidence in identifying foods that cause a bad or unpleasant physical reaction when buying food sold loose

Base: All adults (answering for each food business type); Supermarkets (961); Online supermarkets (951); Independent shops (949); Food markets (945)

When comparing across the different outlets, except for independent shops, adults with food allergy had the least confidence in the information on labels provided by other outlets (12%; 23% and 55% for in store supermarkets, online supermarkets and food markets respectively). Between hypersensitive groups, those with coeliac disease (mean = 3.5, SD = 0.6) reported being significantly more confident than those with food allergy (mean = 3.2, SD = 0.7), food intolerance (mean = 3.3, SD = 0.7) and multiple hypersensitivities (mean = 3.3, SD = 0.7) about the information on labels found within in store supermarkets. Those with food allergy (mean = 2.9, SD = 0.9) were significantly less confident in the information on labels provided by online supermarkets than those with food intolerance (mean = 3.2, SD = 0.7) and coeliac disease (mean = 3.3, SD = 0.7), and were also less confident (allergy mean = 2.8, SD = 0.8) in the information provided by independent shops than those with coeliac disease (mean = 3.0, SD = 0.7; all *p*s <.008). There were no significant differences between the hypersensitive groups for information provided by food markets/stalls.

Approximately 40% of adults in each hypersensitivity group were not very or not at all confident that they could identify foods that would cause them a bad or unpleasant physical reaction when buying food sold loose from food markets/stalls (see Annex Tables 28-31). When purchasing food sold loose from in store supermarkets, those with food intolerance (mean = 2.9, SD = 0.9) were significantly more confident in identifying foods that cause a bad or unpleasant physical reaction than those with coeliac disease (mean = 2.6, SD = 1.0) and multiple hypersensitivities (mean = 2.4, SD = 0.9; all *p*s<.001). Further, those with food intolerance (mean = 2.9, SD = 0.9) were significantly more confident in identifying foods that cause a bad or unpleasant physical reaction when purchasing loose food from online supermarkets than those with food allergy (mean = 2.6, SD = 0.9), coeliac disease (mean = 2.5, SD = 1.0) and multiple hypersensitivities (mean = 2.4, SD = 1.0; all *p*s <.001). Those with food intolerance (mean = 2.6, SD = 0.9) were more confident in identifying foods sold loose from independent shops than those with multiple hypersensitivities (mean = 2.3, SD = 0.9, *p* = .002). Participants with food intolerance were also more confident (mean = 2.4, SD = 0.9) than those with coeliac disease (mean = 2.0, SD = 0.9) and multiple hypersensitivities (mean = 2.0, SD = 0.8) in identifying foods that cause a reaction when purchasing from food markets/stalls (both *p*s <.001).

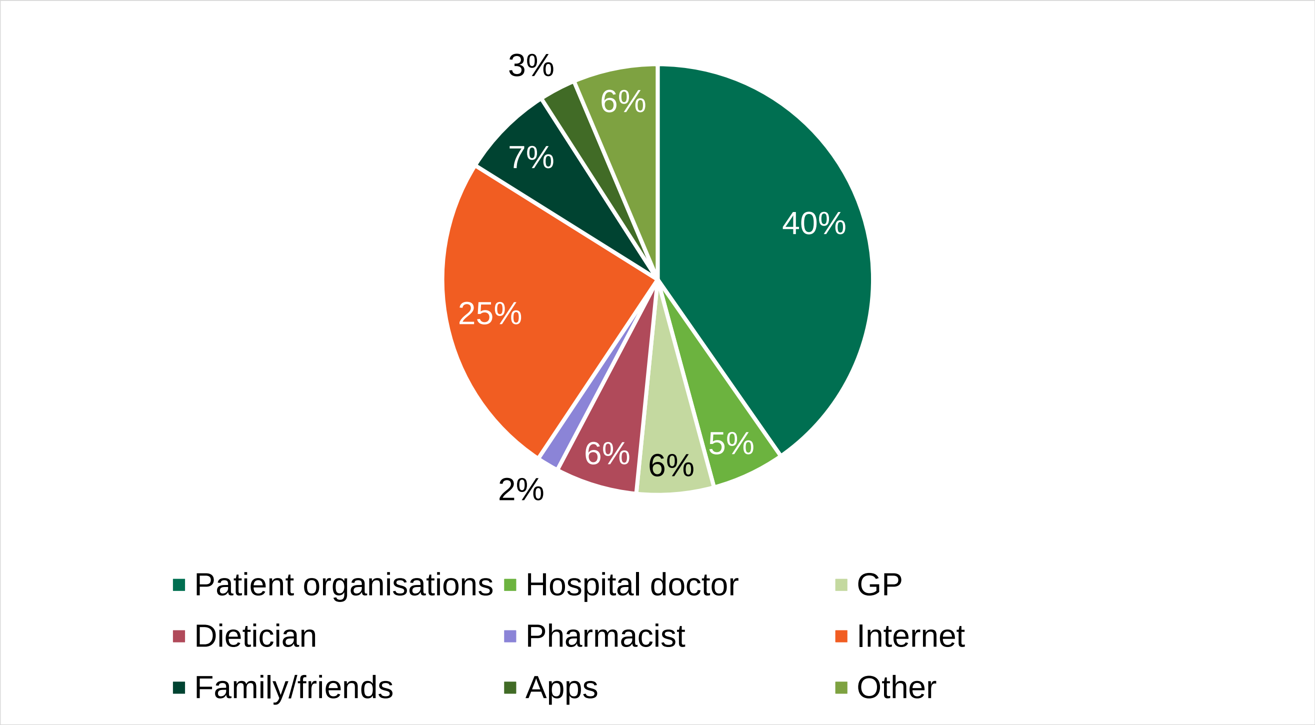
Sources of information

Adults were asked about the sources of information they use to help manage their hypersensitivity (see Annex Table 32). Participants could choose as many from the list that applied and so numbers may add up to more than the total number for each group (or 100%).

One of the most frequently used sources of information for all adults was patient organisations (49%), although 60% of these adults were from the coeliac group, likely reflecting the successful recruitment of this group through Coeliac UK (89% of the coeliac group were members of Coeliac UK). For food intolerance, self-managing (56%; n = 120) and the internet (n = 65; 30%) were the most common forms of support. More adults with food allergy (42%) also reported self-managing their condition, compared to using any other sources of information, including patient organisations. For those with multiple hypersensitivities, patient organisations (67%), and the internet (44%) were the most frequently used sources of information (for a full breakdown see Annex A Table 32).

Whilst 40% of the sample reported self-managing their condition, the most helpful resource reported across all adults with hypersensitivity was patient organisations (40%), although the internet was adult participants’ second most helpful information source (25% of the total sample reported this as most helpful; Figure 20).

Figure 20: Most helpful source of information for all adults



Base: All adults (913).

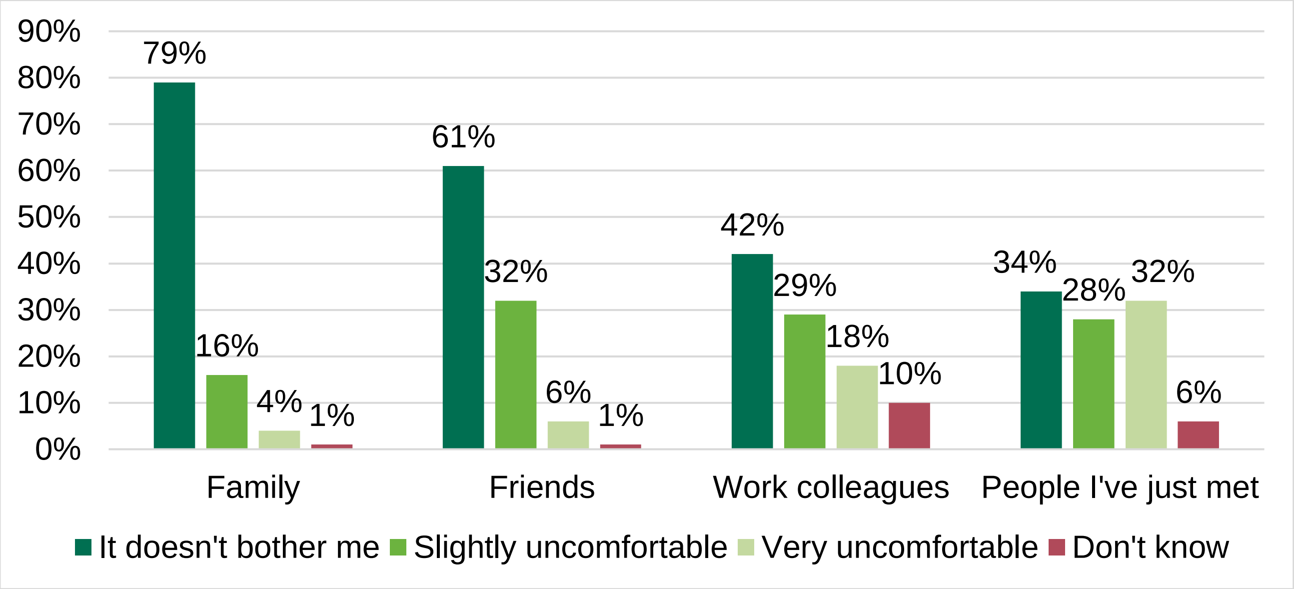
Perceived helpfulness also varied according to hypersensitivity. Those reporting food allergy (n = 45; 30%), coeliac disease (n = 236; 62%) and multiple hypersensitivities (n = 58; 46%) found patient organisations (such as Allergy UK, Anaphylaxis Campaign and Coeliac UK) most helpful. For those reporting food intolerance however, the internet was the most helpful source of information reported (n = 75, 42%). Those with food intolerance (n = 24, 13%) were also more likely to find family and friends helpful, compared to any other hypersensitive group. Compared to other groups, those with food allergy were more likely to report that their hospital doctor was the most helpful source of information (n = 24; 16% of those with food allergy; 48% of those who found hospital doctors most helpful; see Annex A Table 33).

Social situations

Participants were asked how they felt about mentioning their food hypersensitivity or experiencing a reaction in front of others, including friends, family, work colleagues and people they've just met.

Overall adult participants were comfortable mentioning their hypersensitivity in front of family and friends (Figure 21). However, with people they didn't know, adults responded almost equally with ‘it doesn’t bother me’ (n = 322; 34%) and ‘very uncomfortable’ (n = 309; 32%).

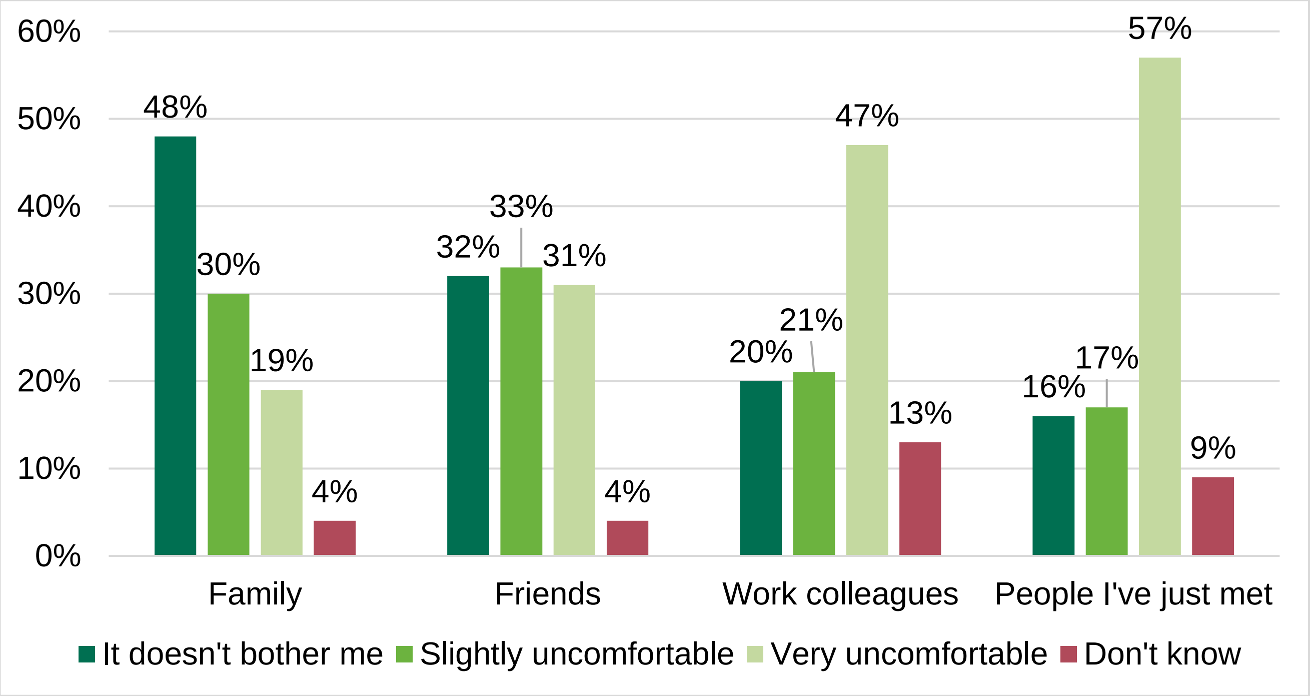
Figure 21: How comfortable adults felt about mentioning their hypersensitivity in front of different groups



Base: All adults (answering for each social group); Family (962); Friends (961); Work colleagues (939); People they’ve just met (957).

Participants were asked ‘how do you feel about experiencing symptoms of an allergic or intolerant reaction in front of other people?’ and were prompted about different groups (Figure 22). With family, many (48%) respondents said it didn’t bother them and for friends, adults were almost equally split across not being bothered (32%), feeling slightly uncomfortable (33%) and very uncomfortable (31%). The majority (n = 544; 57%) felt very uncomfortable about experiencing symptoms of a reaction in front of people they had just met. They also felt less comfortable experiencing a reaction in front of work colleagues, with 47% reporting this as ‘very uncomfortable’ (n = 438).

Figure 22: How comfortable adults felt about experiencing symptoms of a reaction in front of different groups



Base: All adults (answering for each social group); Family (961); Friends (957); Work colleagues (940); People they've just met (950)

Across hypersensitivities, adults were most comfortable mentioning their hypersensitivity in front of family or friends, and most divided about doing so in front of people they had just met (with around 30% for each responding ‘it doesn’t bother me’, ‘I feel slightly embarrassed or uncomfortable’ and ‘I feel very embarrassed or uncomfortable’ respectively). (Annex Tables 34-37).

On a scale of 1 (it doesn’t bother me) to 3 (very uncomfortable), those with multiple hypersensitivities felt significantly more uncomfortable (mean = 1.6, SD = 0.7) mentioning their hypersensitivity in front of friends than those with food intolerance (mean = 1.4, SD = 0.6; *p* =.007). With a Bonferroni correction applied for multiple comparisons, there were no other significant differences (all *ps* >.008).

Those with coeliac disease and multiple hypersensitivities were most uncomfortable about experiencing symptoms of a reaction in front of work colleagues (50% and 52% respectively) and people they had just met (60% and 67% respectively; Annex Tables 38-41).

Again, using the scale 1 (It doesn’t bother me) to 3 (Very uncomfortable), for experiencing symptoms in front of friends, people they’d just met and work colleagues, participants with coeliac disease and multiple hypersensitivities felt significantly more uncomfortable than those with food intolerance (all *p*s <.008; for means see Table 42). There were no significant differences for those with food allergy and other hypersensitivities (all *p*s>.008).

Quality of Life

Food hypersensitivity specific quality of life

Participants were asked to complete a health-related quality of life scale appropriate to the type of self-reported food hypersensitivity they reported for their first food. Those with food allergy completed the Food Allergy Quality of Life Questionnaire (FAQLQ)[2], those reporting food intolerance completed the Food Intolerance Quality of Life Questionnaire (FIQLQ), for Coeliac Disease participants completed the Coeliac Disease Quality of Life scale (CDQoL). Respondents reporting multiple different hypersensitivities completed the scale relevant to the first food they reported (those reporting food allergy = 33; those reporting food intolerance = 21, those reporting coeliac disease = 81). For example, if someone reported food allergy to their first food, food intolerance to their second and third, they only completed the FAQLQ as it was considered too difficult for respondents to identify the different impacts on quality of life that their different hypersensitivities may have.

Quality of life in all adults

The FAQLQ and FIQLQ are rated on a scale from 1 (least impairment on quality of life) to 7 (maximal impairment on quality of life). The CDQoL is rated on a five-point scale, with totals adding up from 20-100 and cut off points (1-20, 20-40, 40-60, 60-80, 80-100) to denote different levels of quality of life. On all scales, higher scores indicate a bigger impact on quality of life.

---

[2] More information on the scales can be found in the methods and technical report

While it is hard to compare quality of life across the hypersensitivities using these different scales, the FAQLQ and FIQLQ used the same scale of 1 to 7, with mean impairment being 4 (response option ‘moderately’ on the scale from 1 to 7), and the CDQoL mean score is 50 (which would be equivalent to selecting response option ‘moderately’ on the 1 to 5 scale). Thus, those reporting a food allergy to their first food reported the highest score (5 out of 7) above the mean of the scale, and therefore most impairment of their condition on quality of life (see Table 1).

Table 1: Mean Quality of Life scores for each FH-specific scale (all adults)

Measure	**FAQLQ (Food allergy)** **N = 180 (incl. 32 with multiple food hypersensitivities)**	**FIQLQ (Food intolerance)** **N = 215 (incl. 18 with multiple food hypersensitivities)**	**CDQoL (Coeliac disease)** **N = 465 (incl. 79 multiple food hypersensitivities)**
Mean Total (SD)	5.2 (1.5)	4.5 (1.7)	52.6 (17.7)

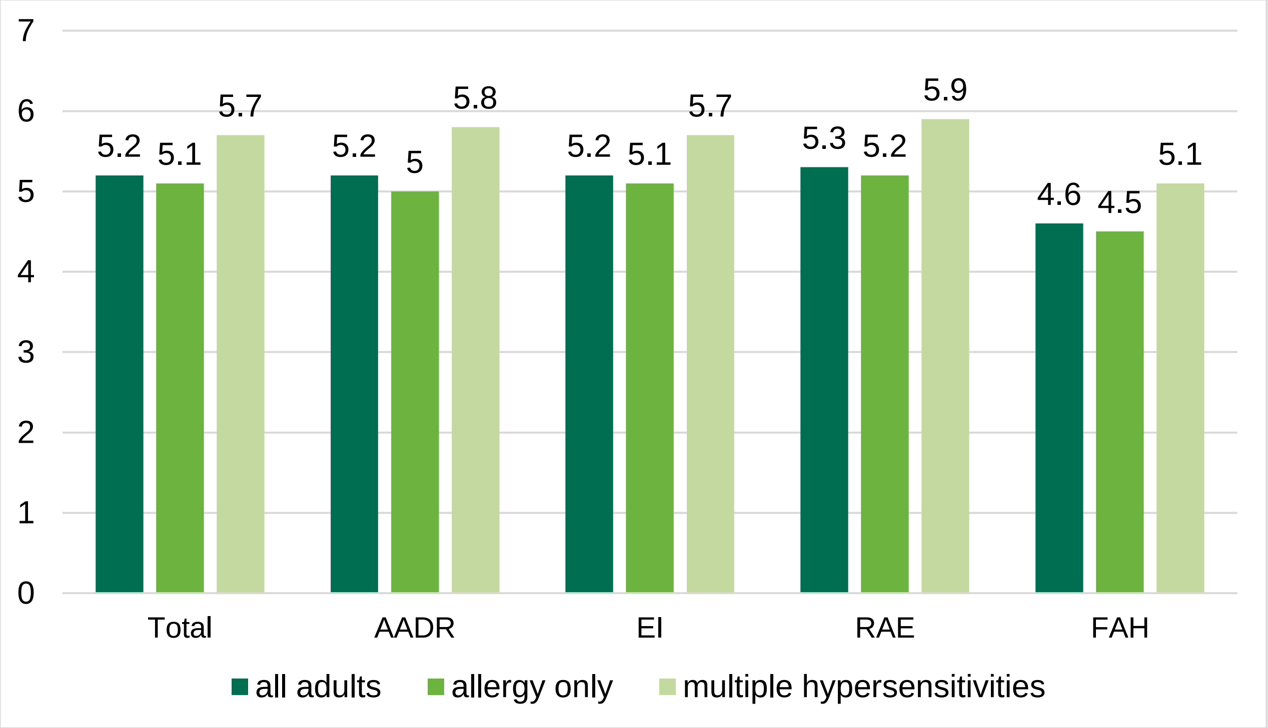
QoL in adults reporting allergy

Each scale consists of food hypersensitivity specific subscales. For those completing the FAQLQ, these are: Allergen Avoidance and Dietary Restrictions (AADR), which considers the impact that a restrictive diet has on quality of life and the impact this also has on social activities; Emotional Impact (EI) relating to the worries and concerns about having an allergic reaction or consuming allergens; Risk of Accidental Exposure (RAE), relating to vigilance and awareness needed to avoid ingesting allergens; and Food Allergy related Health (FAH), relating to specific health anxiety about having an allergy or reaction. A total of 180 adults completed the FAQLQ (of which 147 were from the allergy only group; the remaining 33 from the multiple hypersensitivities – see below section on this group).

On the scale from 1 (least impairment) to 7 (most impairment on quality of life) used by the FAQLQ, participants scored similarly high for total impact on quality of life and for all subscales. Scores for the total mean (5.2 out of 7, SD = 1.5; response option ‘quite’ troubled or worried) and all subscales of the FAQLQ were above the mean level of 4 (out of 7). The lowest mean score was for the Food Allergy related Health subscale (mean = 4.6 out of 7, SD = 1.7; response option ‘moderately’), indicating less impairment on quality of life from health related anxiety about having allergies, compared to other aspects such as avoiding allergens, concerns about having a reaction and other social and dietary limitations that come with having a food allergy.

While it appears that those with multiple hypersensitivities who completed the FAQLQ had the most impaired quality of life, this group was a lot smaller than those with just food allergy and so means may be inflated for this group. Means for both groups are shown in Figure 23.

Figure 23: Mean FAQLQ scores for all adults, allergy only adults and adults with multiple hypersensitivities



Base: Adults responding to FAQLQ (180); Allergy only group (147); Those with allergy as part of multiple hypersensitivities (33)

Clinical factors were examined to see whether they were significantly associated with impairment to quality of life in adults with food allergy. Quality of life was significantly more impaired in those who reported having a long-term condition (e.g. diabetes, heart disease, mean=5.49 SD=1.20) compared to those who did not (mean=4.90 SD=1.63; t(153.86)=2.63). This was also the case for those with asthma (mean=5.47 SD=1.23) compared to those without (mean=4.84 SD=1.55; t(148.87)=2.76) and for those with eczema (mean=5.44 SD=1.42) compared to those without (mean=4.85 SD=1.55; t(146)=2.41) (all *p*s <.05).

The number of foods reported which result in an adverse reaction was significantly positively correlated with impairment to quality of life in adults reporting food allergy (r = .32), as was the reported severity of participants' reaction (r = .47; both ps <.001). Those prescribed an auto-injector had significantly greater impairment to quality of life (mean=5.62 SD=1.18) than those without (mean=4.69 SD=1.59; t(141.01) =4.12). Those who had experienced anaphylactic shock to their first stated food reported greater impairment (mean=5.66 SD=1.17) than those who had not (mean=4.60 SD=1.59; t(133.95) =4.65). Those who had been admitted to hospital in an emergency for the reaction to food one also reported greater impairment to their QoL (mean=5.75 SD=1.09) than those who had not (mean=4.86 SD=1.55; t(149.64)=4.26), (all *p*s <.001).

Other factors related to eating out were also significantly correlated with quality of life in adults with allergy. Whilst frequency of eating out was significantly negatively correlated with impairment to quality of life (r = -.23), how often they checked information before choosing where to eat (r = .53), frequency of reviewing this information before ordering (r=.51), and asking staff for available information (r = .59) were all significantly and positively correlated to impairment of quality of life (all *p*s<.01). The same was also true for how often they checked labels for ingredients that may cause an adverse reaction when shopping (r = .44) and checked labels for the possible presence of foods that may cause an adverse reaction (r = .35, both ps<.001). However, how comfortable participants were in asking for information from staff when eating out (r = -.30) and how confident they were in the written information (r = -.32) and verbal information (r = -.36) provided when eating out, were significantly negatively correlated with impairment to quality of life (all *p*s <.001).

A regression model was run to see which of the variables described above might predict level of food allergy specific quality of life. All the variables above which had a significant association with quality of life were included in the model (n=17 predictors). The overall model was significant (p<0.001) and 53% of the variance in quality of life was explained, indicating that 47% of the variance was due to other unknown factors. Greater self-reported severity significantly predicted poorer QoL (standardised beta 0.21). How often participants checked information before choosing where to eat out (standardised beta -0.21) and how often they asked a member of staff for information (standardised beta -

.034) predicted poorer QoL. However, feeling more comfortable in asking staff for information about food when eating out predicted better QoL (standardised beta 0.21). The frequency of asking a member of staff for information to allow identification of food that caused a reaction was the strongest predictor of QoL. None of the other predictors were significant (standardised betas ranged from -0.01 to 0.07 and confidence intervals for each predictor crossed zero).

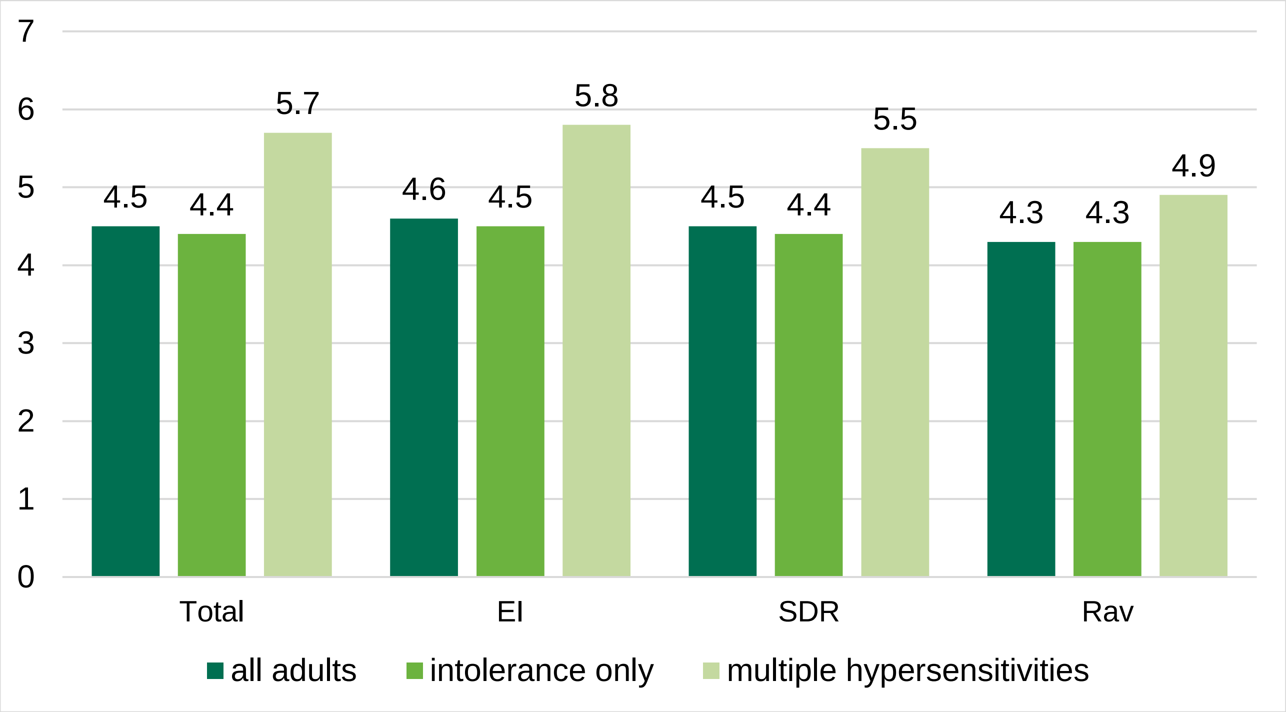
QoL in adults reporting food intolerance

The FIQLQ was also scored on a scale of 1 (least impairment on quality of life) to 7 (maximum impairment on quality of life). Subscales comprise: Emotional Impact (EI), related to the stresses and concerns of having to be aware of foods that could cause a reaction; Social and Dietary restrictions (SDR), related to the impact that having an intolerance has on diet and social activities (e.g. eating out); and Reactions and Avoidance (RAv), related to negative feelings about having a reaction (e.g. embarrassment and discouragement). A total of 195 adults with food intolerance completed the FIQLQ.

Adults with food intolerance reported a mean score of 4.5 (out of 7, response option ‘moderately’ or ‘quite a bit’; SD =1.7) for impairment on quality of life across all subscales (see Figure 24), with the mean score for Reactions and Avoidance showing least impairment in quality of life than the other FIQLQ subscales. This could indicate that those with food intolerance may be least concerned about negative feelings as a result of a reaction, and their quality of life is instead more impacted by the everyday concerns about managing their intolerance and the dietary and social limitations it has (see Figure 24).

For those with multiple hypersensitivities, 20 completed the FIQLQ. These individuals reported a greater impact on quality of life compared to those who only reported food intolerance (see Figure 24), however again this may be inflated due to the comparatively small numbers.

Figure 24: Mean FIQLQ scores for all adults, adults with food intolerance only and adults with multiple hypersensitivities



Base: Adults responding to FIQLQ (215); Intolerance only group (195); Those with food intolerance as part of multiple hypersensitivities (20)

Quality of life was significantly more impaired in those who reported having a long-term condition (e.g. diabetes, heart disease, mean=4.88 SD=1.71) compared to those who did not (mean=4.10 SD=1.52; t(203)=3.45). This was also the case for those with a disability (mean=5.34 SD=1.49) compared to those without (mean=4.29 SD=1.65; t(199)=3.66) and for those with non-food allergies such as venom or medication, (mean=5.40 SD=1.51) compared to those without (mean=4.18 SD=1.71; t(66)=2.54) (all *ps* <.01). Those prescribed an auto-injector also had significantly greater impairment to quality of life (mean=5.95 SD=1.01) than those without (mean=4.49 SD=1.65; t(7.22) =3.67, p<0.05).

The number of foods reported which result in an adverse reaction (r = .18, p = .01) was significantly positively correlated with impairment to quality of life, as was the reported severity of participant's reaction (r = .56; p <.001).

Factors related to eating out that were significantly positively correlated with impairment to quality of life in adults with intolerance included: how often they checked information before choosing where to eat out (r = .63), reviewing available information before ordering (r=.60), and asking staff for available information (r = .57) (all *p*s<.001). The same was also true for checking labels for ingredients that may cause an adverse reaction when shopping (r = .59) and checking labels for the possible presence of foods that may cause an adverse reaction (r = .53, both ps<.001). However, how comfortable participants were in asking for information about food when eating out (r = -.20, p= .01) and how confident they were in the verbal information (r = -.29, p = .001) provided when eating out, were significantly negatively correlated with impairment to quality of life.

A regression model was run to see which of the variables described above might predict levels of quality of life. All the variables above which had a significant association with quality of life were included in the model (n=13 predictors). The overall model was significant (p<0.001) and 44% of the variance in quality of life was explained. The only significant predictor was severity rating, with greater self-reported severity significantly predicting poorer QoL (standardised beta 0.29). None of the other predictors were significant (standardised betas ranged from -.001 to 0.25 and confidence intervals for each predictor crossed zero).

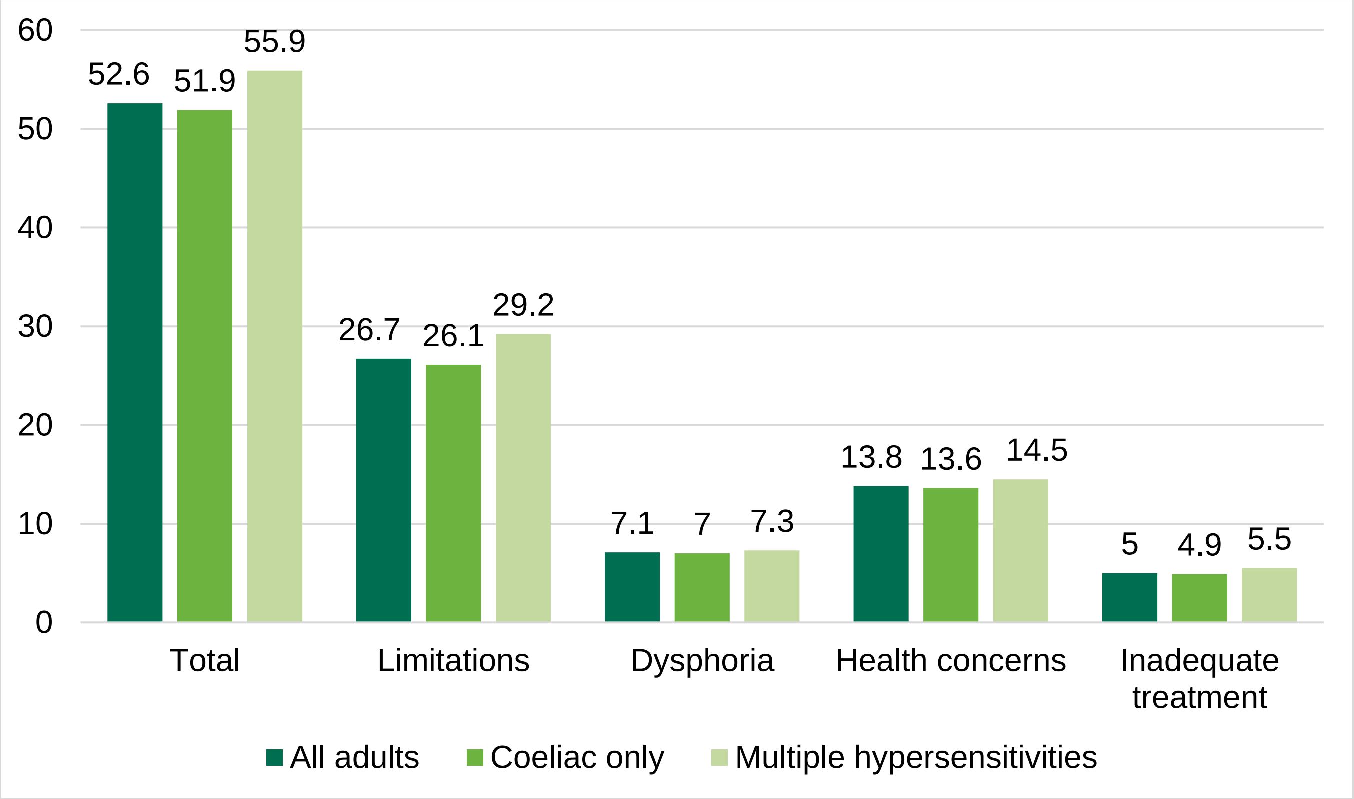
QoL in adults reporting coeliac disease

For the CDQoL scale, subscales comprise of: Limitations, relating to social and dietary limitations of having coeliac disease; Dysphoria, related to negative feelings of having coeliac disease; Health Concerns, concerns about the wider impact having coeliac disease will have on health; and Inadequate treatment, feelings that there are not enough treatment options for the disease. A total of 387 adults reporting only coeliac disease completed the CDQoL, with total scores from 20 (least impact) to 100 (maximal impact).

For adults completing the CDQoL, total scores reflected ‘moderate’ impairment on quality of life (mean = 52.6 out of 100, SD = 17.7). Scores on the subscales were a lot more varied as these subscales had a different range by which they were scored, (e.g. Limitations subscale was scored 9 – 45; Dysphoria was scored 4 – 20). However, adults scored around the mean for each of these scales (means = 26.2 for Limitations subscale, scored from 9 (least impairment) – 45 (most impairment); 7.0 for Dysphoria scale scored from 4 (least) -20 (most), 13.6 for Health concerns scored 5 (least) – 25 (most) and 4.9 for Inadequate treatment scale scored from 2 (least impairment) -10 (most impairment)), meaning impairment was ‘moderate’ for those with coeliac disease for all aspects of quality of life.

For those reporting multiple hypersensitivities, 79 completed the CDQoL. Again, these individuals scored within the mean range (40-60), however scores were slightly higher compared to those with just coeliac disease, indicating a slightly higher impact on quality of life for adults with coeliac disease as part of multiple hypersensitivities. See Figure 25 for means.

Figure 25: Mean CDQoL scores for all adults, adults with coeliac disease only and adults with multiple hypersensitivities



Base: Adults responding to CDQoL (465); Coeliac disease only group (387); Those with food intolerance as part of multiple hypersensitivities (79)

Significant factors related to impairment to quality of life in adults reporting coeliac disease included the reported severity of participant's reaction which was significantly positively associated with impairment to quality of life (r = .19; *p* <.001). Quality of life was also significantly more impaired in those who had previously had to call an ambulance because of a reaction to food (mean=61.67 SD=21.25) compared to those who had not (mean=52.23 SD=17.51; t(437)=2.04, p<0.05).

Other factors related to eating out were also significantly correlated with quality of life in adults with coeliac disease. Whilst frequency of eating out (r = -.19, *p*<.001) was significantly negatively correlated with impairment to quality of life, how often they checked information before choosing where to eat out (r = .12, p = .02) was significantly positively correlated to impairment of quality of life. However, how comfortable participants were in asking for information (r = -.23, *p*<.001) and how confident they were in the written information (r = -.12, *p* = .02) and verbal information (r = -.14, *p* = .004) provided was significantly negatively correlated with impairment to quality of life.

A regression model was run to see which of the variables described above might predict level of quality of life. All the variables above (n=7 predictors) which had a significant association with quality of life were included in the model. The overall model was significant (p<0.001) and 17% of the variance in quality of life was explained. Greater self-reported severity significantly predicted poorer QoL for coeliac respondents (standardised beta 0.15). Feeling more comfortable in asking staff for information about food when eating out predicted better QoL (standardised beta 0.32), and this was the strongest predictor of QoL. None of the other predictors were significant (standardised betas ranged from -.04 to 0.14 and confidence intervals for each predictor crossed zero).

Differences in Quality of Life by hypersensitivity

Where possible, comparisons in quality of life scores were made for clinical vs self-diagnosed adults, gender of those reporting hypersensitivities, number of foods reported and severity of reaction. Comparisons for different ethnic groups could not be made as there were not enough adults from each ethnic group to make meaningful comparisons. Furthermore, for some groups, caution should be taken with interpreting some results, as some groups were extremely small. Where more than two groups are compared, a Bonferroni correction has been applied to the significance level of 0.05 (/3 in all cases), thus a new level of .016 was used for more than two comparisons.

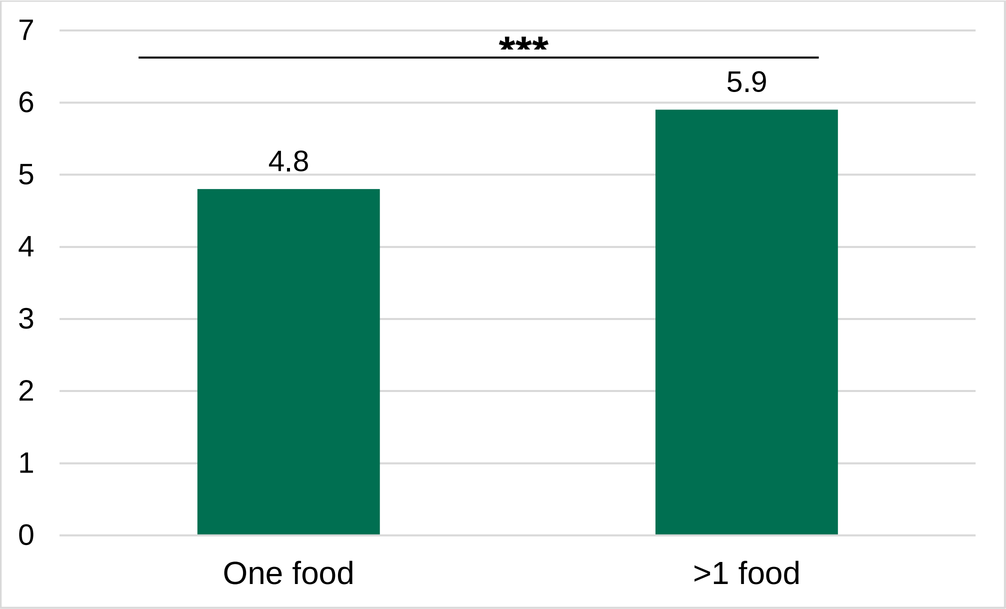
Food allergy only

Of the food allergy only group, 134 adults completed the FAQLQ. Subsample sizes were not sufficient for comparisons to be made by gender (males 27, females 107) or clinical diagnosis (103 clinically diagnosed, 27 self-diagnosed).

Number of foods

To be able to assess meaningful differences by number of foods reported by participants, respondents were recoded into those who reported just one food (n = 94) and those reporting two or three foods (n = 40). There was a significant difference between those reporting adverse reactions to only one food, and those reporting reactions to more than one food, $F(1) = 14.7$, $p < .001$, $\eta p^2 = .10$. The means indicated that those reporting more than one food (mean = 5.9, SD 1.1) had higher impairment to their quality of life, than those reporting just one food (mean = 4.8, SD = 1.5; Figure 26).

Figure 26: Mean quality of life scores across numbers of foods for allergy group

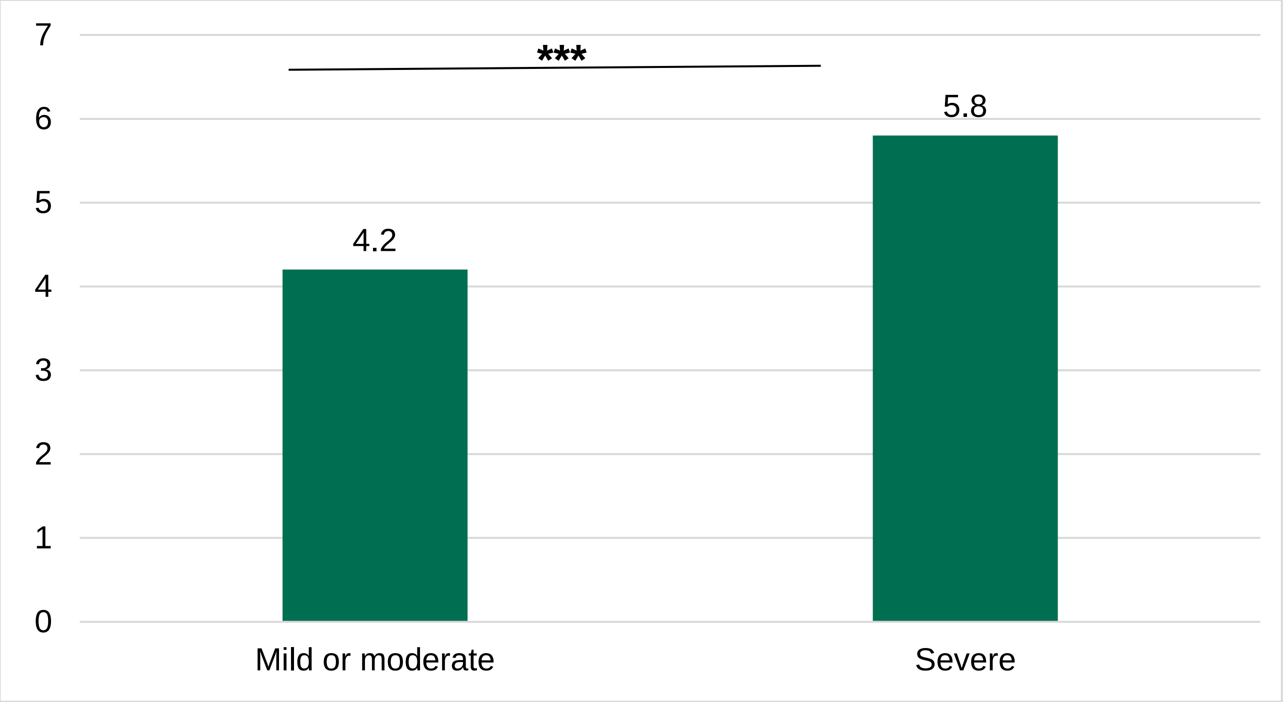


Base: Adults with allergy reporting number of foods (134): One food (94); Two or three foods (40); line with *** indicates significance; *** $p < .001$

Severity

As the numbers of those experiencing a mild reaction was too small, categories were also recoded for severity, to make meaningful comparison between those with a mild or moderate reaction (n = 59) and those with a severe reaction (n = 75). There were significant differences in impairment to quality of life by the severity of reaction for those with food allergy, $F(1) = 52.1$, $p < .001$, $\eta p^2 = .28$. Those reporting a mild or moderate reaction to their first food (mean = 4.2, SD = 1.6) reported significantly less impairment to quality of life than those reporting a severe reaction, (mean = 5.8, SD = 1.0; Figure 27).

Figure 27: Mean quality of life scores by severity of reaction for allergy group



Base: Adults with allergy reporting severity of reaction (134): Mild or moderate (59); Severe (75); *** *p* <.001

Food intolerance only

Of the food intolerance only group, 189 adults completed the FIQLQ.

Gender

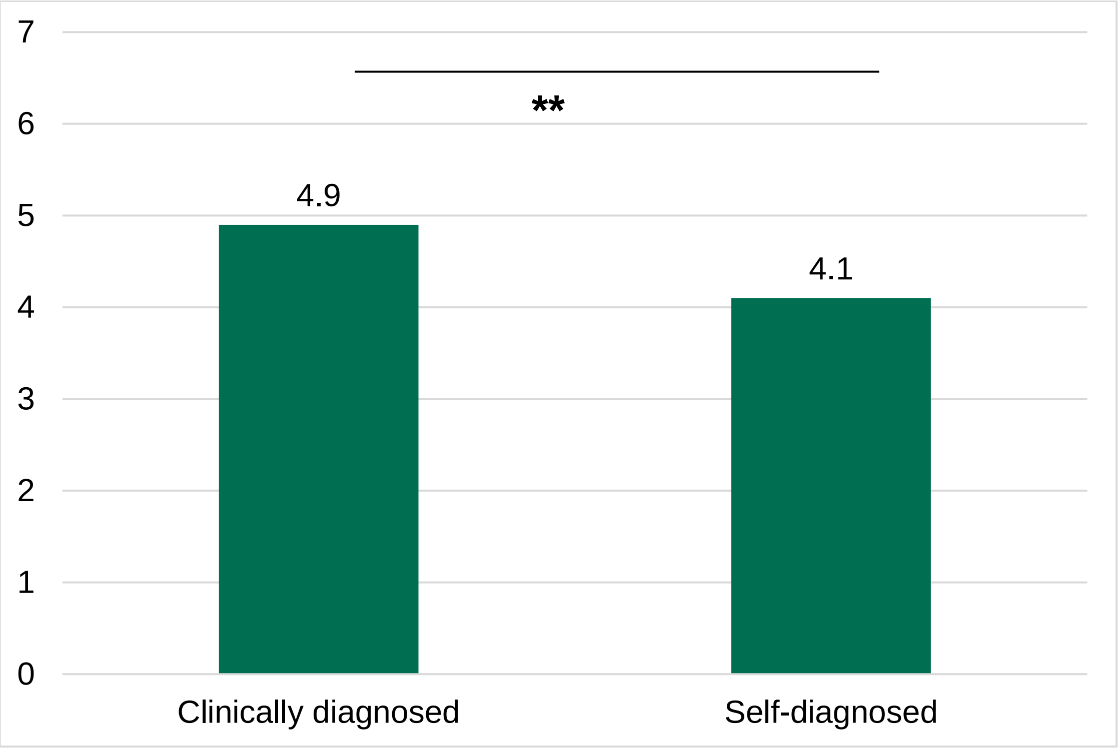
Of those with food intolerance and who completed the FIQLQ, 41 were men, 148 were women. As these groups were not equal sizes, results should be taken with caution.

Women with food intolerance (mean = 4.7, SD = 1.6) scored significantly worse on the FIQLQ, $F(1) = 13.3$, $p < .001$, $\eta p^2 = .07$, than males (mean = 3.6, SD = 1.6), indicating that women with intolerance had more impairment to their quality of life from food intolerance than men with food intolerance.

Clinical diagnosis

Of the adults reporting food intolerance, the quality of life of those with a clinical diagnosis (mean = 4.9, SD = 1.5) was significantly more impaired than those who reported being self-diagnosed (mean = 4.1, SD = 1.7), $F(1) = 12.7$, $p = .001$, $\eta p^2 = .06$ (Figure 28).

Figure 28: Mean quality of life scores by diagnosis for food intolerance group



Base: Adults with intolerance reporting diagnosis type (180): Clinically diagnosed (78); Self-diagnosed (102); ** *p* <.01

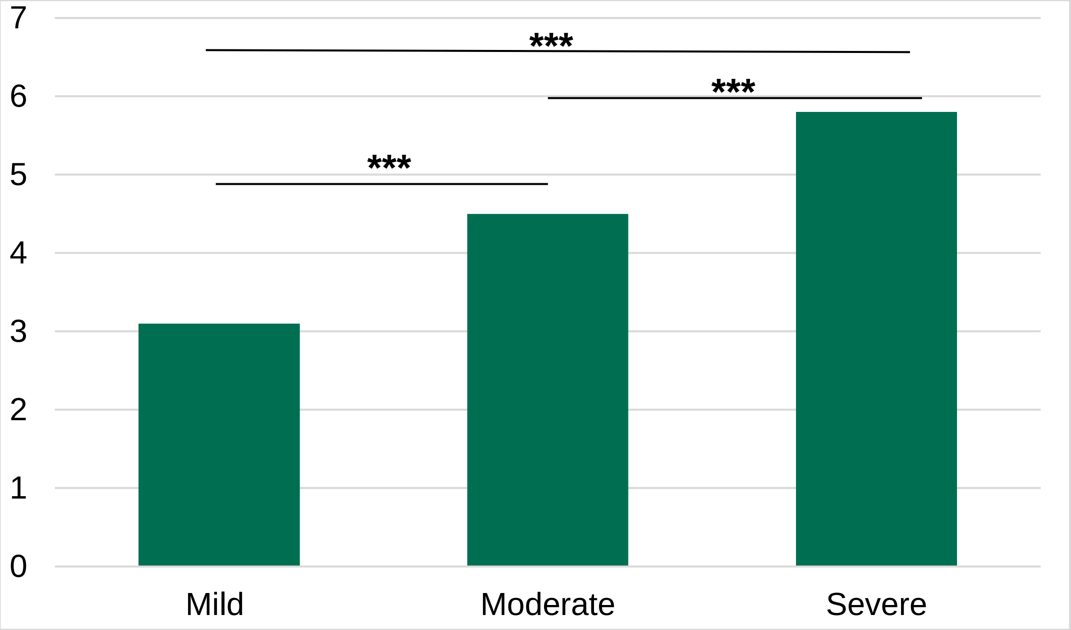
Number of foods

There were no significant differences in quality of life for those reporting one (n = 150, mean = 4.4, SD = 1.7), or more than one food (n = 39, mean = 4.7, SD = 1.7), *F*(1) = 1.0, *p* = .31, ηp^2 = .01.

Severity

There were significant differences in QoL according to severity of reaction to the first food amongst food intolerant participants, *F*(2) = 46.4, *p* <.001, ηp^2 = .31. Those with self-reported mild reactions had significantly better QoL (n = 50; mean = 3.1, SD = 1.2) than those with moderate reactions (n = 97; mean = 4.5, SD= 1.5), *t*(145) = - 5.4, *p* <.001. Those with mild reactions also had significantly better QoL than those with severe reactions (n = 42; mean = 5.8, SD = 1.2), *t*(90) = -10.5, *p* <.001 and those with moderate reactions had significantly better QoL than those with severe reactions, *t*(101.4) = -5.3, *p* <.001 (Figure 29).

Figure 29: Mean quality of life scores by severity of reaction, in food intolerant adults



Base: Adults with food intolerance reporting severity of reaction (189): Mild (50); Moderate (97); Severe (42); *** *p* <.001

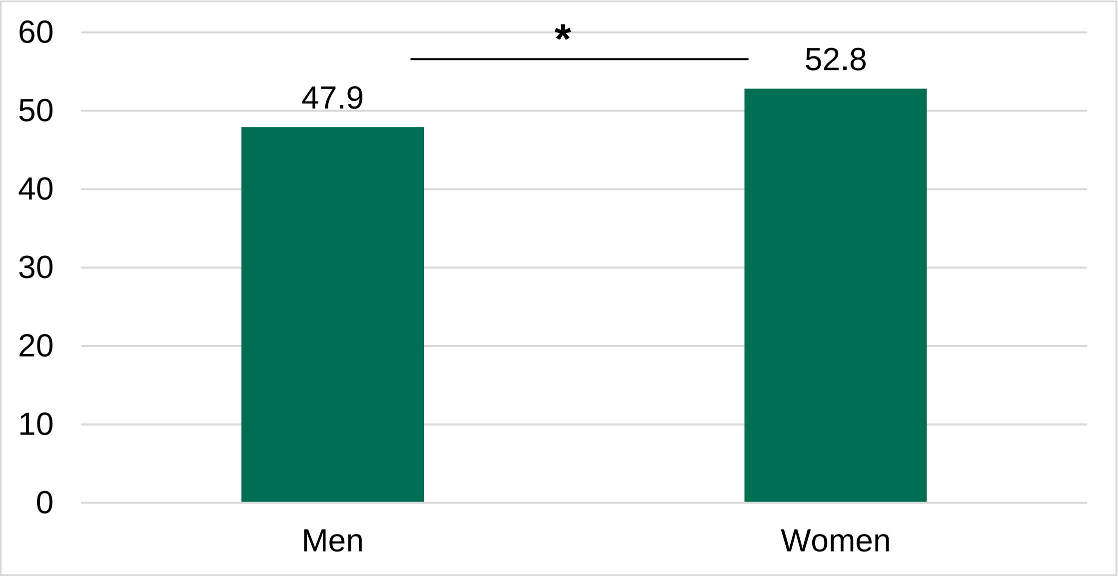
Coeliac disease only

For those in the coeliac group, 367 completed the CDQoL. It was not possible to make comparisons for diagnosis or by number of foods reported as the subsample sizes were too small.

Gender

For gender, the number of men was 70 and the number of women was 296, 1 person classed themselves as ‘Other’, however as no significant differences would be detected this person was excluded from this analysis (gender only). There was a significant difference in QoL between genders, $F(1) = 4.5$, $p = .03$, $\eta p^2 = .01$, with women (mean = 52.8, SD = 17.7) reporting significantly more impairment to quality of life compared to men (mean = 47.9, SD = 17.9; Figure 30).

Figure 30: Mean quality of life scores between genders for adults with coeliac disease

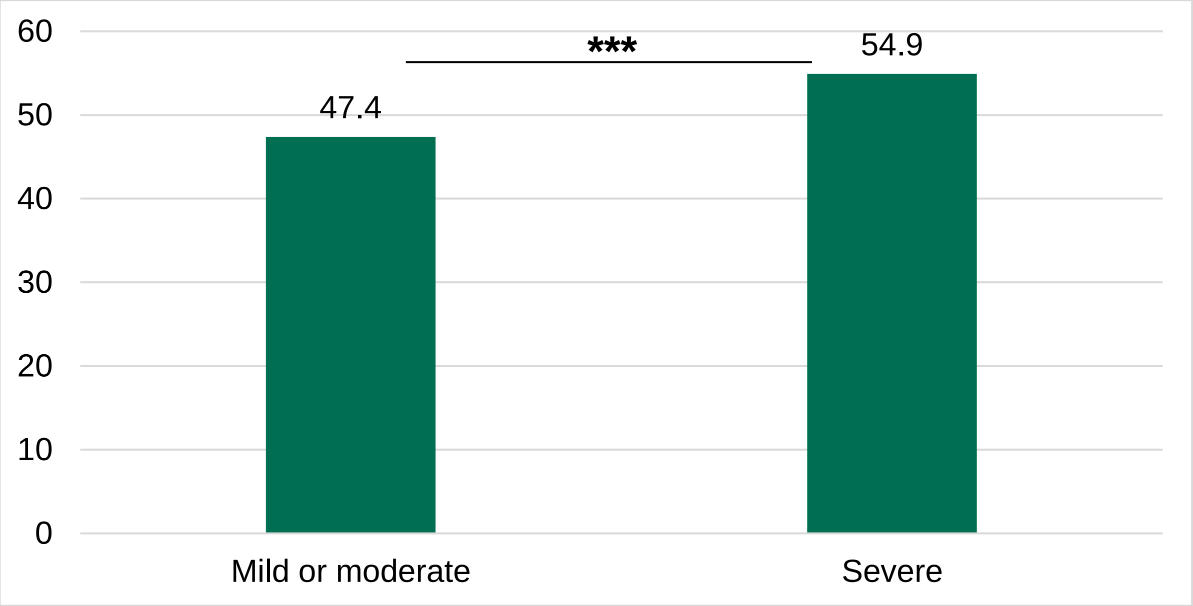


Base: Adults with coeliac disease reporting gender (366): Men (70); Women (296); * *p* <.05

Severity

Numbers were recoded to account for the small numbers of those experiencing a mild reaction (n = 23), and so comparisons were made for those experiencing a mild or moderate reaction (n = 146) and those experiencing a severe reaction (n = 221). There were significant differences in impairment on quality of life according to severity, $F(1) = 15.9$, $p < .001$, $\eta p^2 = .04$. Those reporting severe reactions (mean = 54.9, SD = 18.2) had significantly more impaired quality of life than those with a mild or moderate reaction (mean = 47.4, SD = 16.1; Figure 31).

Figure 31: Mean quality of life scores by severity of reactions for adults with coeliac disease



Base: Adults with coeliac disease reporting severity of reaction (367): Mild or moderate (146); Severe (221); *** $p < .001$

Multiple hypersensitivities

For those with multiple hypersensitivities, 32 completed the FAQLQ, 18 completed the FIQLQ and 75 completed the CDQoL. Comparisons for those with multiple hypersensitivities could not be made as sample sizes were too small to allow for accurate comparisons.

Generic quality of life

All adults completed the EQ-5D-5L which measures generic quality of life. On the visual analogue scale (0-100 with 0= death and 100= full health) quality of life scores are very similar for coeliac disease (n=384, mean = 75.97, SD = 17.43) and food allergy (n=149, mean = 75.19, SD = 20.28) with the scores for adults with a food intolerance noticeably lower (n=199, mean = 70.76, SD = 20.96). This pattern across FHs was similar for the EQ-5D overall mean score (mean coeliac = 0.82; allergy = 0.80; intolerance = 0.74).

Distributions of scores on the EQ-5D-5L sub-domains were examined against known values for the UK population. Pearson's chi-squared tests indicate that the distributions of scores were different at the 1% level for Mobility (χ^2_4= 18.75, Pr = 0.001), Usual

Activities (χ_4^2 = 13.74, Pr = 0.008), Pain (χ_4^2= 48.3, Pr = 0.000) and Anxiety (χ_4^2 = 171.17, Pr = 0.000). There was no difference on the dimension of Selfcare (χ_4^2 = 5.87, Pr = 0.209). Inspection of the data suggest that the adults with FH have higher scores for mobility and Usual Activities but significantly lower scores on the Pain and Anxiety dimensions.

These differences appear greater for younger age groups. Differences in the distributions of Pain and Anxiety scores between adults in this study and the UK population were analysed in the oldest (65+ years) and youngest (under 35 years) age groups. For the Anxiety scores, differences between adults in this study and UK population were evident in both the youngest (χ_4^2= 100.16, Pr = 0.000) and the oldest groups (χ_4^2= 9.9, Pr = 0.041), although the scale of the difference was smaller in the older group. For the Pain scores, the difference between adults in this study and UK population was evident in the under 35s (χ_4^2= 12.94, Pr = 0.012) and was absent in those aged 65 and above (χ_4^2= 6.4, Pr = 0.174); there was no difference from the UK population in the distribution of Pain scores among the oldest adults in this study.

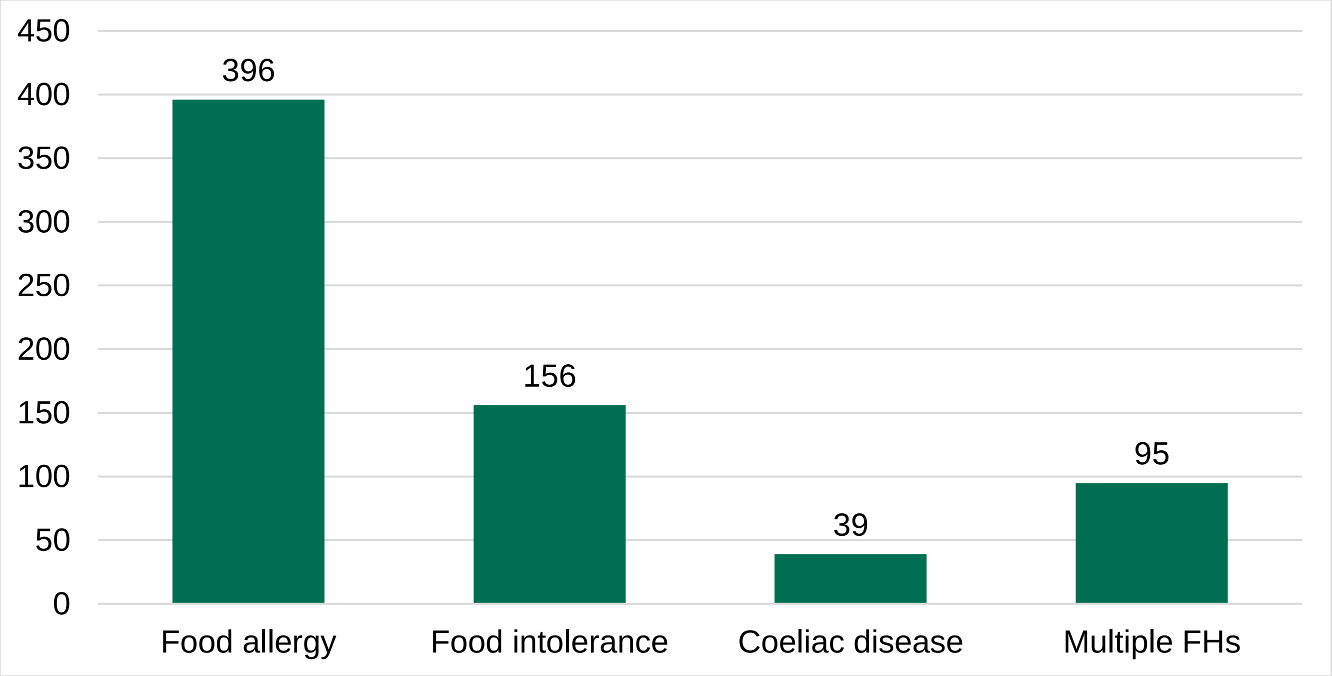
Part 2 - Parents of children with FH

Parents/caregivers were surveyed to capture their experiences of managing the food hypersensitivities of their children, as well as how they perceive their child's quality of life is impacted by their child's food hypersensitivity. A total of 793 parents of children (under 18 years) with FH completed the survey, which included n=107 reporting 'Other' or 'Don't know' when asked to describe these reactions to food. These participants are not reported on as a subgroup but are included in the 'all parents' figures.

Prevalence of food hypersensitivities

The majority of parents reported children who had food allergy only (n = 396; 58%) or food intolerance only (n = 156; 23%). Fewer parents reported children with coeliac disease only (n = 39; 6%) or multiple hypersensitivities (e.g. parents of one child with multiple food hypersensitivities or multiple children with different food hypersensitivities; n = 96; 14%) (Figure 32).

Figure 32: Prevalence of parents with children with each food hypersensitivity within the sample



Base: All parents reporting children with a hypersensitivity, excluding 'other' and 'don't know' (686).

Profile of parent participants

Parents' key characteristics

From a total of 793 parent participants, 69% (n = 538) of those reporting a child with a food hypersensitivity were female (31%; n = 238 were male; 1 reported 'Other'; 0.1%, and 2 'Prefer not to say'; 0.3%). The mean age of all parent participants was 38.3 years old (SD = 8.1), with a range from 18 to 72 years old. The majority of parents were of White British ethnicity (n = 676; 86%. See Annex B Table 43).

Parents of children with coeliac disease (mean age: 40.6; SD = 8.1) and food allergy (mean age: 39.2 years old; SD = 7.6) were significantly older than those reporting children with a food intolerance (mean age: 36.2 years old; SD = 8.6; all *p*s <.008). There was no significant difference in age for parents of children with multiple food hypersensitivities (mean age: 38.7; SD = 7.9).

As with the whole sample, across all hypersensitivities, the majority of parents were of White British ethnicity (see Annex B Table 43 for a full breakdown). The most common region for all parents living with a child with a food hypersensitivity was London (n = 140, 18%). This was also true across the hypersensitivities, except for parents in the food allergy group, who most commonly lived in the South East of England (n = 75; 19%; see Annex B Table 44 for a full breakdown).

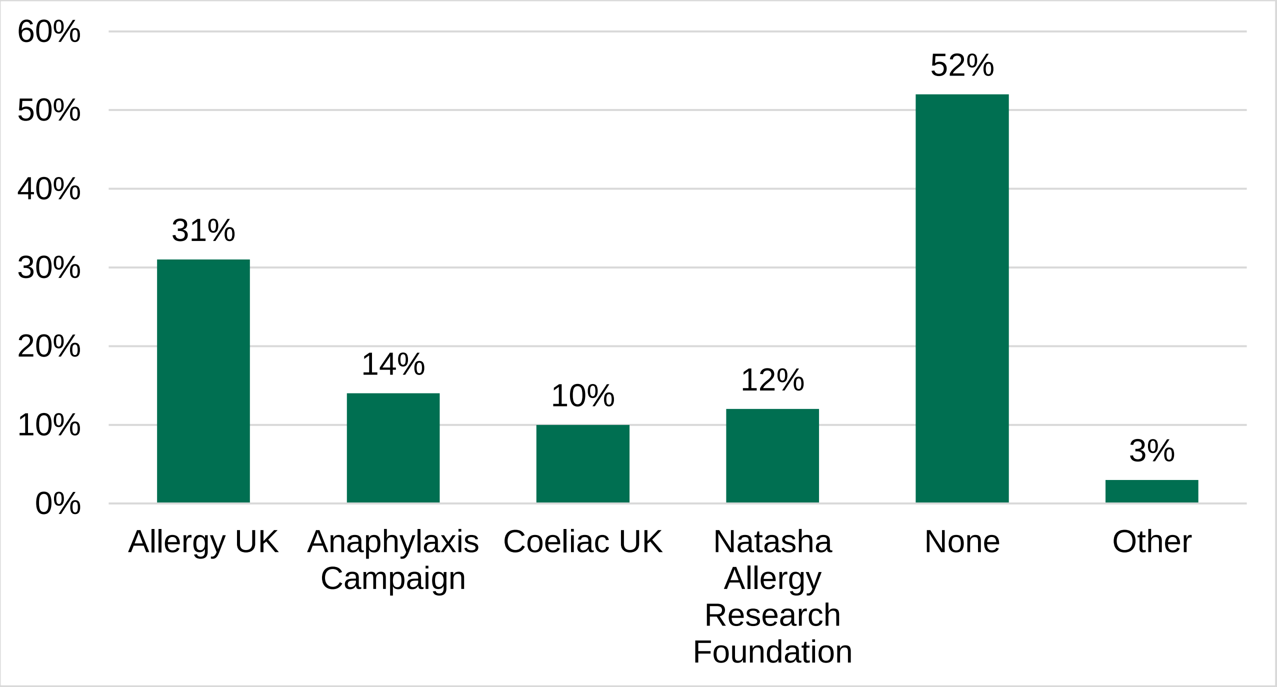
Fifty seven percent (n = 444) of the sample were in full-time employment, 23% (n = 176) were in part-time employment but 14% (n = 112) were not working (for a full breakdown see Annex B Table 45). Across the hypersensitivities, children with food intolerance had the highest percentage of parents in full-time employment (66%, n = 101), whilst children with food allergy had the highest percentage of parent respondents who were not working (17%; n = 67). See Annex Table 47.

Parent participants were asked how many children between 0-17 years they had in their household, as well as how many with food hypersensitivities. Parents most commonly reported having two children in total living at home (n = 341; 45%) aged 0-17 years, and most commonly reported only one child (n = 502; 66%) living at home with a food hypersensitivity.

Patient organisation membership

Parents were asked to report on whether they were a member of any patient organisations because of their children's reactions to food. The majority of parents were not members of any patient organisation (n = 409; 52%; see Figure 33). The most commonly reported organisation that parents belonged to was Allergy UK (31%; n =242), followed by The Anaphylaxis Campaign (n = 110; 14%). Of those reporting 'Other', this included support groups on social media, such as Facebook support groups (e.g. gluten free/nut free/ allergy support groups); Facebook pages and websites of the patient organisations already mentioned (e.g. Allergy UK, Coeliac UK; Cow's Milk Protein Allergy support).

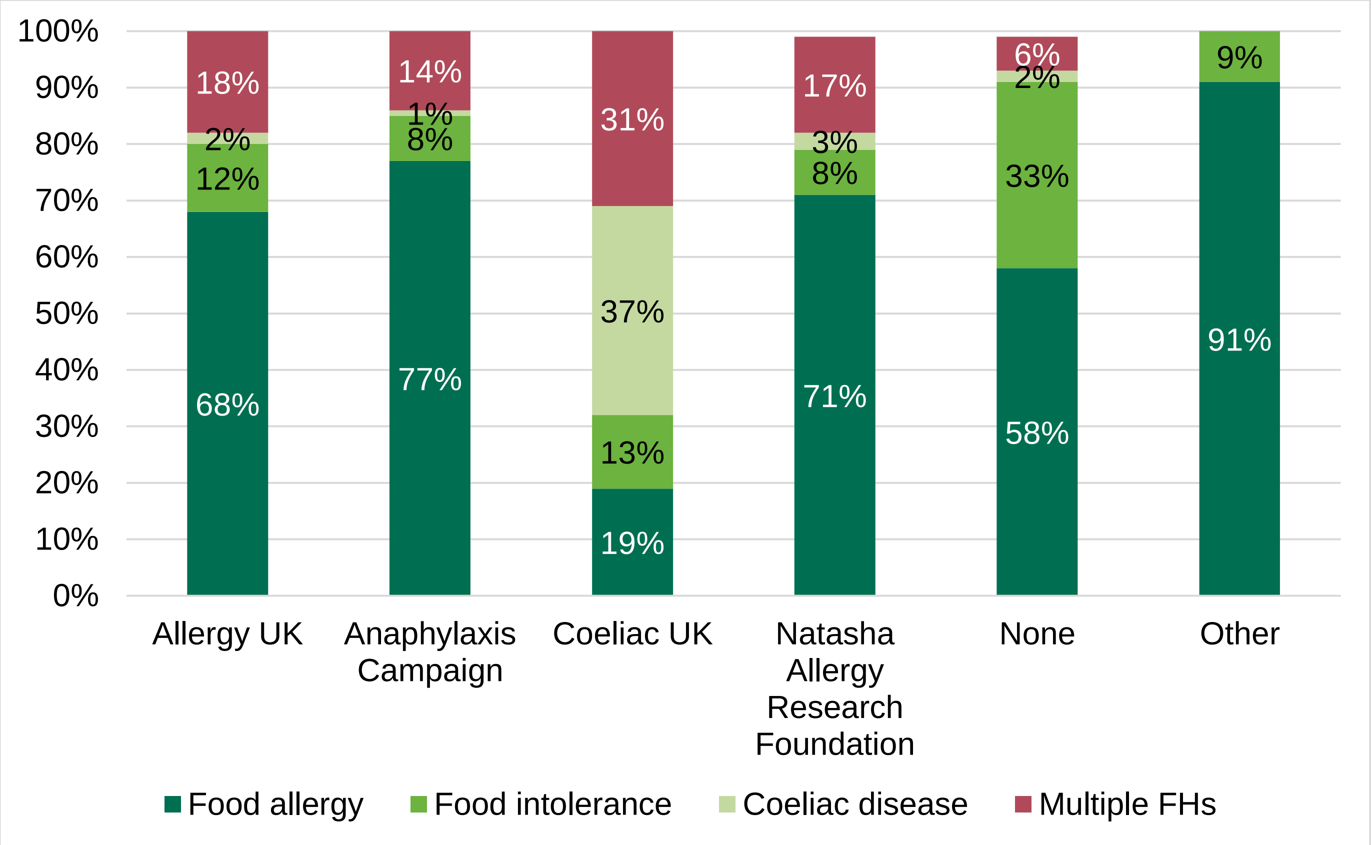
Figure 33: Membership of patient organisation groups



Base: All parents (793)

Membership of a patient organisation differed according to hypersensitivity. For parents of children with food allergy the most subscribed to organisation was Allergy UK (n = 156; 40%); for parents of children with coeliac disease, the most subscribed to was Coeliac UK (n = 28; 72%); and for parents of children with multiple hypersensitivities the most subscribed to was Allergy UK (n = 41; 43%) (Figure 34).

Figure 34: Membership of patient organisations by hypersensitivity



Base: All parents reporting children with a hypersensitivity (686): Food allergy (396); Food intolerance (156); Coeliac disease (39); Multiple FHs (95)

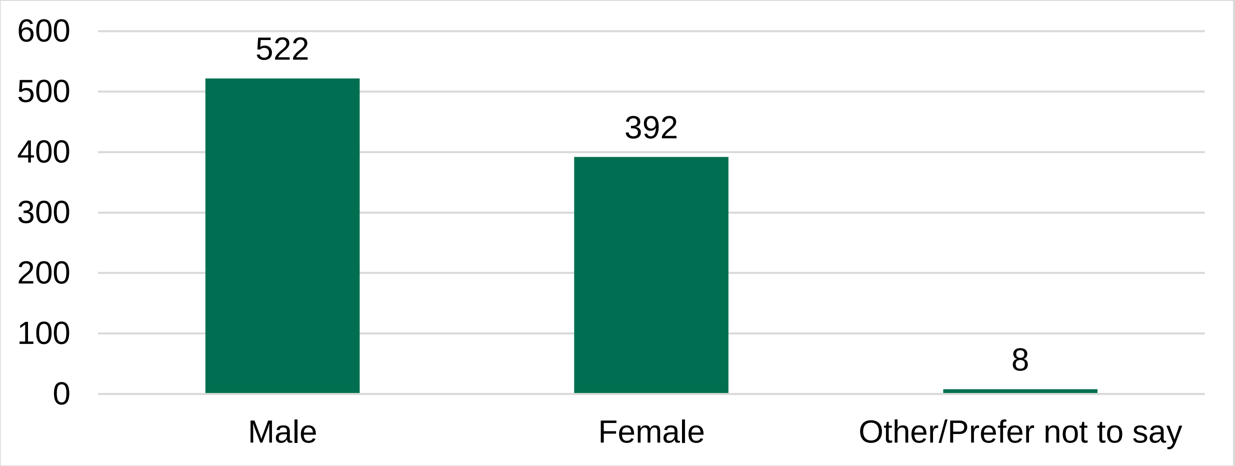
A majority of parents of children with food intolerance did not subscribe to any organisations (n = 118; 69%). A large proportion of parents of children with food allergy also reported not being a member of a support group or patient organisation (n = 108; 46%) in contrast to parents of children with coeliac disease (n = 7; 18%) and multiple hypersensitivities (n = 21; 22%; Figure 36).

Child’s key characteristics

Parents could report in more detail on up to 3 children in their household with food hypersensitivities. Within this section, characteristics across all children reported have been combined unless otherwise stated.

Of all children reported by participants (n = 932), 56% of children with a food hypersensitivity were male and 42% were female (Figure 35).

Figure 35: Gender of all children reported by parent participants



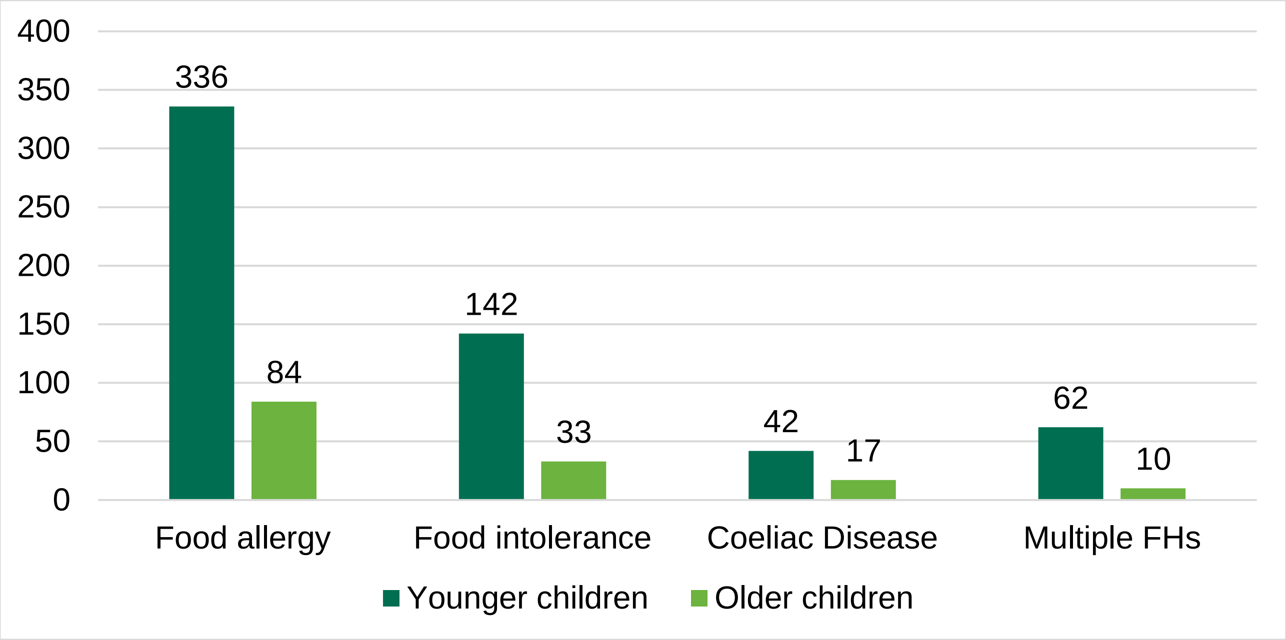
Base: All children reported by parents, for gender (922); Male (522); Female (392); Other/Prefer not to say (8)

The mean age of all children reported was 9.5 years old (average SD = 6.7). Across all children, parents reported on 675 younger children (0-12 years old) and 168 older children (13-18 years old). The majority of parent participants reported that their children were of White British ethnicity (n = 752; 81%. See Annex B Table 46).

Children with coeliac disease were typically reported by their parents to be older (mean age across all 3 children: 9.7 years old; SD = 4.6) than those reporting a food intolerance (mean age: 7.3 years old; SD = 4.6), multiple hypersensitivities (mean age: 8.7; SD = 6.5) or food allergy (mean age: 9.0; SD = 4.8) (Figure 36).

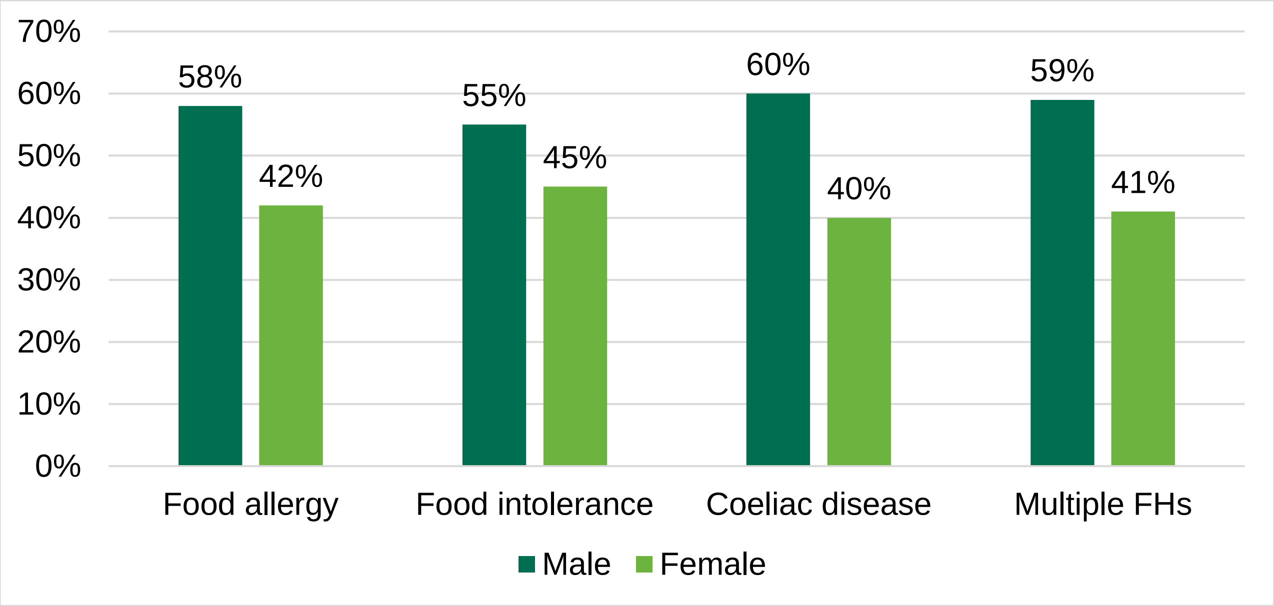
Parents also reported more male children across each of the hypersensitivities than females, although this difference was biggest amongst parents reporting children with food allergy (58% males; see Figure 37).

Figure 36: Numbers of younger and older children reported by parents, by hypersensitivity



Base: All children reported by parents in the hypersensitive groups (726): Younger children (0-12-year olds; 582); Older children (13-17-year olds;144)

Figure 37: Gender of children reported by parents, by hypersensitivity



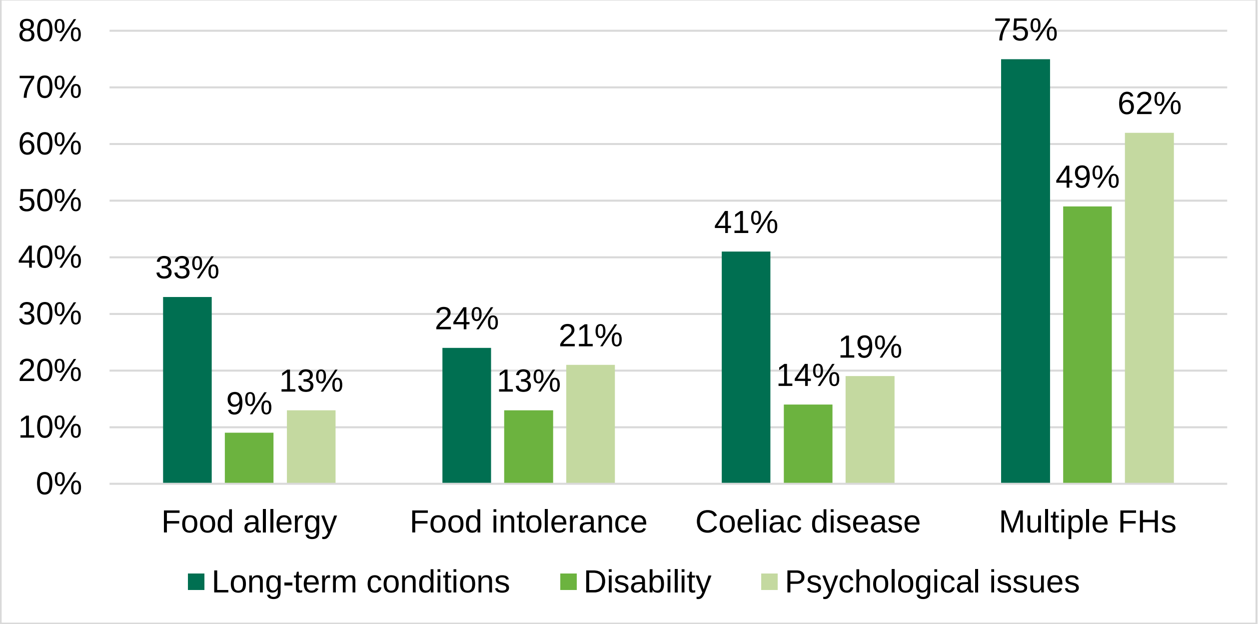
Base: All children reported by parents in the hypersensitive groups (794): Food allergy (433); Food intolerance (191); Coeliac disease (72); Multiple FHs (98)

As with the overall sample, for ethnicity, across the hypersensitivities, the majority of children were of White British ethnicity (81%; see Annex Table 46).

Other long-term conditions

Parents reported that 33% (n = 308) of children had another long-term condition (e.g. diabetes), 14% (n = 130) had a disability and 19% (n = 181) were receiving treatment for psychological issues such as anxiety and depression. There were also significant differences (all *ps*<.001) between parents of children with the different food hypersensitivities in terms of reporting their children having a long-term condition, disability, and psychological therapy. Parents reported that children with multiple hypersensitivities had higher percentages for all these conditions compared to the other hypersensitive groups (Figure 38).

Figure 38: Other long-term conditions by hypersensitivity



Base: All children with other conditions (588); Long-term condition (296); Disability (120); Psychological issues (172)

Excluding foods

Parents were asked if their children excluded foods from their diet for any other reasons apart from their food hypersensitivity (e.g. religious reasons, vegetarian/vegan diets, to lose weight). While parents reported that the majority of their children did not exclude foods (61%, n = 568), the most common reasons across all hypersensitivities for doing so was because of following a vegetarian, pescatarian or vegan diet (13%, n = 120; Annex B Table 47).

Reactions to food

Parents were asked to report the reactions their children experience for each child separately, up to a maximum of three children in their household. For each child, participants were asked to report all foods they experience adverse reactions to, before reporting in detail on up to three foods per child. Results for all children and foods are combined. For this reason, percentages are not presented in tables as numbers vary depending on how many children and how many foods were reported.

When asked to initially report all foods their children react to, peanuts (n = 252, 9%), milk (n = 252, 9%) and eggs (n = 234, 8%) were the most frequently reported foods, with peanuts most common for those reporting their child's reaction as food allergy (n = 205, 10%), milk for those with children with food intolerance (n = 76, 20%), cereals for children with coeliac disease (n = 52, 42%) and celery (n = 31, 11%) for children with multiple hypersensitivities. Please see Annex B Table 48 for a full breakdown of frequencies of foods reported by hypersensitivity.

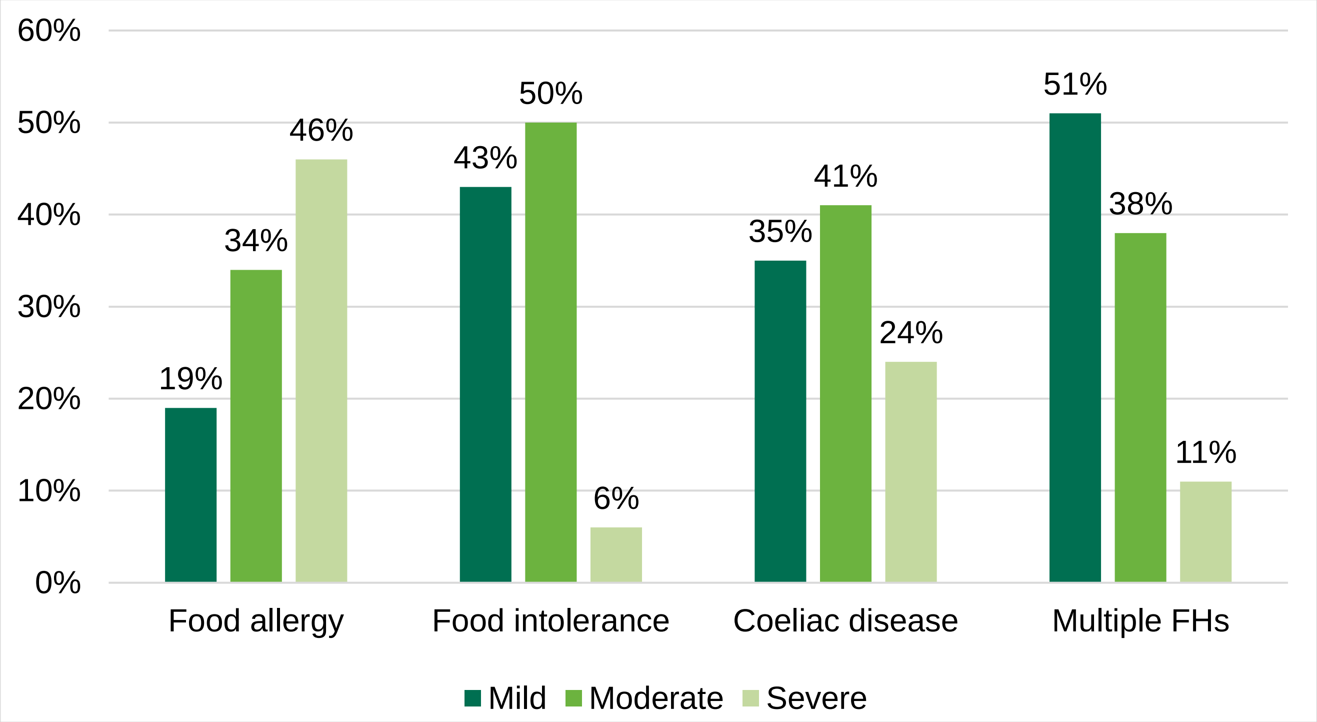
Foods with adverse reactions

When asked to report on three foods in detail, parents reported a total of 1,399 foods that their children reacted to. Parents reported their child's reaction as food allergy (n = 706; 50%), food intolerance (n = 352; 25%), coeliac disease (n = 166; 12%), other or don't know (n = 175; 13% not focussed on exclusively in this report).

The most common foods to be reported in detail for all children with a hypersensitivity were tree nuts (n = 256; 18%), milk (n = 204; 15%), peanuts (n = 169; 12%) and eggs (n = 167; 12%). The majority of those reporting a reaction to peanuts (81%; n = 137) and egg (61%; n = 102) were those with food allergy. Milk was also commonly reported by parents of children with food allergy (49%; n =100) and for parents of children with food intolerance (26%; n = 66). Other foods included cheese, bread, onions/garlic, condiments, and tea. For a full breakdown of foods by hypersensitivity please see Annex B Table 49.

Across all three children and all foods, parents rated their child's condition as mild (total number of reactions reported by parents (n = 479), moderate (n = 518) or severe (n = 369). Parents of children with food allergy were most likely to report their reaction as severe (46%), whereas parents of children with food intolerance (50%) or coeliac disease (41%) were most likely to report their reaction as moderate. Parents of children with multiple food hypersensitivities were most likely to report their children had a mild reaction (51%; Figure 39).

Figure 39: Severity of reaction to foods, by hypersensitivity



Base: All reactions reported on by parents for children in hypersensitivity groups (1,253): Food allergy (637); Food intolerance (242); Coeliac disease (102); Multiple FHs (272)

Symptoms

Parent participants reported that their children experienced a wide range of symptoms, which were grouped into breathing (e.g. coughing/sneezing, wheezing, breathless), skin (rash, itchy, dry skin, swelling of face, eczema), gastrointestinal (e.g. abdominal pain, sickness/vomiting/diarrhoea, loss of weight), mouth/throat/ear symptoms (e.g. tingling/itching, tight throat, tongue swelling) and other reactions (e.g. anaphylaxis, incontinence, collapse or seizure). Parents could choose as many symptoms as they felt applied to their child’s reaction, so numbers reflect how many times/occurrences each symptom type was chosen.

The majority of symptoms experienced across all foods were breathing symptoms (27%, n = 2110), of which 61% (n = 1283) were reactions reported by parents of children with food allergy. However, for children with food intolerance (38%, n = 433) and coeliac disease (43%, n = 236) the most common symptoms experienced were gastrointestinal. For parents of children with multiple hypersensitivities, the most common symptom type experienced was breathing symptoms (24%, n = 346; Annex B Tables 50-52).

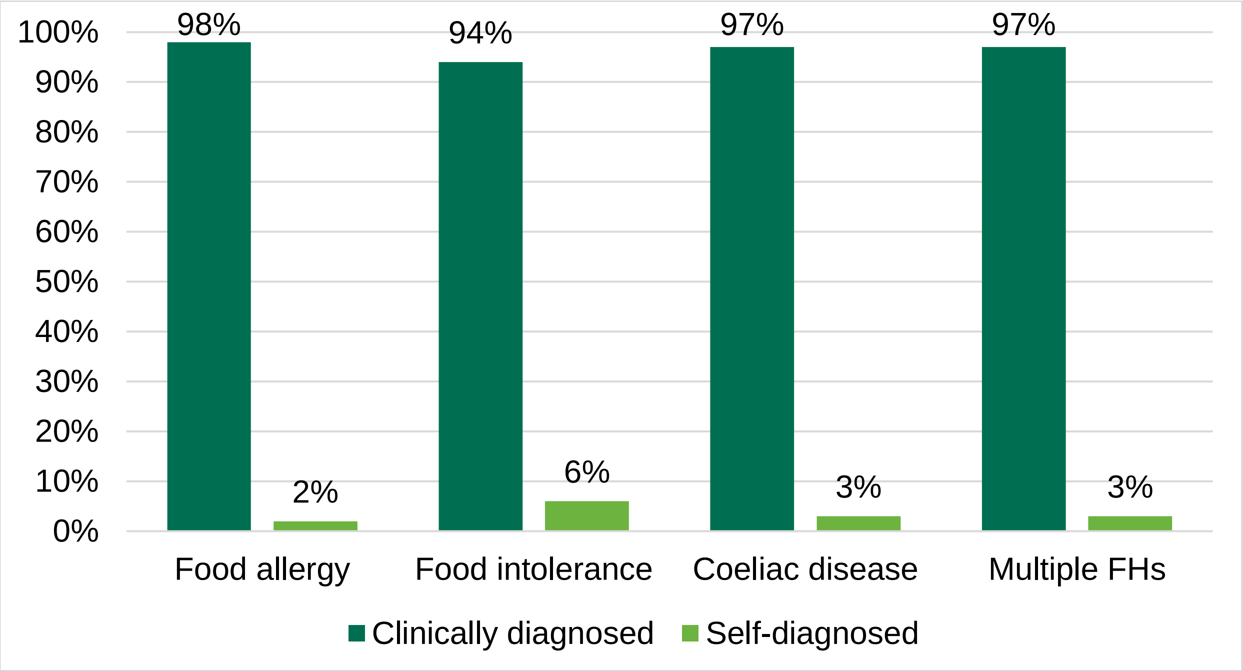
The most severe symptoms experienced to all foods were skin symptoms (25%; 1,318), of which 58% (n = 763) were reported by parents of children with food allergy. For parents of children with food intolerance (34%, n = 297), coeliac disease (42%, n = 174) and multiple hypersensitivities (24%, n = 303) the most common severe symptoms were gastrointestinal (Annex B Table 53).

Most parents reported that their child’s symptoms started within 5 minutes (33%), but the majority (78%) of these were parents of food allergic children. For parents of children with other hypersensitivities, reactions most commonly started between 5 to 30 minutes for those reporting reactions of children with food intolerance (36%) and multiple food hypersensitivities (32%), whereas this was between 30 minutes to an hour for those reporting on children with coeliac disease (35%) (Annex B Table 54).

Diagnosis

Parents were asked how their children’s reactions had been diagnosed and who by, to determine whether they had been clinically diagnosed or were self-diagnosed. For the whole sample and across all hypersensitivities, the majority reported that their child’s reaction to food was clinically diagnosed (total n = 1,224; 87% of all foods reported, Figure 40).

Figure 40: Diagnosis by hypersensitivity



Base: Diagnosis for all foods reported on in each hypersensitivity group (1169): Food allergy (597); Food intolerance (219); Coeliac disease (95); Multiple FHs (258)

Most parents reported that their children were diagnosed by a hospital doctor (n = 544; 44%), GP (n = 234, 19%), or Nurse at the hospital (n = 92; 7%) or Nurse at the GP's (n = 114; 9%). Most parents reported that children were diagnosed by either a skin prick test (n = 434; 27%) or blood test for allergy (n = 326; 20%). See Annex B Table 55 for full breakdown.

The mean age for diagnosis of their child's reaction across all foods was 5.2 years old (combined SD = 4.0).

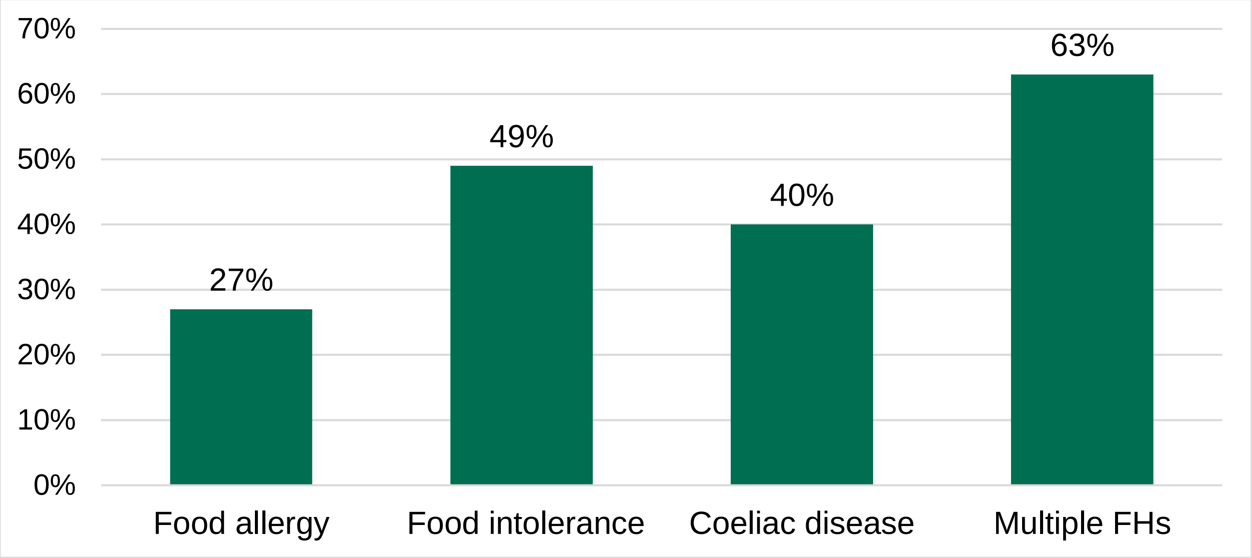
About their reaction

For the first food reported on for each child, 40% of parents (n = 466) reported that their child had been able to eat it previously and not have a reaction to it; 60% (n = 706) reported their child had not been able to eat the food without experiencing a reaction.

Parents of children with food allergy reported that these children were least able to previously consume their first food without a reaction occurring (72%; n = 400 out of 550 children with food allergy). Parents of children with multiple food hypersensitivities were most able to previously consume their first stated food without a reaction occurring (63%; n = 154 out of 244 children; Figure 45).

Although many parents reported that their children had not had a reaction to their stated food in the previous 12 months (n = 427; 33%), for parents of children with intolerance or coeliac disease, a reaction was most likely to have occurred twice in the last 12 months. For those reporting children with food allergy and multiple hypersensitivities, a reaction was most likely to have occurred just once in the last 12 months (if they had experienced a reaction; Annex B Table 56).

Figure 41: Children able to eat stated food previously, as reported by parents



Base size: All foods reported by parents according to hypersensitivity groups (1090); Food allergy (550); Food intolerance (212); Coeliac disease (84); Multiple hypersensitivities (244)

Anaphylaxis

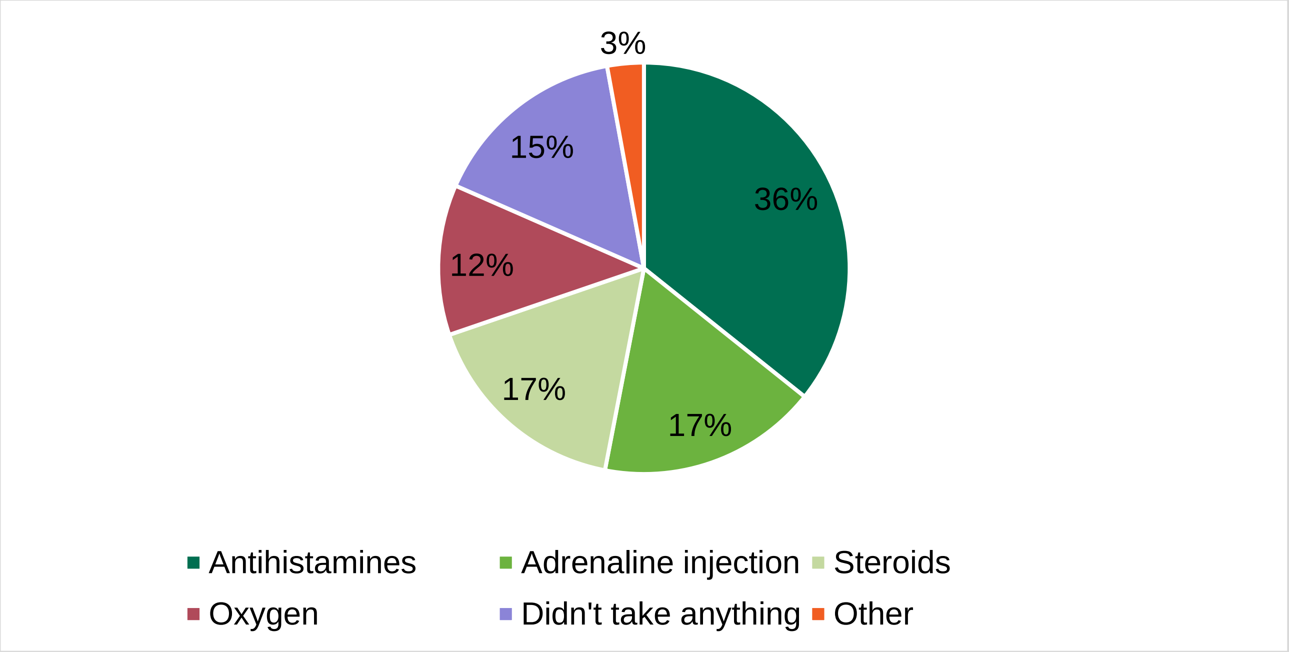
The total number of anaphylactic reactions reported by parents was 509 (39%), of which 50% (n = 254) of these reactions were experienced by children in the food allergy group, 13% (n = 67) were experienced by those with food intolerance, 4% (n = 22) with coeliac disease and 30% (n = 155) were those with multiple hypersensitivities, indicating that children with food allergy were most at risk of anaphylaxis.

Further, for 57% (n = 752) of all reactions reported, parents reported that their child had been prescribed an adrenaline auto-injector, of which 57% (n = 427) of these responses were reported by parents of children in the food allergy group, 11% (n = 80) were those in the food intolerance group, 4% (n = 31) were those with coeliac disease and 26% (n = 198) with multiple hypersensitivities.

Treatment

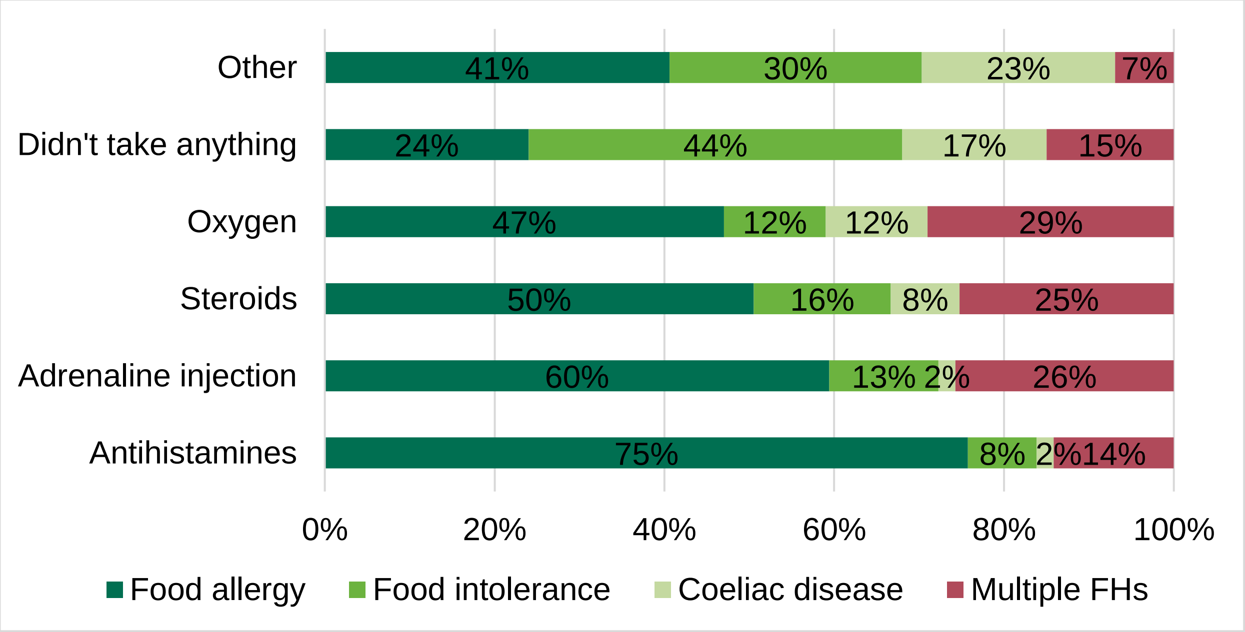
Parents were asked about the treatments their children had received for the reactions to food reported. For 36% (n = 560) of all foods and children reported on, parents reported antihistamines as the most common treatment. Treatments were most commonly reported by parents of children with food allergy (see Figures 42-43).

Figure 42: Treatments for reaction to foods



Base: All treatments for all foods reported by parents (1,544)

Figure 43: Treatments given across food hypersensitivity



Base: All treatments for foods reported on in each hypersensitive group (1,473): Food allergy (840); Food intolerance (241); Coeliac disease (103); Multiple FHs (289)

Hospital admission

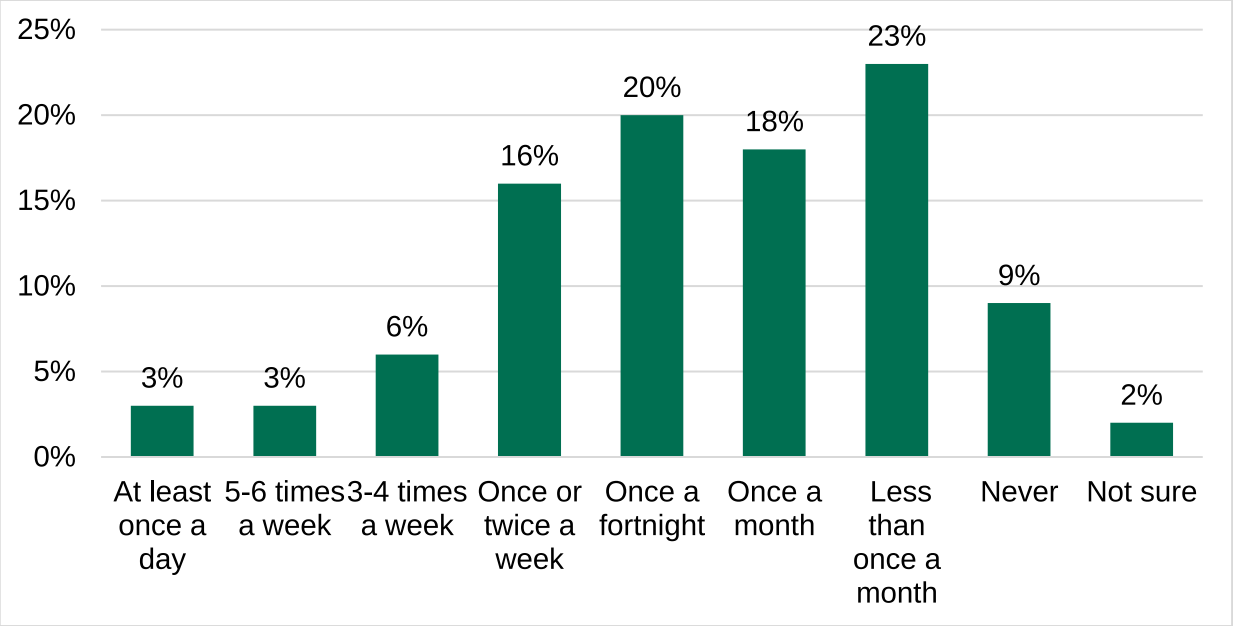
For 39% (n = 503 out of 1301) of reactions to foods, parents reported they had called an ambulance for their children, and for 44% of all reactions (n = 575 out of 1,314 who answered) parents reported that their children had been admitted to hospital. For those that had been admitted to hospital (n = 569 respondents to this question), 42% (n = 240) had been admitted once, 30% (n = 170) were admitted twice and 18% (n = 105) were admitted between 3-6 times, 6% (n = 33) were admitted between 7-10 times, 3% (n = 15) were admitted more than 10 times and 1% (n = 6) did not know. For 70% (n = 403) of those going to hospital, parents reported that their children went to hospital the first time that they reacted to the stated food. Across hypersensitivities, 46% (n = 266) of those being admitted to hospital were children with food allergy and 73% (n = 193) of these 266 went the first time they reacted.

Eating out

Parents were asked how often their households eat out or get food to take away from a restaurant or other food outlet. They were also asked how comfortable they felt with various aspects of eating out, such as asking for information from a member of staff. Participants were asked questions about their current eating out behaviour, however this was during the COVID-19 pandemic when restrictions on eating out were variable, and so responses may not reflect participants' usual behaviour.

Parent participants most commonly reported that their households eat out less than once a month (n = 154; 23%), however 66% (n = 447) eat out more frequently than this (Figure 44).

Figure 44: How often parents' households eat out or get food to take away



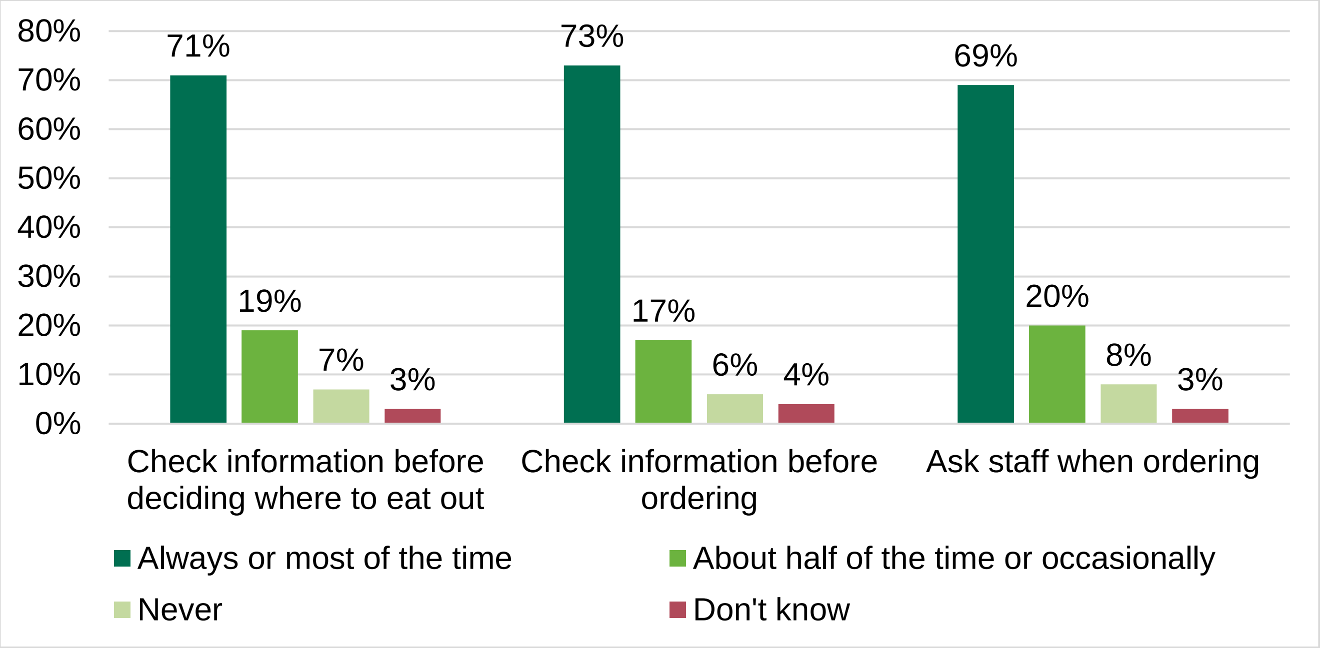
Base: All parents (680)

There were significant differences by type of food hypersensitivity in terms of how often parents reported eating out, $F(3) = 19.8$, $p < .001$, $\eta p^2 = .09$. Parents of children with multiple hypersensitivities reported eating out on average once a fortnight, which was significantly more often than those with food allergy, food intolerance and coeliac disease, who on average ate out around once a month (all $ps < .008$; see Annex B Table 57).

Checking information when eating out

Parents were asked how often they check that information is available that will allow them to identify foods that cause their children a bad or unpleasant physical reaction, before deciding where to eat out. They were also asked how often they review this information, and how often they ask a member of staff for this information. Parents reported that they almost always or most of the time check or review this information at each stage of eating out (see Figure 45).

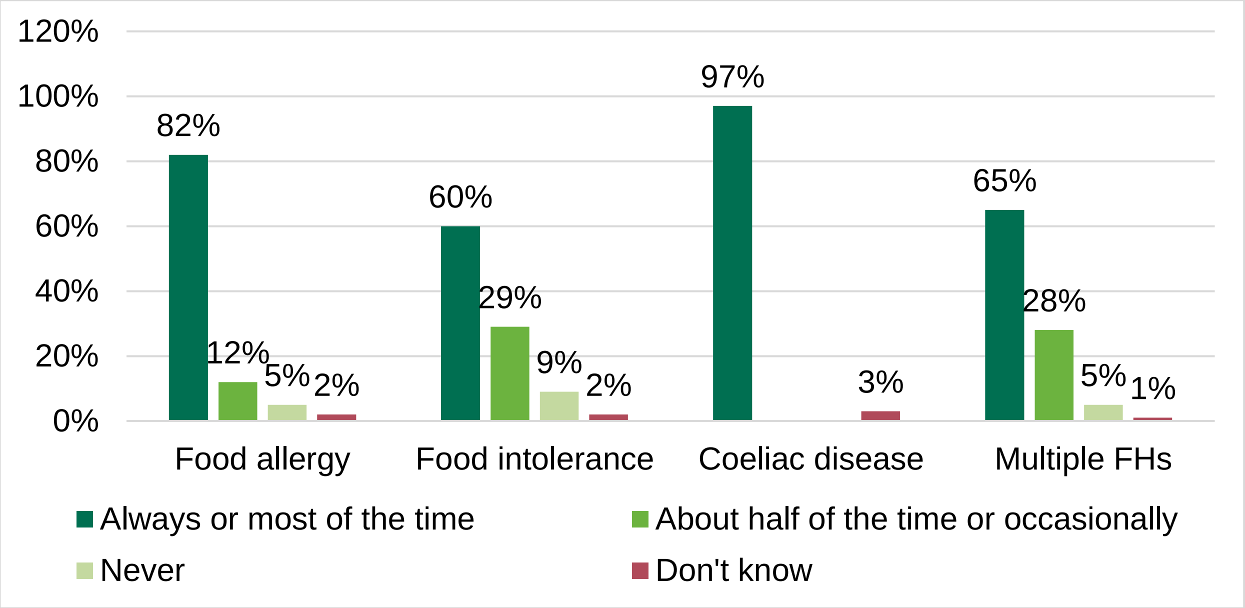
Figure 45: How often participants review information when eating out



Base: All parents: Check information before choosing where to eat out (614); Check information when ordering (604); Ask staff when ordering (612)

There were significant differences between hypersensitivity groups for how often parents reported checking and reviewing information. Participants with children with food allergy (mean = 4.3, SD = 1.1) and coeliac disease (mean = 4.9, SD = 0.3) reported they check that there is information available before deciding where to eat out significantly more often than those with children with food intolerance (mean = 3.7, SD = 1.4) or multiple hypersensitivities (mean = 3.9, SD = 1.3; all *p*s<.008), on average reporting that they always check this (Figure 46).

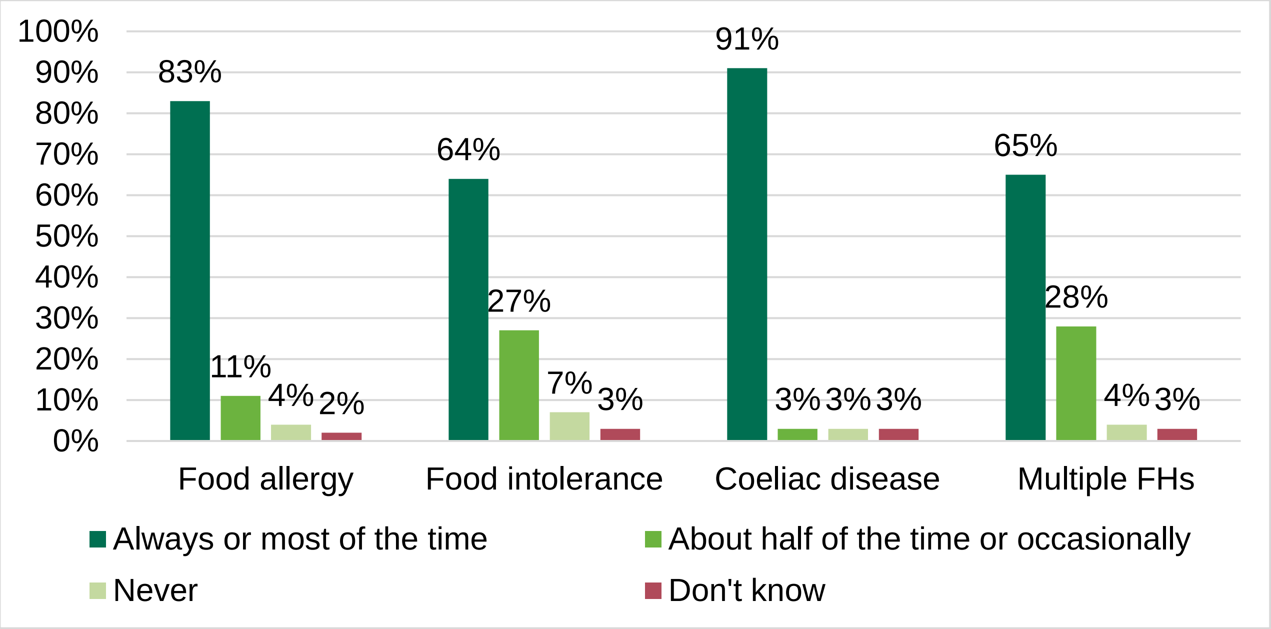
Figure 46: How often parents check information before choosing where to eat out, by hypersensitivity



Base: All parents of children with a hypersensitivity (535): Food allergy (301); Food intolerance (125); Coeliac disease (35); Multiple FHs (74)

When asked how often parents review the available information before ordering food, parents of children with food allergy (mean = 4.4, SD = 1.1) and coeliac disease (mean = 4.8, SD = 0.8) reviewed this information always or most of the time, and significantly more often than parents of children with food intolerance and multiple hypersensitivities (all *ps* <.001), who only checked either about half or most of the time (Figure 47).

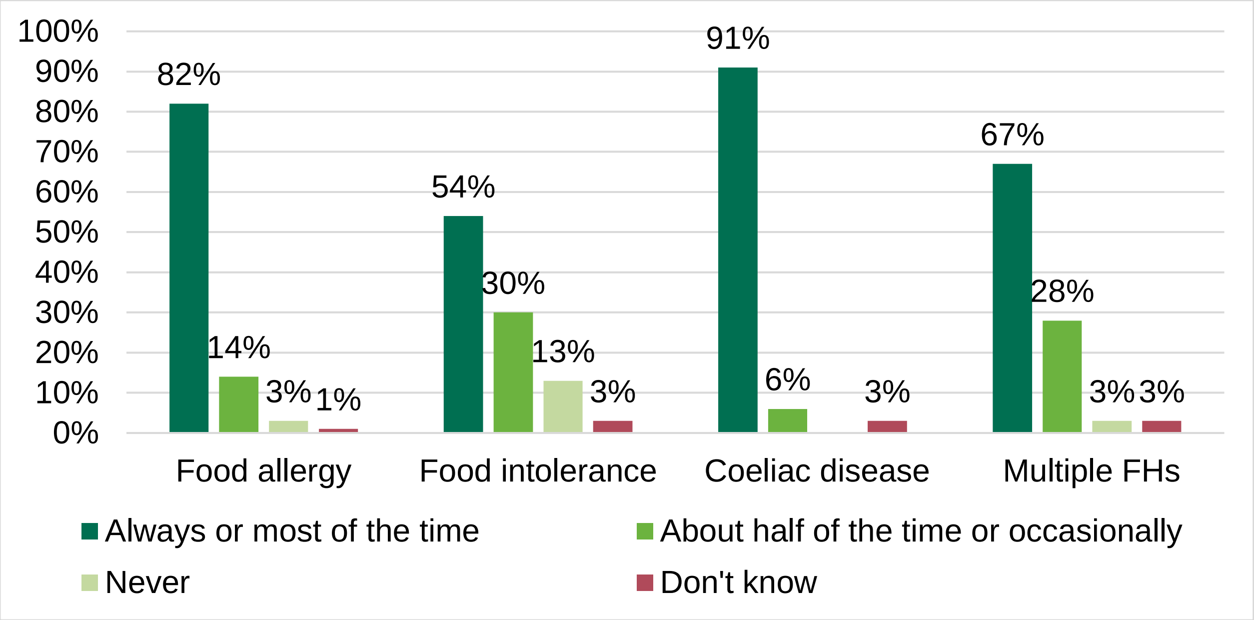
Figure 47: How often parents review any available information before ordering food, by hypersensitivity



Base: All parents of children with a hypersensitivity (528): Food allergy (298); Food intolerance (124); Coeliac disease (35); Multiple FHs (71)

Finally, parents of children with coeliac disease (mean = 4.7, SD = 0.6) on average reported asking staff for information that enables them to identify foods that cause a bad or unpleasant reaction significantly more often than those with children with food allergy (mean = 4.4, SD = 1.1), food intolerance (mean = 3.6, SD = 1.5) or multiple hypersensitivities (mean = 4.0, SD = 1.1; all *ps* <.008; Figure 48).

Figure 48: How often parents asked staff for information before ordering, by hypersensitivity



Base: All parents of children with a hypersensitivity (532): Food allergy (298); Food intolerance (124); Coeliac disease (35); Multiple FHs (75)

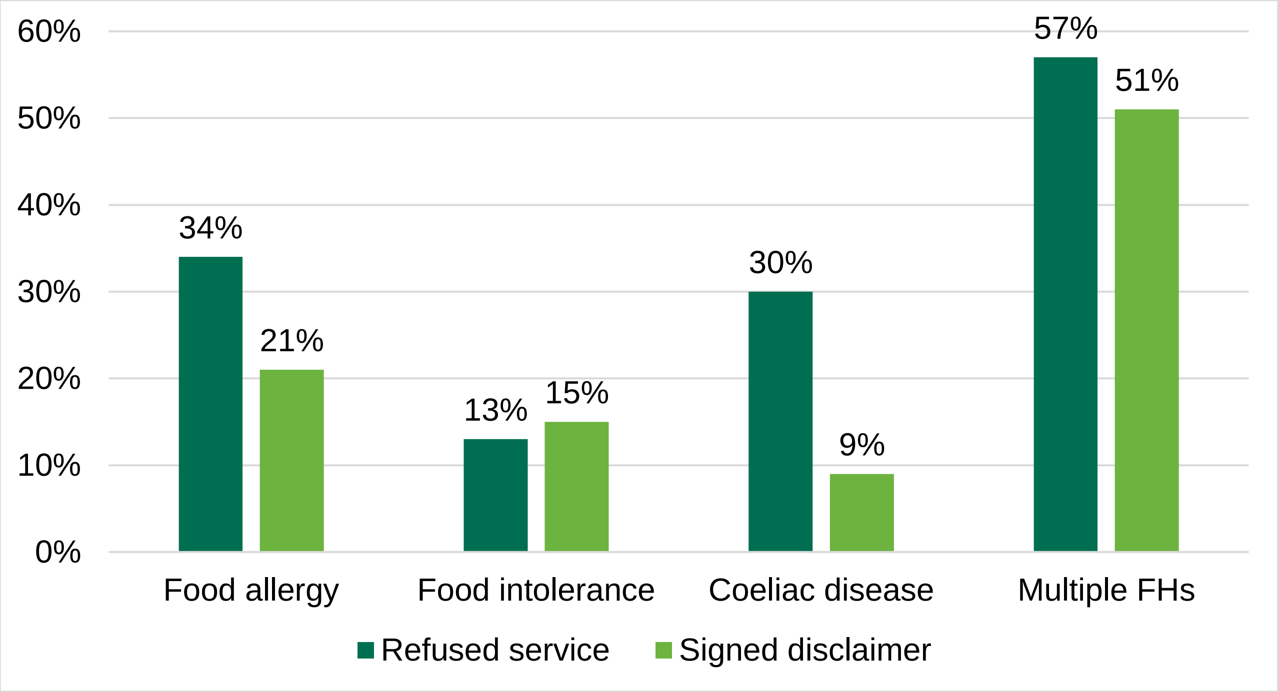
Confidence in information provided when eating out

Parents were asked how comfortable they felt when asking a member of staff for information about the food they are selling because of a concern about their children experiencing a bad or unpleasant physical reaction. Parents were also asked how confident they were that the information provided to them when eating out allows them to identify foods that cause their child a reaction. The majority of participants were comfortable in asking for information when eating out (n = 449; 73% were very or fairly comfortable). This was reflected across the four hypersensitivity groups (Annex B Table 58) and there were no significant differences observed.

Most parent participants were very or fairly confident (n = 397; 65%) that the written information provided when eating out allows them to identify foods that cause a bad or unpleasant physical reaction, and there were no significant differences observed between hypersensitive groups. The majority of participants were also very or fairly confident that information provided verbally by staff allows them to identify foods causing their child a reaction (n = 345; 57%). However, there were differences across hypersensitivities regarding confidence in information provided verbally by staff when eating out. Using a scale from 1 (Not at all confident) to 4 (very confident), parents of children with coeliac disease (mean = 2.4, SD = 0.7) and food allergy (mean = 2.6, SD = 0.9) were significantly less confident in verbal information provided by staff than parents of children with food intolerance (mean = 3.0, SD = 0.8; all *ps* <.008) (see Annex B Tables 59 and 60).

One in five (21%; n = 164) parent participants reported having been previously refused service when eating out because of their child or children's hypersensitivity (n = 405; 51% had not). Sixteen percent (n = 125) reported they had been asked to sign a waiver or disclaimer when eating out (n = 453; 57% had not). Additionally, the relationship between type of food hypersensitivity and being refused service was also significant, $\chi^2(3) = 39.9$, $p < .001$, with parents of children with multiple hypersensitivities (57%) most likely to report being refused service (Figure 49).

Figure 49: Proportion of parents who have been refused service, and asked to sign a disclaimer when eating out, by child's hypersensitivity



Base: All parents of children with a hypersensitivity. Refused service (502). Asked to sign a disclaimer (510): Food allergy (RS: 285; SD: 287); Food intolerance (RS: 118; SD: 117); Coeliac disease (RS: 30; SD: 34); Multiple FHs (RS: 69; SD: 72)

Shopping

Participants were asked how often they check information on food labels for ingredients that may cause them a bad or unpleasant physical reaction. It was common for participants to check labels for ingredients that would cause an adverse reaction always or most of the time (78%; n = 528). Additionally, participants were also asked how often they check labels for information about the possible presence of foods which may cause an adverse reaction (e.g. may contain); 74% of parents reported checking this always or most of the time (n = 501; see Annex Tables 61 and 62).

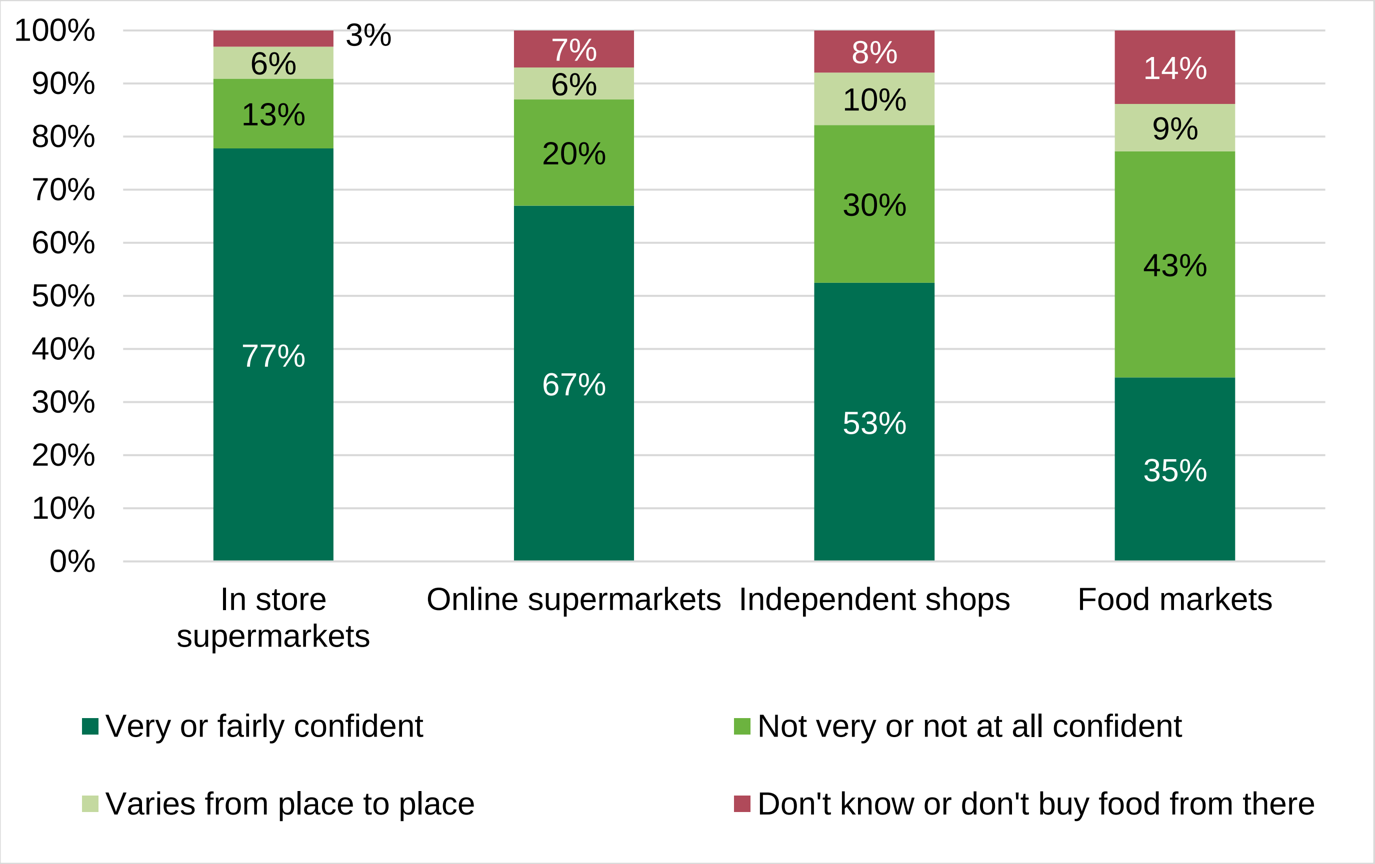
On a scale from 1 (Never) to 5 (Always), there were significant differences for how often parents check food labels for ingredients that would cause an adverse reaction, $F(3) = 11.3$, $p < .001$, $\eta p^2 = .06$. Parent respondents with children with food intolerance (mean = 4.0, SD = 1.2) check labels significantly less often than parents with children with food allergy (mean = 4.5; SD = 0.9) or coeliac disease (mean = 4.6; SD = 0.8; all ps<.008). Parents of children with food intolerance (mean = 3.9, SD = 1.2) also checked labels for information on the possible presence of foods that cause their child an adverse reaction (e.g. ‘may contain) significantly less often than parents of children with food allergy (mean = 4.3, SD = 1.1; p<.001).

Parents were also asked how confident they felt that the information provided on food labelling allows them to identify foods that cause their child a bad or unpleasant physical reaction when buying foods from different types of food shops. While many reported being confident in the information provided on food labelling for food sold from in store supermarkets (n = 518; 77%) , participants were least confident in the information provided on food labelling for food sold from food markets or stalls (n = 286; 43% not very or at all confident; Figure 50). This difference was also significant, with parents reporting they were more confident in the information provided on food labelling for food sold from in store supermarkets (mean = 3.2; SD = 0.8) than the information provided for food sold from online supermarkets (mean = 3.0, SD = 0.9), independent food shops (mean = 2.7, SD = 0.9) and food markets/stalls (mean = 2.3; SD = 1.0; all ps<.001). Higher percentages of parents were also less likely to buy food from food markets, with 15% of parents of children with food allergy and multiple hypersensitivities respectively reporting they do not buy food from food markets, compared to 1% and 5% reporting this for in store supermarkets.

Parents were less confident that they were able to identify foods that cause their child a bad or unpleasant physical reaction when buying food sold loose, compared to labelled food. For example, 77% of all parents felt very or fairly confident that the information provided on food labelling for items sold from in store supermarkets allowed them to identify foods that cause a reaction, whereas this was true for only 49% of parents when asked about identifying foods that cause a reaction when buying food sold loose from in store supermarkets. This was also similar for online supermarkets, with 67% feeling confident about identifying foods using information on food labelling, compared to 47% identifying loose food items.

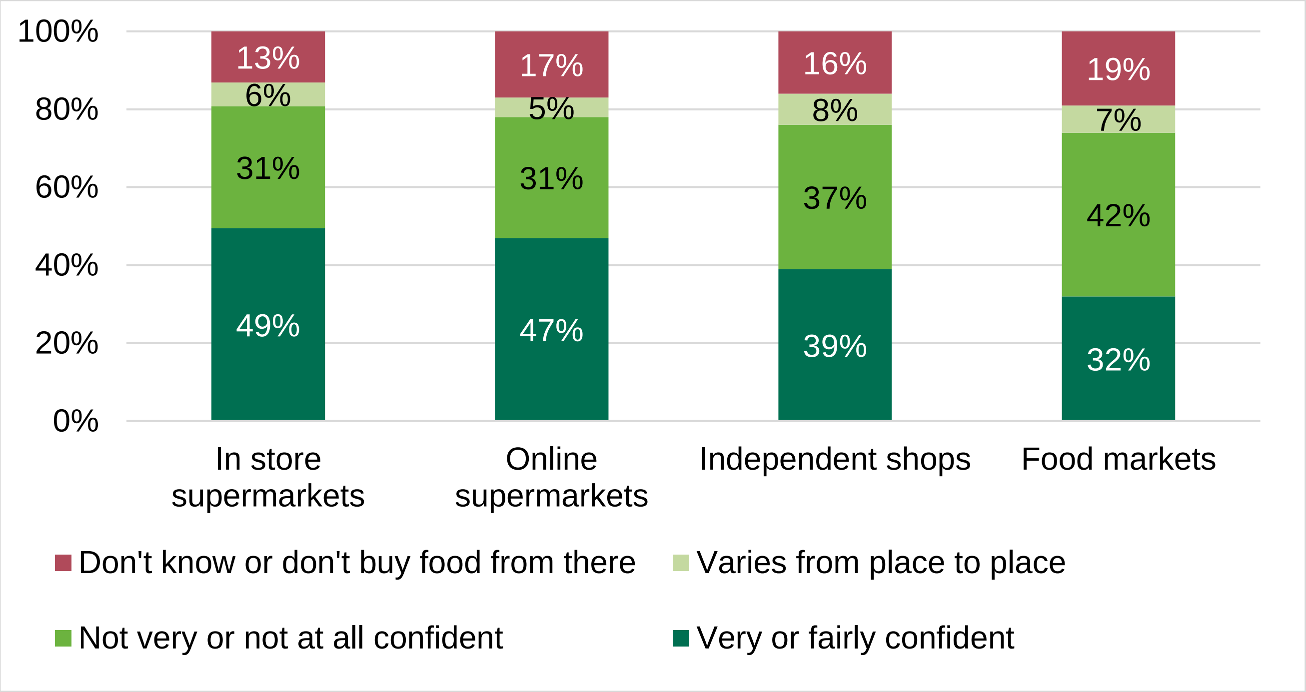
When comparing confidence in identifying loose foods that cause a reaction between the different outlets, parents had significantly more confidence in identifying loose items sold from in store supermarkets (mean = 2.7, SD = 1.1) compared to independent shops (mean =2.5, SD = 1.0) and food markets (mean = 2.4, SD = 1.1). Additionally, parents were also more confident in identifying loose items that cause a reaction when sold from online supermarkets (mean = 2.7, SD = 1.0) compared to independent shops (mean = 2.5, SD = 1.0) and food markets (mean = 2.4, SD = 1.1, all *p*s <.001; see Figure 51).

Figure 50: Confidence in the information provided on food labelling in different food outlets



Base: All parents: In store supermarkets (673); Online supermarkets (664); Independent shops (664); Food markets (662)

Figure 51: Confidence in identifying foods that cause a bad or unpleasant physical reaction when buying food sold loose



Base: All parents: In store supermarkets (671); Online supermarkets (664); Independent shops (664); Food markets (657)

Parents of children with coeliac disease were significantly more confident that the information provided on food labelling for food sold from in store supermarkets (mean = 3.5; SD = 0.5) and online supermarkets (mean = 3.5, SD = 0.5) allows them to identify foods that cause their children an adverse reaction, than parents of children with food allergy and food intolerance. However, parents of children with food intolerance (mean = 2.6' SD = 0.9) were significantly more confident in information provided on labels for food sold by food markets than parents of children with food allergy (mean = 2.2; SD = 1.0) and coeliac disease (mean = 2.0; SD = 0.8; all ps<.001; Annex B Tables 63-66).

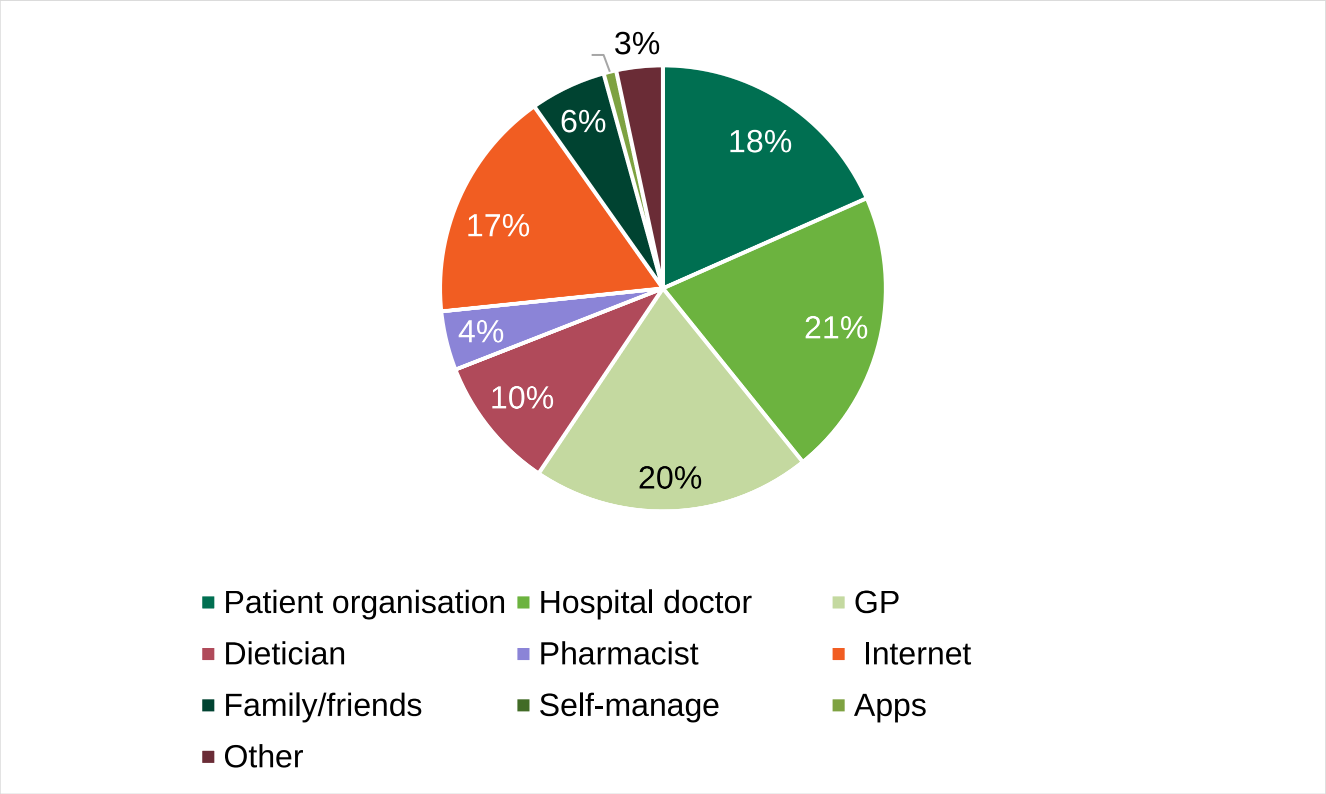
Parent participants of children with food intolerance (in store supermarket mean = 2.9, SD = 1.0; online supermarket mean = 2.8, SD = 1.0; independent shops mean = 2.7. SD = 1.0; food market mean = 2.7, SD = 1.0) were significantly more confident across all outlets that they can identify foods that cause their children a bad or unpleasant physical reaction when that food is sold loose, in contrast to parents of children with food allergy (instore supermarket mean = 2.5, SD = 1.1; online supermarket mean = 2.5, SD = 1.0; independent shops mean = 2.4, SD = 1.0; food market mean = 2.4, SD = 1.0; all *ps* <.008). Parents of children with food intolerance reported they were on average, fairly confident they can identify foods causing an adverse reaction, whereas parents of children with food allergy were on average not very confident (all *p*s < .008). There were no other significant differences (see Annex B Tables 67-70 for full breakdown).

Sources of information

Parents were asked about the sources of information they use to help manage their child's hypersensitivity (see Annex B Table 71). Participants could choose as many sources of information that applied. Overall, one of the most frequently used sources of information was hospital doctors (n = 272; 34%), although 70% of these parents were from the food allergy group, indicating that clinicians are particularly useful for helping parents to manage their children's food allergy. Patient organisations were highly used by parents of children with coeliac disease (56%) and multiple hypersensitivities (37%). For parents of children with food intolerance, GPs were the most used source of information (43%; for a full breakdown see Annex B Table 71).

When asked which of these sources provides the most helpful information on managing their child's hypersensitivities, hospital doctors (n =136; 21%) and GPs (n = 132; 20%) were considered most helpful. Patient organisations (n = 120; 18%) and the internet (n = 110; 17%) were also reported as helpful sources of information for parents (Figure 52).

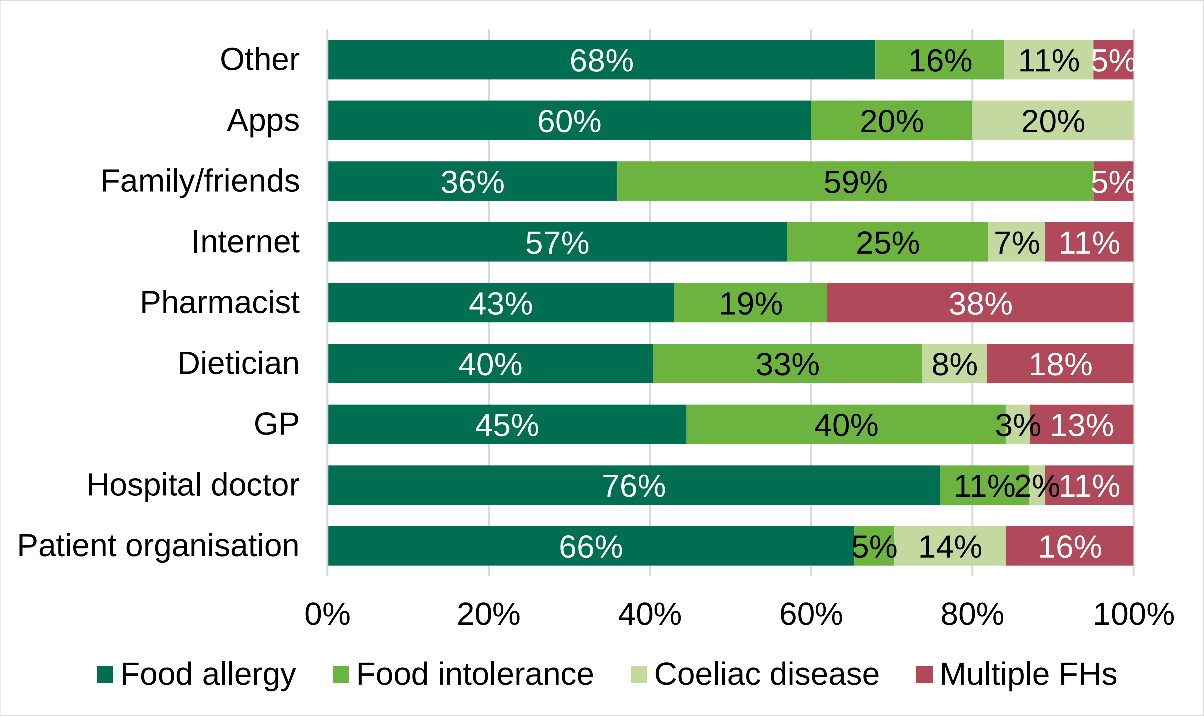
Figure 52: Most helpful sources of information for parents



Base: All parents (653)

Parents reporting children with coeliac disease (n = 16; 46%) and multiple hypersensitivities (n = 18; 23%) found patient organisations (such as Allergy UK, Anaphylaxis Campaign and Coeliac UK) most helpful. For parents reporting on children with food allergy, however, hospital doctors were the most helpful source of information (n = 95; 29%) and for those reporting food intolerance, GPs were the most helpful source of information (n = 44, 35%; Figure 53 and Annex B Table 72).

Figure 53: Proportion of most helpful sources of information across hypersensitivities

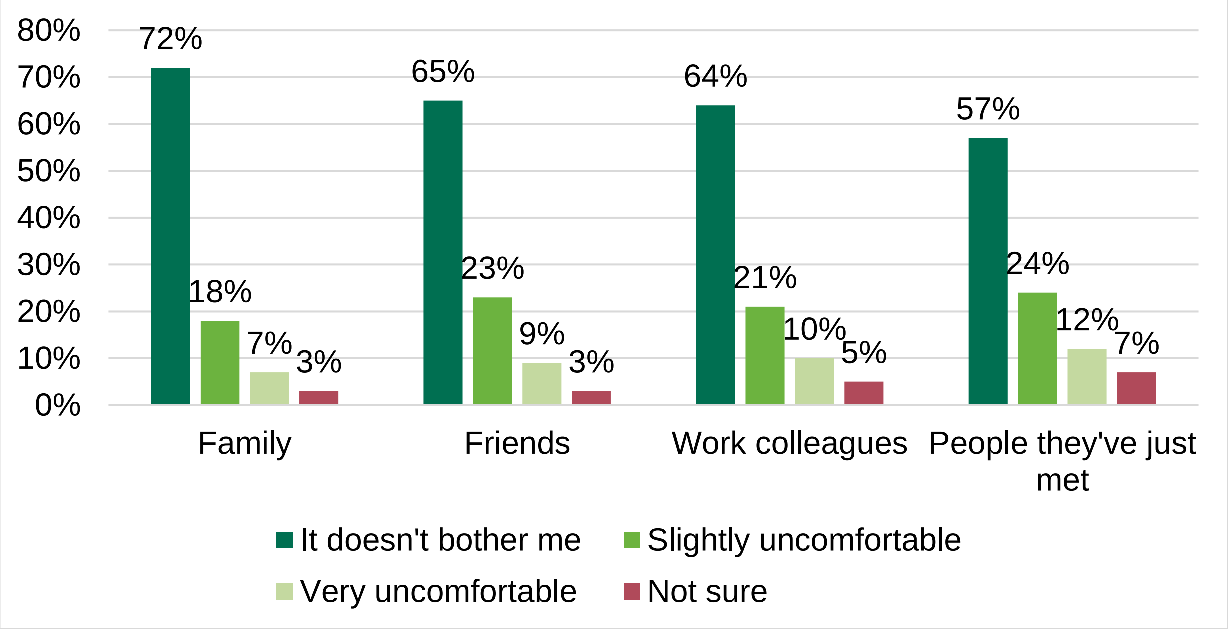


Base: Parents of children in hypersensitive groups (567): Food allergy (328); Food intolerance (127); Coeliac disease (35); Multiple FHs (77)

Social situations

Parents were asked how they felt about mentioning their child's reaction to foods in front of various groups of people including friends, family, work colleagues and people they've just met. Overall, parent participants reported being most comfortable with mentioning their child's hypersensitivity in front of family and friends (72% and 65% reported being not bothered by this respectively). However, parents were least comfortable about mentioning their child's reaction in front of people they've just met, with 57% (n = 375) of parents reporting they weren't bothered by this. More parents reporting feeling very uncomfortable mentioning their child's hypersensitivity to people they've just met, compared to any other social group (12%, n = 81) (see Figure 54).

Figure 54: How comfortable parents felt mentioning their child's hypersensivity in front of different groups



Base: All parents: Family (667); Friends (660); Work colleagues (664); People they've just met (660)

On a scale of 1 (It doesn't bother me) to 3 (Very uncomfortable), parents of children with multiple hypersensitivities (mean = 1.5, SD = 0.7) were significantly more uncomfortable mentioning their child's hypersensitivity in front of family than parents of children with food allergy (mean = 1.24, SD = 0.5; *p* = .001). Parents of children with multiple hypersensitivities (mean = 1.8, SD = 0.8) were also significantly more uncomfortable mentioning their child's hypersensitivity in front of friends than parents of children with food allergy (mean = 1.3, SD = 0.6), food intolerance (mean = 1.4, SD = 0.6) and coeliac disease (mean = 1.3, SD = 0.5; all ps <.008). This was also true for work colleagues (multiple hypersensitivities mean = 1.8, SD = 0.8), as well as people they'd just met (multiple hypersensitivities mean = 1.9, SD = 0.8), with parents of children with multiple hypersensitivities feeling significantly more uncomfortable about this than parents of children with other hypersensitivities (all *ps* <.008; see Annex B Tables 73-76 for frequencies).

Quality of Life

Food hypersensitivity specific quality of life

Parents were asked to complete a parent-proxy Quality of Life scale relevant to the type of hypersensitivity for the first reaction of the first child they reported on in the survey. Parents were only asked to report on one child to minimise the burden on respondents. Parents of children with food allergy completed one of two versions of the Food Allergy Quality of Life Questionnaire (FAQLQ), for either children (age 0-12) or teens (age 13-17). Parents of children with food intolerance completed the Food Intolerance Quality of Life Questionnaire (FIQLQ) (for ages 0-17), for Coeliac Disease, parents completed the Coeliac Disease Quality of Life scale (CDDUX). Parents of children with multiple hypersensitivities completed whichever of these was appropriate to the first child they reported (e.g. if someone reported food allergy to their child's first food, intolerance to their second and third, they completed the FAQLQ).

Quality of life, as reported by all parents

The FAQLQ and FIQLQ were rated on a scale from 1 (least impact on QoL) to 7 (most impact on QoL). The CDDUX was rated on a five-point scale. On all scales, the means were used, with high scores indicating most impact on quality of life (scores for the FAQLQs and FIQLQ are out of 7, which is the highest score, and for the CDDUX, scores are out of 5). Two separate versions of the FAQLQ were used, a child (8-12) and teen (13-17) appropriate scale, which were scored in the same way as above .These different scales use age-appropriate phrases to refer to common aspects of having food allergy (e.g. child FAQLQ: 'Because of food allergy my child's ability to take part in preschool/school events involving food (class parties/treats/lunchtime) has been limited vs. Teen FAQLQ: 'School trips away are not easy for my teenager'). Parents could then score the extent of the impairment on their child's quality of life from 1 (least impairment) to 7 (most impairment to QoL).[3]

---

[3] For further information please see the technical report.

Parents of children with food allergy reported high mean scores (4.6 and 4.7 out of 7), indicating that parents of children with food allergy believe their child's quality of life is impaired either 'quite a bit' or 'very much'. Parents of children with coeliac disease also rated the mean impairment on their child's quality of life as 3.9 out of 5, indicating high impairment (Table 2).

Table 2: Mean Quality of Life scores for each FH-specific scale (all parents)

Measure	FAQLQ Child - (Food allergy) N = 238	FAQLQ Teen (Food allergy) N = 77	FIQLQ (Food intolerance) N = 151	CDDUX (Coeliac disease) N = 44
Mean Total (SD)	4.7 (1.3)	4.6 (1.4)	4.2 (1.4)	3.9 (0.7)

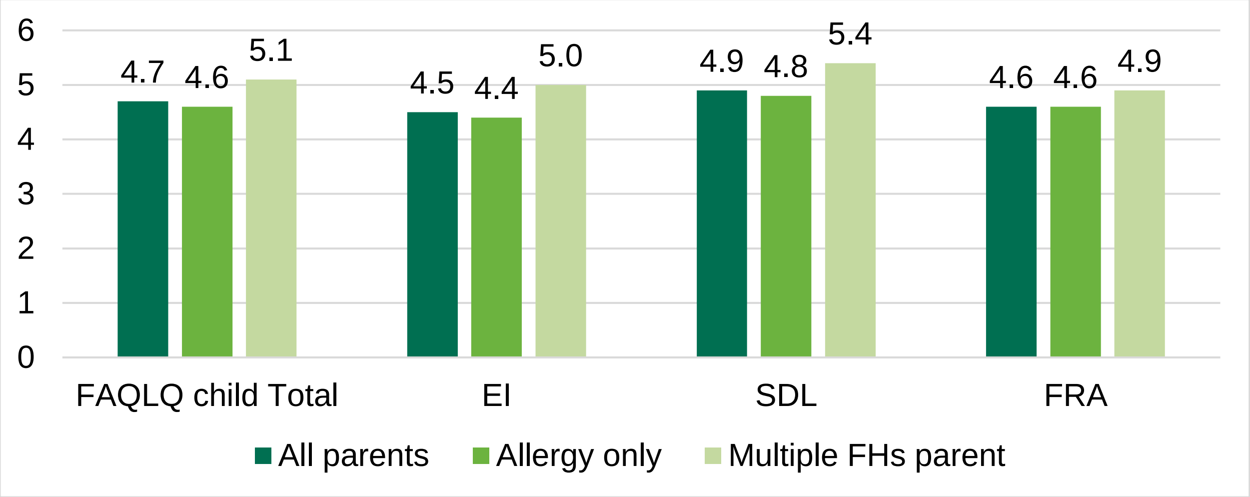
Quality of Life in younger children with food allergy, reported by parents

Each quality of life scale consists of food hypersensitive specific subscales. For the child FAQLQ, these are: Emotional Impact (EI), which refers to the worries and concerns related to having the food allergy their child experiences; Social and Dietary Limitations (SDL), which refers to how restricted their child's diet and social activities are as a result of having a food allergy; and Food Allergy Related Anxiety (FRA), which refers to the anxiety they think their child experiences around eating and trying foods as a result of having food allergy. A total of 238 parents of 8-12-year-olds with food allergy completed the FAQLQ (of which 209 were from the food allergy only group; the remaining 29 from the multiple hypersensitivities group).

Parents scored their child's QoL similarly high for total and all subscales, indicating a higher impact on quality of life than average (median quality of life = 4; mean total for sample = 4.7, SD = 1.3). For the food allergy only group, the mean total score for the FAQLQ was also higher than average (mean = 4.6, SD = 1.3). This was also true for the subscales, particularly for the social and dietary limitations subscale (mean = 4.8, SD = 1.4), which indicated that parents perceived that social and dietary limitations due to food allergy had the most impact of their child's quality of life.

Parents of children with multiple hypersensitivities scored the impact on their child's quality of life higher than those with reporting only food allergy (mean = 5.1, SD = 1.2). However, numbers of parents of children with food allergy as one of multiple hypersensitivities were small (<30), and so this result should be interpreted with caution. Means for each of subscale are shown in Figure 55.

Figure 55: Mean FAQLQ Child scores by all parents, parents of children with food allergy only, and parents of children with multiple hypersensitivities



Base: All parents completing the FAQLQ for children with allergy aged 8-12 (238): Children with only food allergy (209); children with allergy as multiple hypersensitivities (29)

Clinical factors were examined to see if they were significantly associated with parents perceived impairment to food-related quality of life in younger children with food allergy. Those with children who have a long-term condition had significantly more impairment of quality of life (mean=4.94 SD=1.24) than those who did not (mean=4.45 SD=1.31, t(172)=2.41). Those parents whose children were receiving psychological therapy for issues such as anxiety or depression had significantly more impairment of quality of life (mean=5.40 SD=1.15) than those who were not (mean=4.53 SD=1.32, t(176)=3.21).

Children who had asthma had significantly more impairment of quality of life (mean=5.03 SD=1.23) than those who had not (mean=4.38 SD=1.32, t(156)=3.22). This was also the case for children who had eczema (mean=4.90 SD=1.28) compared to those who had not (mean=4.24 SD=1.36, t(159)=3.11). Children with other non-food allergies (e.g. cat/dog, bee/wasp, medication) also had significantly more impairment of quality of life (mean=5.19 SD=1.05) than those who didn’t (mean=4.29 SD=1.40, t(142.58)=4.49) (all *p*s <.01).

Parents’ reported severity of their child’s reaction was significantly positively correlated with perceived impairment to quality of life (r = .24; p =.001). Those who had been prescribed an auto-injector had significantly more impairment of quality of life (mean=4.89 SD=1.28) than those who had not (mean=3.99 SD=1.26, t(175)=4.10). Children who had experience of anaphylactic shock to the first stated food also had significantly more impairment of quality of life (mean=4.97 SD=1.32) than those who had not (mean=4.22 SD=1.27, t(156)=3.59). This was also the case for children who had been admitted to hospital in an emergency for their reaction to food one (mean=4.88 SD=1.29) compared to those who had not (mean=4.41 SD=1.33, t(175)=2.37) (all *p*s <.05).

Other factors related to eating out were also significantly correlated with parent’s perceived quality of life of younger children with food allergy. How often they checked information before choosing where to eat out (r = .30), reviewed this information before ordering (r=.30) and asked staff for available information (r = .28) were all significantly and positively correlated to impairment of their child’s quality of life (all *p*s<.001). The same was also true for checking labels for the possible presence of foods that may cause an adverse reaction (r = .24, p =.001).

A regression model was run to see which of the variables described above might predict level of quality of life. All of the variables above which had a significant association with quality of life were included in the model (n=13 predictors). The overall model was significant (p<0.001) and 19% of the variance in quality of life was explained, indicating that 81% of the variance was due to other unknown factors. Only one predictor was significant with the child currently receiving psychological therapy or medication for psychological issues predicting poorer QoL (standardised beta -0.23). None of the other predictors were significant (standardised betas ranged from -0.02 to 0.020 and confidence intervals for each predictor crossed zero).

Quality of Life as reported by parents, in teens with food allergy

The teen scale of the FAQLQ is made up of the subscales: Emotional Impact which refers to the teenager’s anxiety and worries about consuming a food which will result in a food allergic reaction; Dietary Frustrations and Social Restrictions, which refers to the frustrations and social impact felt by their teenager as a result of restricting their diet and social activities due to having a food allergy; and Food Allergy Awareness which refers to behaviours (e.g. checking labelling) and the need for awareness around food their teenager has, due to having a food allergy. A total of 77 parents of teens completed the FAQLQ. This comprised of 72 parents from the food allergy only group, and 5 parents of children who have multiple hypersensitivities (thus, this subgroup will not be reported on).

Overall, mean totals for the food allergy only parents and all parents were identical, and indicated higher than average impact on quality of life (mean = 4.6, SD = 1.5). Scores on the dietary frustrations (mean = 4.7, SD = 1.5) and food allergy awareness (mean = 4.7, SD = 1.5) subscales were highest, indicating these elements of managing food allergy have the most impact on quality of life in teens with food allergy, according to their parents.

Clinical factors were examined to see if they were significantly associated with parents perceived impairment to quality of life in teens with food allergy. Teens who had asthma had significantly more impairment of quality of life (mean=5.19 SD=1.33) than those who had not (mean=4.10 SD=1.19, t(58)=3.35). This was also the case for teens who had hay-fever at certain times of the year (mean=4.90 SD=1.47) compared to those who had not (mean=4.15 SD=1.04, t(59)=2.14). Teens with other non-food allergies (e.g. cat/dog, bee/wasp, medication) also had significantly more impairment of quality of life (mean=5.24 SD=1.31) than those who didn’t report this (mean=4.20 SD=1.22, t(63)=3.31) (all *p*s <.01).

Parents’ reported severity of their teen’s reaction was significantly positively correlated with perceived impairment to quality of life (r = .24; p =.001). Those who had been prescribed an auto-injector had significantly more impairment of quality of life (mean=5.19 SD=1.11) than those who had not (mean=3.95 SD=1.39, t(65)=4.06). Teens who had experience of anaphylactic shock to the first stated food also had significantly more impairment of quality of life (mean=5.13 SD=1.24) than those who had not (mean=4.05 SD=1.38, t(59)=3.21). This was also the case for teens who had been admitted to hospital in an emergency for their reaction to food one (mean=5.08 SD=1.17) compared to those who had not (mean=4.27 SD=1.46, t(65)=2.51) (all *p*s <.01).

Other factors related to eating out were significantly correlated with parent’s perceived quality of life of older children with food allergy. How often parents checked information before choosing where to eat out (r = .51), how often they reviewed available information before ordering (r=.52), and how often they asked staff for available information (r = .36), were all significantly and positively correlated to impairment of their adolescent's quality of life (all *ps*<.01). The same was also true for checking labels for ingredients that may cause an adverse reaction (r = .34, p = .004) and checking labels for the possible presence of foods that may cause an adverse reaction when shopping (r = .30, p =.01). Additionally, how comfortable parents were about asking a member of staff for allergen information when eating out (r = -.26), as well as the confidence in written information (r = -.32) provided when eating out, were both significantly negatively correlated with parents' perceived impairment to their adolescent's quality of life (both ps <.05).

A regression model was run to see which of the variables described above might predict level of quality of life. All of the variables above which had a significant association with quality of life were included in the model (n=14 predictors). The overall model was significant (p<0.001) and 46% of the variance in quality of life was explained, indicating that 54% of the variance was due to other unknown factors. However, no single predictor was significant as confidence intervals for each predictor crossed zero.

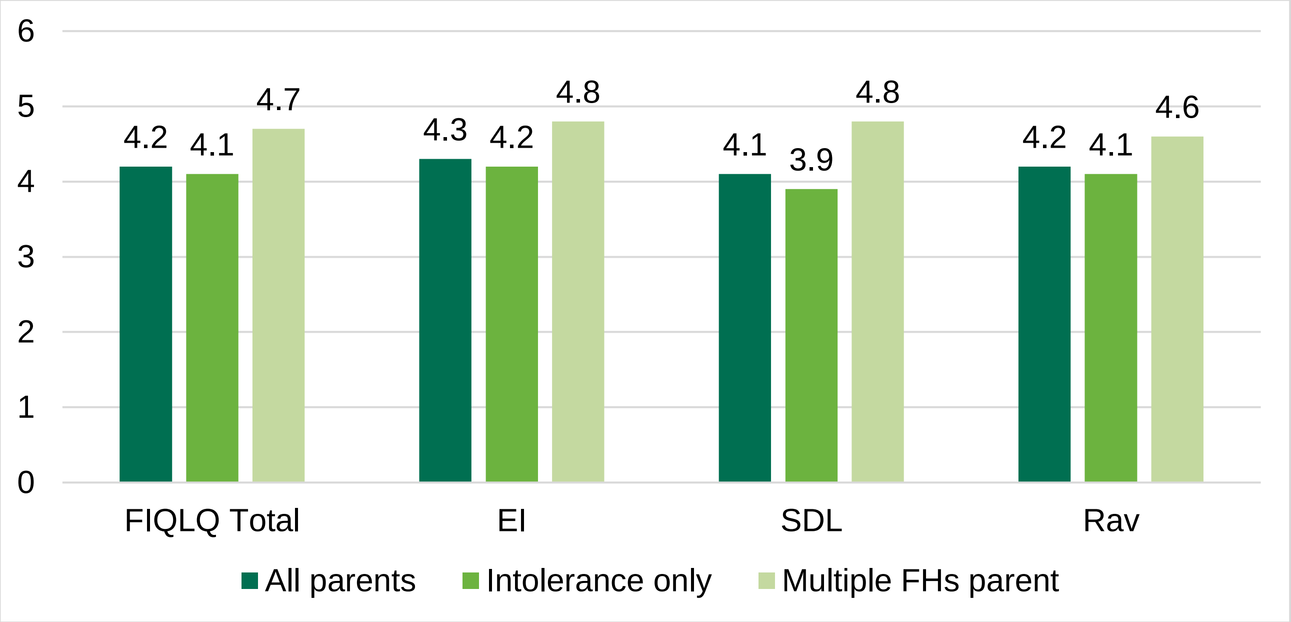
Quality of Life in children with food intolerance, reported by parents

For the FIQLQ, subscales are: Emotional Impact (EI), which refers to the worries and concerns of their child about having food intolerance; Social and Dietary limitations (SDL), which refers to the impact and limitations on social activities and diet as a result of having food intolerance; and Reactions and Avoidance (RAv), which refers to the awareness needed by their child to avoid and check foods in relation to their food intolerance. A total of 151 parents of children with food intolerance completed the FIQLQ, of which 120 were those with children with food intolerance only and 30 were those with children with multiple hypersensitivities.

Parents reported slightly higher than average impact on quality of life for children with food intolerance (median = 4; mean = 4.2, SD = 1.4) and this was similar across all subscales (see Figure 60). On average, parents of children who only had food intolerance reported slightly less impact on quality of life (mean = 4.1, SD = 1.4) than parents of children with food intolerance as part of multiple hypersensitivities (mean = 4.7, SD = 1.2).

The scores for the social and dietary limitations subscale were the most diverse. Parents of children with food intolerance only, reported less impact of having a food intolerance on quality of life (mean =3.9, SD = 1.5) in relation to their child's social and dietary restrictions than those with multiple hypersensitivities (mean = 4.8, SD = 1.3; see Figure 56). However, again it is noted that the total for the multiple hypersensitivities group was small (n = 27) and so this should be interpreted with some caution.

Figure 56: Mean FIQLQ scores by all parents, parents of children with food intolerance only, and parents of children with multiple hypersensitivities



Base: All parents completing the FIQLQ for children with intolerance (151): Children with only food intolerance (120); children with intolerance as multiple hypersensitivities (30)

Clinical factors were examined to see if they were significantly associated with parents perceived impairment to quality of life in children with food intolerance. Children who had another long-term condition had more impaired quality of life (mean=4.77 SD=1.26) compared to those who had not (mean=3.97 SD=1.38, t(128)=3.10). This was also the case for those who were currently receiving psychological therapy (mean=4.63, SD=1.25) compared to those who were not (mean=4.08 SD=1.39, t(129)=1.98). Children with asthma had significantly more impairment of quality of life (mean=4.65 SD=1.21) than those who didn't have this condition (mean=3.99 SD=1.43, t(123)=2.45) (all *ps* <.05).

The number of foods parents reported their child had a reaction to was significantly positively correlated with impairment to their child's quality of life (r = .23; *p* =.01). Those who had been prescribed an auto-injector had significantly more impairment of quality of life (mean=4.80 SD=1.17) than those who had not (mean=3.94 SD=1.39, t(130)=3.39). Children who had experience of anaphylactic shock to the first stated food also had significantly more impairment of quality of life (mean=4.78 SD=1.07) than those who had not (mean=4.06 SD=1.38, t(86.77)=3.12). This was also the case for children who had been admitted to hospital in an emergency for their reaction to food one (mean=4.96 SD=1.06) compared to those who had not (mean=3.95 SD=1.39, t(68.15)=4.30) (all *p*s <.01).

Factors related to eating out were also significantly correlated with parent's perceived quality of life of their children with food intolerance. Frequency of eating out was significantly positively correlated (r = .23, p =.01) with parents' perceived impairment to their child's quality of life. How often parents asked staff for available information when eating out (r = .26), as well as how often they checked labels for ingredients which may cause an adverse reaction (r = .27), and checked labels for the possible presence of foods that may cause an adverse reaction (r = .27, p =.001) when shopping, were also all significantly positively correlated to impairment of their child's quality of life (all *p*s<.01).

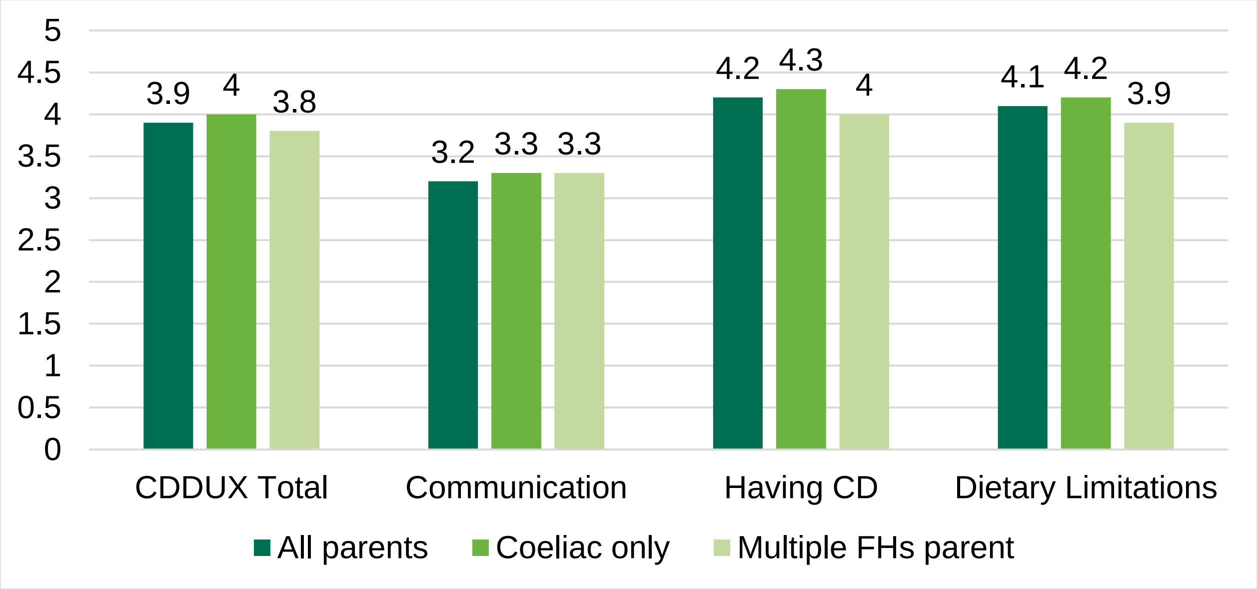
A regression model was run to see which of the variables described above might predict level of quality of life. All of the variables above which had a significant association with quality of life were included in the model (n=11 predictors). The overall model was significant (p<0.001) and 19.5% of the variance in quality of life was explained, indicating that 80.5% of the variance was due to other unknown factors. No single predictor was significant (standardised betas crossed zero).

Quality of Life in children with coeliac disease, reported by parents

For the CDDUX, subscales comprised Communication, referring to the impact felt by their children about talking about having coeliac disease, Having Coeliac Disease, referring to the impact on their child's quality of life when thinking about foods they cannot eat or being offered food containing gluten, and Dietary limitations, referring to the impact that eliminating gluten from their diet has on their child's quality of life. The CDDUX is scored on a 5-point Likert scale and parents of both younger and older children completed the same scale. A total of 44 parents of children with coeliac disease completed the CDDUX, of which 34 parents were those of children with only coeliac disease, and 10 were parents with coeliac disease among multiple hypersensitivities (thus, as numbers are small for the multiple hypersensitivities group, this data will not be reported on here).

Overall, parents of children with coeliac disease reported the impact on their child's quality of life as high (mean = 3.9, SD = 0.7). This was highest on the 'Having Coeliac disease' scale, and indicated that parents rated their children having to manage being offered foods they cannot eat, and thinking about the foods they cannot eat because of having coeliac disease, as having the most impact on their child's quality of life (see Figure 57 for means).

Figure 57: Mean CDDUX scores, by all parents, coeliac disease only parents and those with children with multiple hypersensitivities



Base: All parents completing the CDDUX for children with coeliac disease (44): Children with coeliac disease only (34); children with coeliac disease as one of multiple hypersensitivities (10)

Clinical factors were not examined to see if they were significantly associated with parents perceived impairment to quality of life in children with coeliac disease as numbers were too low in each of the groups.

Differences in Quality of Life by hypersensitivity

Where possible, comparisons in quality of life scores were made for parents reporting age and gender of the first child, numbers of foods and severity of reaction. Comparisons for different ethnic groups could not be made as there were not enough children reported by parents from each ethnic group to make meaningful comparisons. This was also the case for comparing groups based on clinical vs self-diagnosis, and numbers of foods. Where more than two groups are compared, a Bonferroni correction has been applied to the significance level of 0.05 (/3 in all cases), thus a new level of .016 was used for more than two comparisons.

Food allergy only (child FAQLQ)

Of the food allergy only group, 175 parents completed the FAQLQ.

Age

Pearson's correlation was carried out to investigate whether the child's age correlated with FAQLQ scores. However, this was not significant, $r(169) = .15$, $p = .06$, indicating that age of the child had no significant association with the impact of their food allergy on their child's quality of life.

Gender

Of those with food allergy only, parents completed the quality of life scale for 98 male children and 75 female children. There was no significant difference in impact upon quality of life for male and female children with food allergy, $F(1) = 0.16$, $p = .69$, $\eta p^2 = .001$. Means were similar for quality of life between males (mean = 4.6, SD = 1.3) and females (mean = 4.6, SD = 1.4) indicating parents rated the impact on quality of life for both genders as similar.

Severity

As numbers for a mild reaction to food allergy were low, reactions were recoded into mild or moderate (n = 79) and severe (n = 93). There were differences in parent's reported impact upon quality of life for the severity of their child's allergic reaction, $F(1) = 21.3$, $p < .001$, $\eta p^2 = .11$. Parents reporting a mild or moderate reaction for their child's first food (mean = 4.2, SD = 1.2) reported significantly less impact on quality of life than those reporting a severe reaction (mean = 5.1, SD = 1.3).

Food allergy only – (teen FAQLQ)

Of the food allergy only group, 68 parents completed the FAQLQ about their teen with allergy.

Age

For the teen FAQLQ, Pearson's correlation was also carried out to see if older children's age correlated with the Teen FAQLQ scores, however this was not significant, $r(66) = .08$, $p = .54$, indicating that the age of teens was not associated with their reported impact upon quality of life.

Gender

Parents reported 47 male children and 21 female teens with food allergy. However, there was no significant difference between impact upon quality of life between male and female teenagers with food allergy, $F(1) = 3.57$, $p = .06$, $\eta p^2 = .05$. Means however indicated that parents reported that female teenager's quality of life was more impacted (mean = 5.1, SD = 1.4) than male teenager's quality of life (mean = 4.5, SD = 1.3), thus it may be that if groups were bigger, this difference would be significant.

Severity

Categories were recoded into mild or moderate (n = 33) and severe (n = 34). There were significant differences in parent's reported impact upon their teen's quality of life, for the severity of their teen's allergic reaction, $F(2) = 16.1$, $p < .001$, $\eta p^2 = .20$. Parents reporting a mild or moderate reaction for their teen's first food (mean = 4.1, SD = 1.3) reported significantly less impact on quality of life than those reporting a severe reaction (mean = 5.3, SD = 1.2; Figure 63). Again, however, groups were still small and so these results may change with larger numbers.

Food intolerance only

Of the food intolerance only group, 111 parents completed the FIQLQ. Differences in severity of reaction were not compared as numbers were too small in subgroups to allow for this.

Age

There was no significant difference in parents' scores between younger (0-12s) (mean = 4.1, SD = 1.4) and older children (13-18s; mean = 4.1, SD = 1.3), $F(1) = 0.00$, $p = .94$, $\eta p^2 = .00$. Groups were, however, unequal (83 and 24) and so results should be taken with some caution.

Gender

Of those with food intolerance and who completed the FIQLQ, 53 were male, 57 were female. There were no significant differences in impact upon quality of life reported by parents for male children (mean = 4.3, SD = 1.2) or female children (mean = 4.0, SD = 1.5) with food intolerance, $F(1) = 0.84$, $p = .36$, $\eta p^2 = .01$.

Coeliac disease only

For those parents in the coeliac group, only 38 completed the CDDUX and so comparisons for this group will not be reported on.

Multiple hypersensitivities

For those with multiple hypersensitivities, 14 completed the child FAQLQ, 3 completed the teen FAQLQ, 19 completed the FIQLQ and 5 completed the CDDUX. Therefore, due to very small numbers, differences for this group will not be reported on.

Generic quality of life

Parents completed the EQ-5D-3L for the first child they reported on. Mean VAS scores (0=death and 100=full health) were highest for children with coeliac disease (N=42, mean = 83.31, SD = 14.90), followed by food allergy (n=349, mean = 81.13, SD = 17.83), food intolerance (n=143, mean = 76.18, SD = 22.10). Children with multiple FHs scored lowest of all (n=56, mean = 72.57, SD = 22.77). Across all children with FH on the EQ-5D-3L sub-domains, Pain and Anxiety dimensions were markedly worse than the other dimensions.

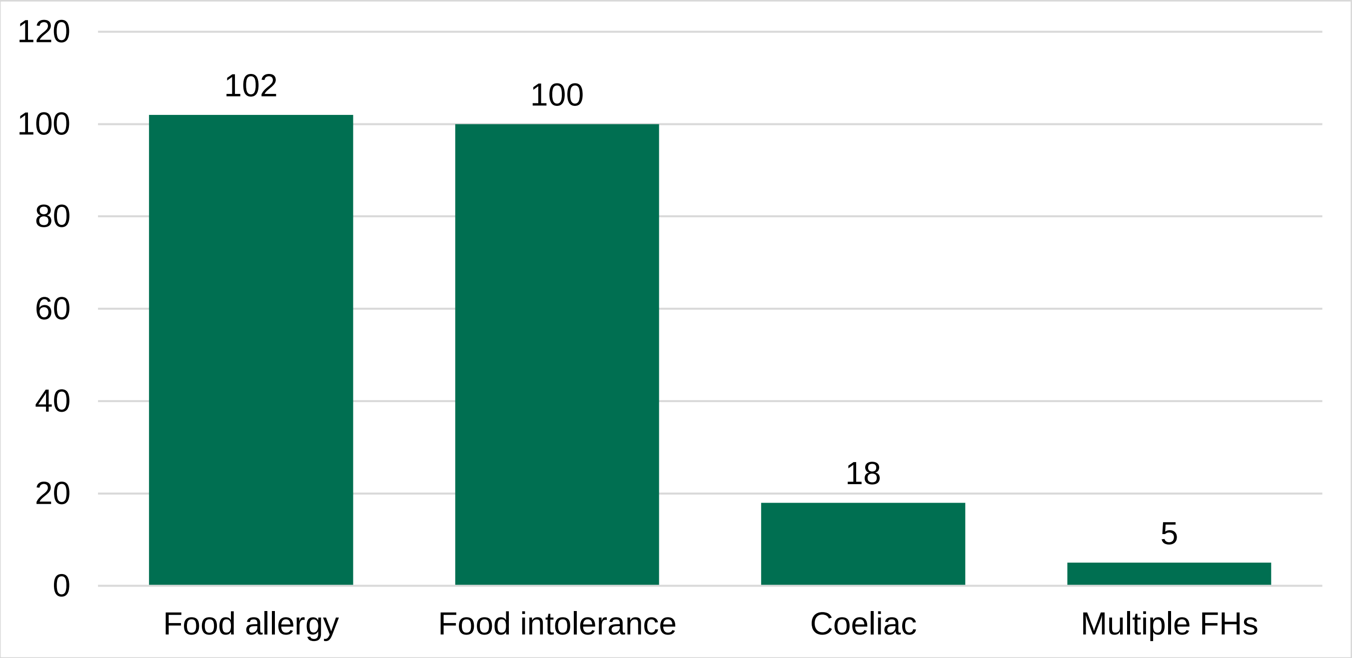
Part 3 - Children with FH

A total of 267 children aged 8-17 years with FH completed the survey, which included 42 reporting ‘Other’ conditions or ‘Don’t know’ when asked to describe their reaction to food. These participants are not reported on as a subgroup but are included in the ‘all children’ figures. Key statistics and comparisons for the food allergy and food intolerance groups are reported on, however due to small numbers of those with coeliac disease (n = 18) and multiple hypersensitivities (n =5), analysis for these groups is not included.

Prevalence of food hypersensitivities

Most of the child sample was made up of those with food allergy only (45%, n=102) and food intolerance only (44%, n=100). Group sizes for coeliac disease (n = 18; 8%) and multiple hypersensitivities (n = 5; 2%) were small (Figure 58).

Figure 58: Prevalence of children within the sample with each food hypersensitivity



Base: All children (excluding those reporting only ‘other’ or ‘don’t know’; 225): Food allergy (102); Food intolerance (100); Coeliac disease (18); Multiple FHs (5)

Profile of child participants

Children’s key characteristics

From a total of 267 children, 56% (n = 146) of those reporting a food hypersensitivity were female (43%; n = 111 were male). The mean age of all children was 13.2 years old (SD = 2.9), with a range from 8 to 17 years old. The majority of children were from a White background (n = 230; 86%. See Annex C Table 77).

More female child respondents reported each of the hypersensitivities than males, with the highest percentage of females reporting food allergy (n = 55 out of 102, 54%). As with the whole sample, across all hypersensitivities, the majority of children were of White British ethnicity (86%; see Table 77 for a full breakdown).

The most common region for all children living with a food hypersensitivity was the South West of England (n = 36, 14%). However, for those reporting food allergy, the most common region was London (17 out of 102; 17%) and for those with food intolerance, the most common region was the South East of England (16 out of 100; 16%). Those with coeliac disease and multiple hypersensitivities were equally split across a few regions. See Annex C Table 78 for a full breakdown.

Other long-term conditions

Other diagnosed long-term conditions included conditions such as diabetes. Twenty eight percent (n = 73) of the whole sample reported a long-term condition and 1% (n = 2) preferred not to say (71%, n = 188 did not have another long-term condition).

Excluding foods

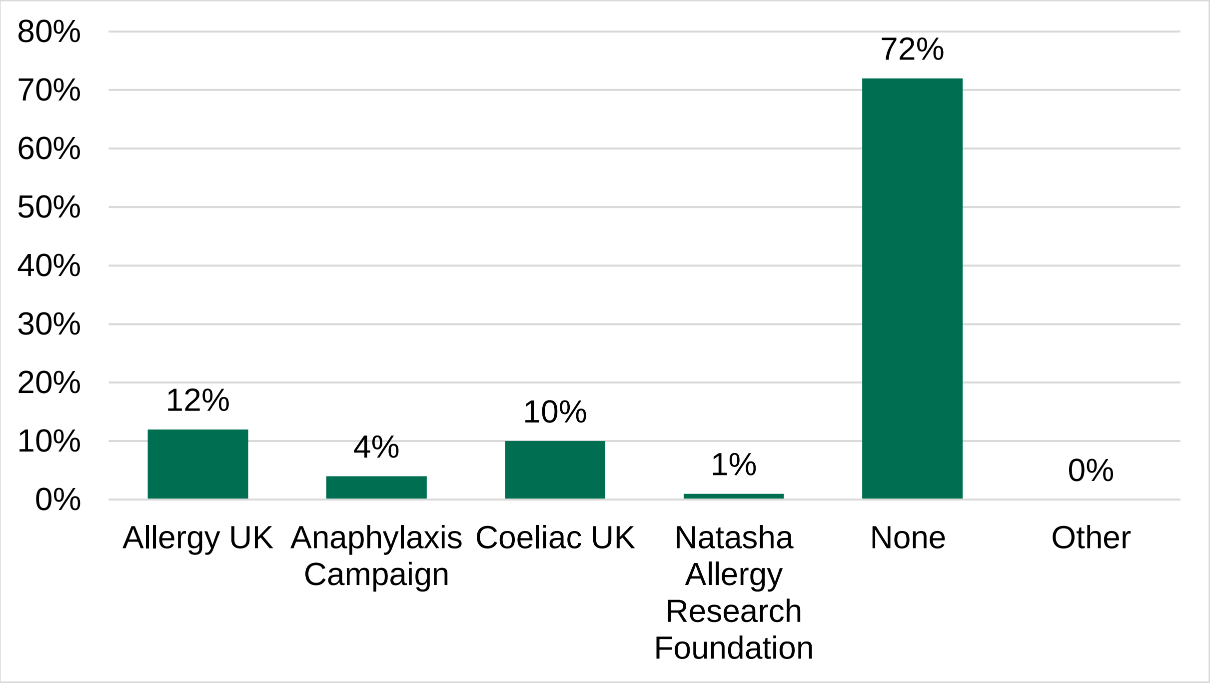
Children were asked if they excluded foods from their diet for any other reasons apart from their food hypersensitivity (e.g. religious reasons, vegetarian/pescatarian/vegan diets, to lose weight). Children could select all that applied. While the majority of children did not exclude foods (70%, n = 188), the most common reasons for doing so across all children (n = 32, 12%) and those with food allergy (n = 15; 15%) was for health reasons.

However, for those with food intolerance the most common reason was because of following a vegetarian, pescatarian or vegan diet (n = 14; 14%; Annex C Table 79).

Patient organisation membership

Children were asked to report on whether they were a member of any patient organisations. The majority (72%, n = 193) were not members of any organisation (see Figure 59). However, for those who were members of organisations, the most common were Allergy UK (n = 31; 12%) and Coeliac UK (n = 26, 10%). Of those who reported belonging to Allergy UK, 65% (n = 20) were children from the food allergy group.

Figure 59: Membership of patient organisation groups



Base: All children (267)

Reactions to food

Children were first asked to report all foods they experience a bad or unpleasant physical reaction to, and there were no limits on the number of foods that could be reported. Milk (12% of all children reported this as one of the foods they reacted to), cereals (8%), eggs (8%) and peanuts (8%) were the most frequently reported foods. ‘Other’ foods included chocolate, vinegar, sugar, pasta, spicy foods, herbs and spices (e.g. chilli), pulses, condiments (e.g. mayonnaise) and coconut. Please see Annex C Table 80 for a full breakdown of foods reported by hypersensitivity.

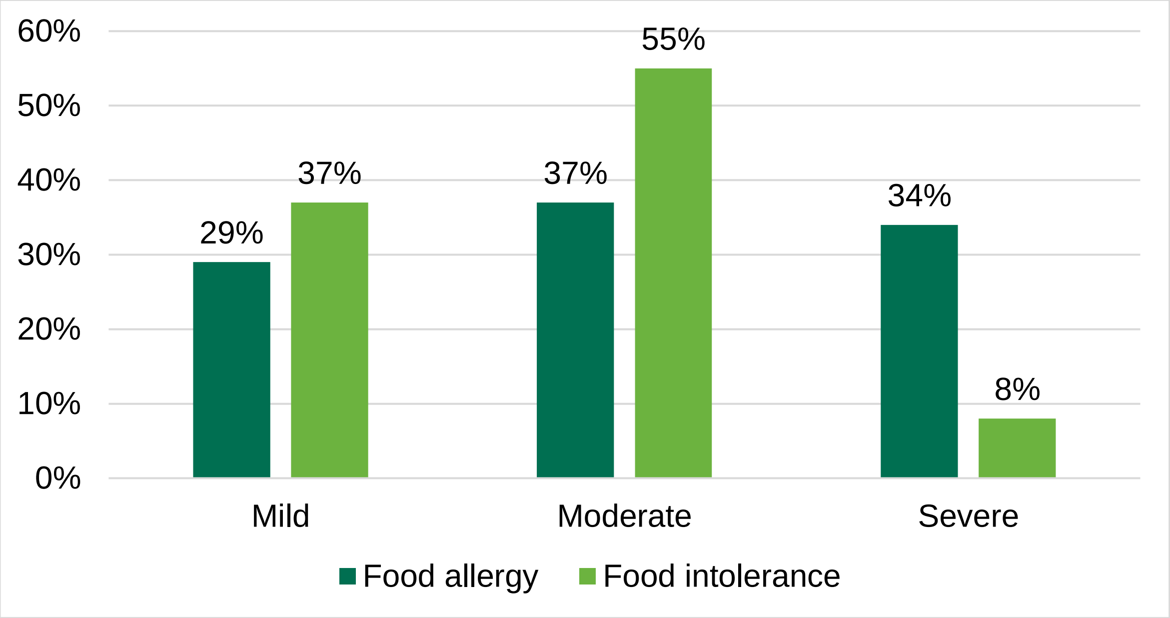
Foods with an adverse reaction

Children were also asked which foods had the most impact on their lives and could report on up to three foods in more detail. The most common number of foods reported was one (n = 234, 88%), with only 20 (7%) children reporting a second food and 13 (5%) reporting three foods. Across all foods reported (n = 310), the most common food to result in an adverse reaction was milk (n = 65; 21%). Of those reporting a reaction to milk, 60% were children with food intolerance (n = 39). Peanuts were the most frequently reported food for those with food allergy (n = 31; 25%), as well as milk (n = 19; 15%) and tree nuts (n = 18; 14%). In addition to milk (n = 39; 36%), eggs (n = 16; 15%) were also commonly reported by children with food intolerance. For a full breakdown of foods by hypersensitivity please see Annex C Table 81.

Children could categorise their reaction for each food they reported as food allergy (n = 129), food intolerance (n = 113), coeliac disease (n = 19), other or don’t know (n = 52; not focussed on exclusively in this report).

For 22% (n = 68) of the reactions to food reported, children rated their reaction as severe, 45% (n = 140) rated their reactions as moderate and 32% (n = 100) as mild. Reactions reported by children as food allergy (n = 47; 37%) and food intolerance (n = 58; 55%) were most commonly rated as moderate. However, more reactions reported by children with food allergy (n= 43; 34%) were rated as severe compared to those with food intolerance (n= 8; 8%; Figure 60).

Figure 60: Severity of reaction, by hypersensitivity



Base: All reactions reported by children from hypersensitive groups (Food allergy and intolerance only; 231): Food allergy (126); Food intolerance (105)

Symptoms

Across all foods, the most frequently reported symptoms experienced by the participants were gastrointestinal (34%). This was also true for those with food intolerance (54%). However, for children with food allergy reactions, the most common symptoms experienced were breathing symptoms (31%; Annex C Tables 82-84).

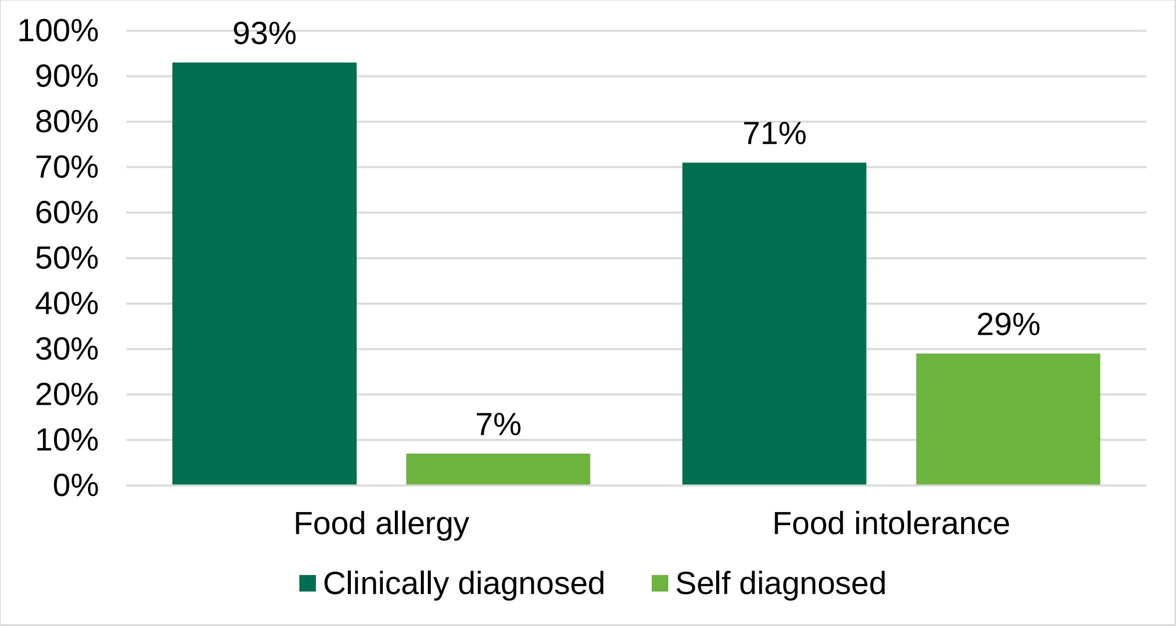
When asked to report the worst symptoms participants had ever had after eating the foods, the most severe symptoms for reactions experienced by all children (34%) and those reactions to foods reported by children with food intolerance (49%), were gastrointestinal. However, for reactions reported by children with food allergy, the most frequently reported severe symptoms were skin symptoms (26%, n = 158; Annex C Table 85).

Symptoms for most reactions (n = 111; 37%) started between 5-30 minutes of children consuming their stated food, except for reactions reported by children with food allergy, who typically reacted within 5 minutes of consuming their stated food (n = 47; 38%; Annex C Table 86).

Diagnosis

Children were asked how and who they had been diagnosed by, to determine whether they had been clinically diagnosed or were self-diagnosed. A majority of the sample reported that their reactions to the foods were clinically diagnosed (total n = 245; 83%). Across all hypersensitivities most participants reported their reaction as clinically diagnosed, with 93% of children reporting their food allergy reactions and 71% of children reporting their food intolerance reactions as having been clinically diagnosed (Figure 61).

Figure 61: Diagnosis by hypersensitivity

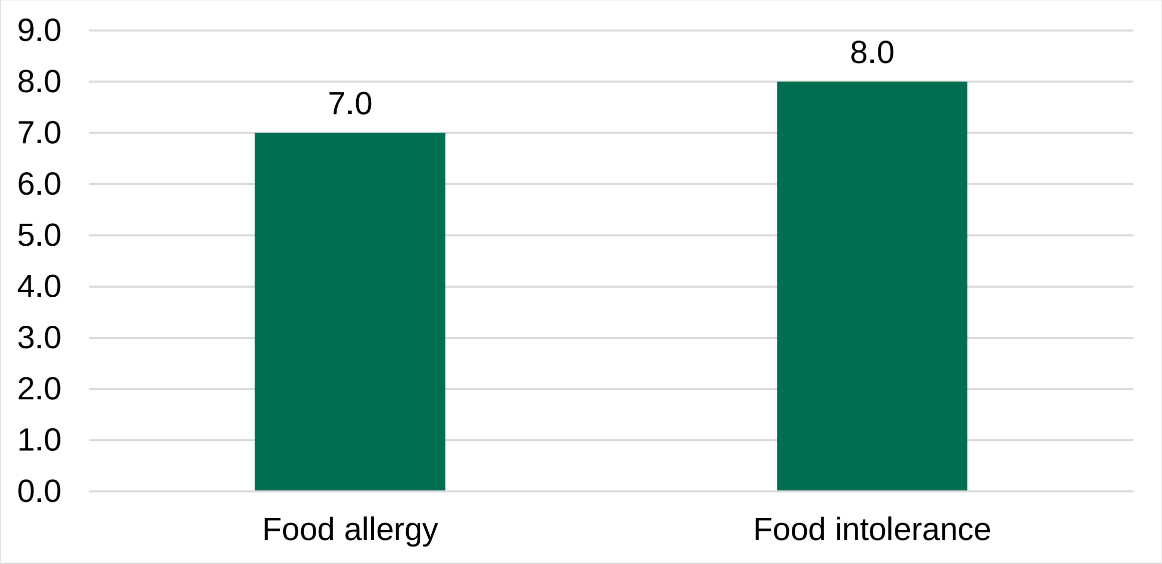


Base: All reactions to food given a diagnosis (221); Food allergy (123); Food intolerance (98)

The majority of all reactions to foods reported were diagnosed by a hospital doctor, nurse or a GP (or nurse; n = 252, 83%). The most commonly reported diagnosis methods included a blood test (n = 70, 18%), healthcare professional's diagnosis (n = 61; 16%) or skin prick test (n = 63; 16%). For 16% (n = 61) of reactions to foods, children reported that they had been informed by their caregiver (this could be in addition to other forms of diagnosis, as participants could choose as many diagnosis methods as they liked; see Annex C Table 87).

For 28% (n = 84) of the reactions reported, children reported always having their adverse reaction to the stated food. However, participants' average age that they remember starting to react to their first food was 7.8 years old (SD = 4.1). Those with food allergy (mean = 7.0, SD = 4.3) tended to start reacting at a younger age (Figure 62). Comparisons were not made for foods two and three, due to small numbers in these groups

Figure 62: Mean age (in years) children with each hypersensitivity were diagnosed for the first food they reported



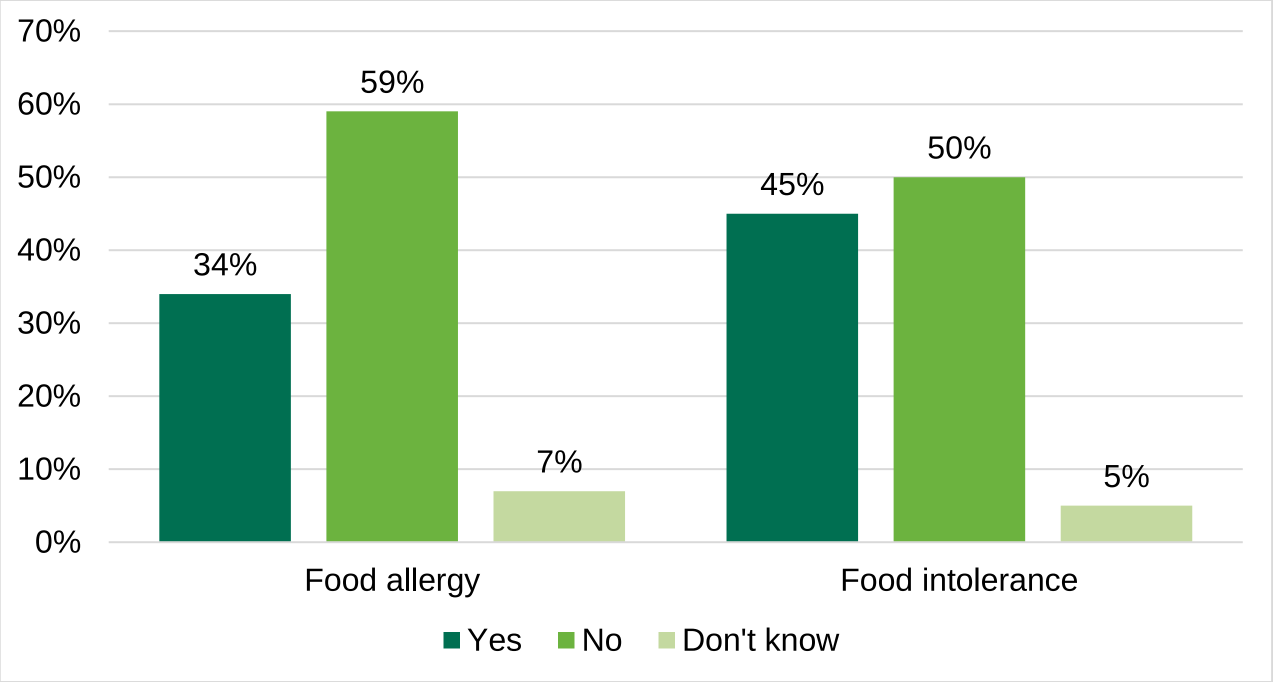
Base: All children with hypersensitivities (102); Food allergy (54); Food intolerance (48)

About their reaction

Thirty nine percent of the sample (n = 106) reported having been able to eat their stated food previously and not have a reaction to it (n = 147; 54% had not; n= 20, 7% reported ‘Don’t know’). This was also reflected for food allergy and food intolerance with children reporting that for 59% and 50% of reactions, they were unable to previously consume their stated food without experiencing a reaction (Figure 63).

For 21% (n = 63) of all reactions to foods, children reported that they had not reacted to their first food in the previous 12 months, however a further 21% reported they had reacted once (n = 62) and for 18% they had reacted twice (n = 53). Across hypersensitivities it was most common for no reaction to have occurred in the previous 12 months. Of those with a food allergy who had reacted to their stated food in the previous 12 months, it was most common to have reacted once (n = 29; 25%); for food intolerance it was most common to have experienced a reaction twice (n = 23; 23%). Participants with food intolerance also reported reacting more frequently to foods (e.g. 20% had reacted between 3-6 times and 19% more than 10 times; Annex C Table 88)

Figure 63: Percentage of participants able to eat stated foods previously



Base: All children in hypersensitive groups (for all foods) (205): Food allergy (113); Food intolerance (92)

Anaphylaxis

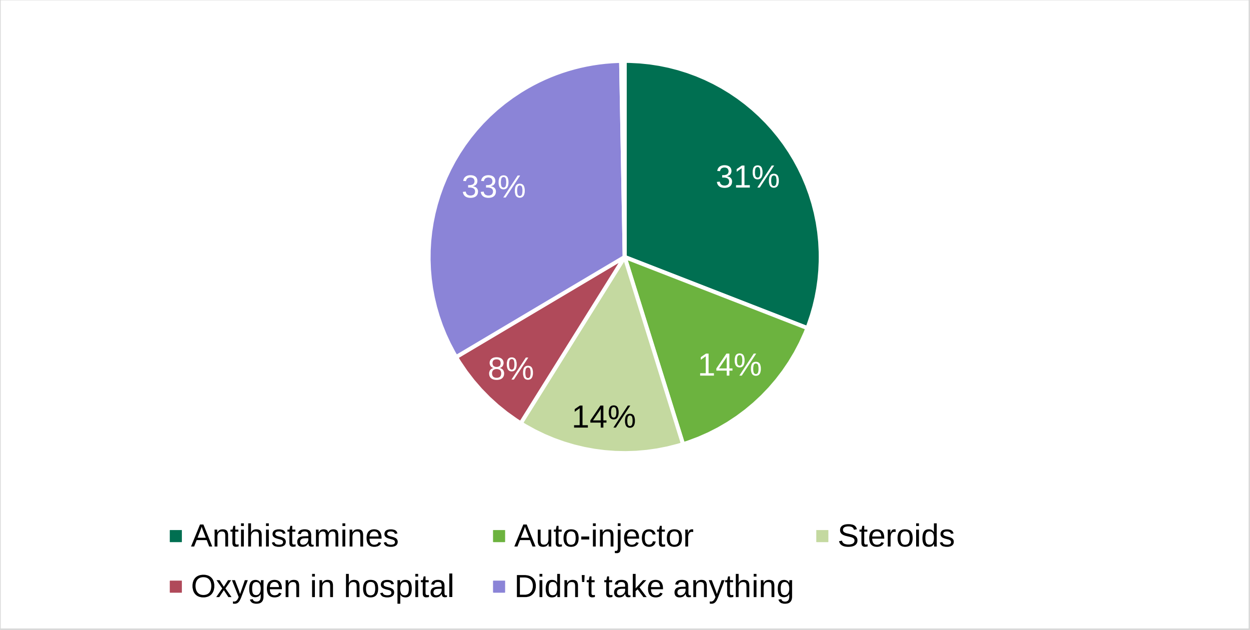
The total number of reactions reported by children who experienced anaphylaxis was 73 (24%), of which 66% (n = 48) were reactions reported by those with food allergy and 12% (n = 9) were reactions reported by those with food intolerance, indicating those with food allergy in this sample were most at risk of anaphylaxis. However, having those with food intolerance report anaphylaxis may indicate that participants may have misunderstood the question or miscategorised themselves, as this is not common for those with food intolerance, thus these results should be taken with some caution.

Similarly, 30% (n = 89) of all children had been prescribed an adrenaline auto-injector, of which 70% (n = 62) were participants with food allergy and 12% (n = 11) were children with food intolerance, again possibly reflecting that participants had either miscategorised themselves or misunderstood the question.

Treatment

Participants were asked about the treatments they had received for the reactions to the food stated. Although 33% reported not taking anything, antihistamines were the most common treatment reported (n = 106; 31%; Figure 64). Treatments were most commonly given for reactions reported by children with food allergy.

Figure 64: Treatments given for all foods



Base: All treatments for all reactions to foods reported by children (343)

Hospital admission

For 80% (n = 241) of the adverse reactions to foods reported, children had never had an ambulance called, and for 73% (n = 219) of reactions, children had never been admitted to hospital. For those that had been admitted to hospital (n = 83, 27% of all foods reported), 61 (73% of those who had been to hospital) were admitted the first time that they reacted. It was most common for children to report being admitted to hospital once (n = 27; 33%) or twice (n = 27; 33%). Across hypersensitivities, the group with the highest percentage of being admitted to hospital was children with food allergy (n = 55; 45%), with 71% (n = 39) of these going the first time that they reacted, and 40% (n = 22) only being admitted once.

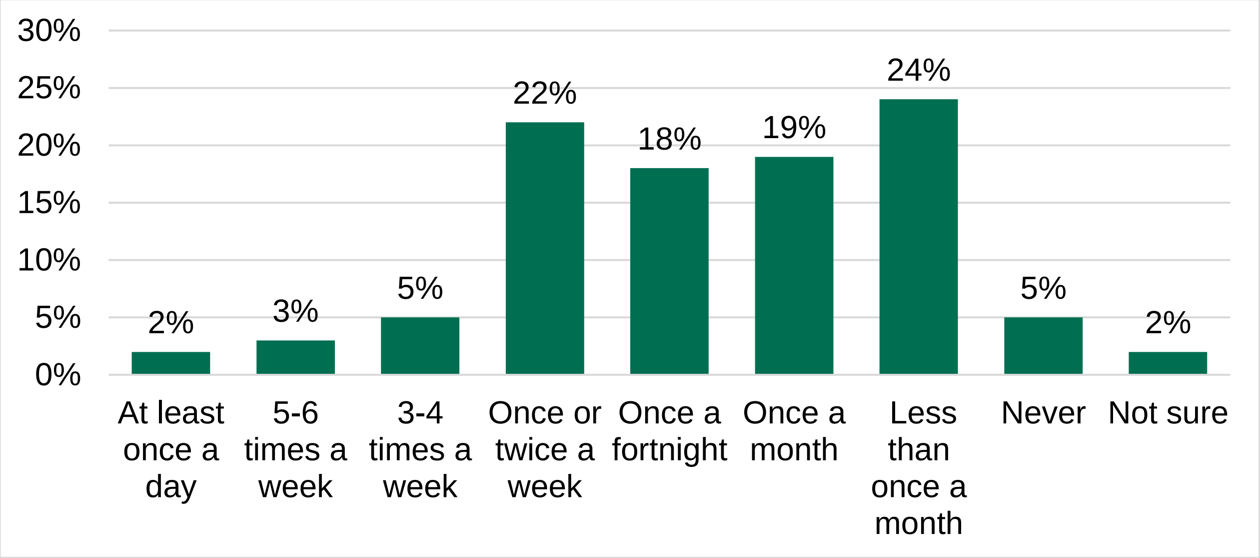
Eating out

Participants were asked how often they eat out, and how comfortable they feel with various aspects of eating out, such as asking for information from a member of staff. Questions asked about current eating out behaviour, however this was during the

COVID-19 pandemic when restrictions on eating out were variable, therefore responses may not reflect participants' usual behaviour.

Children most frequently reported eating out between once or twice a week and less than once a month (n = 211; 83% of all children; Figure 65).

Figure 65: How often participants eat out or get food to take away



Base: All children (252)

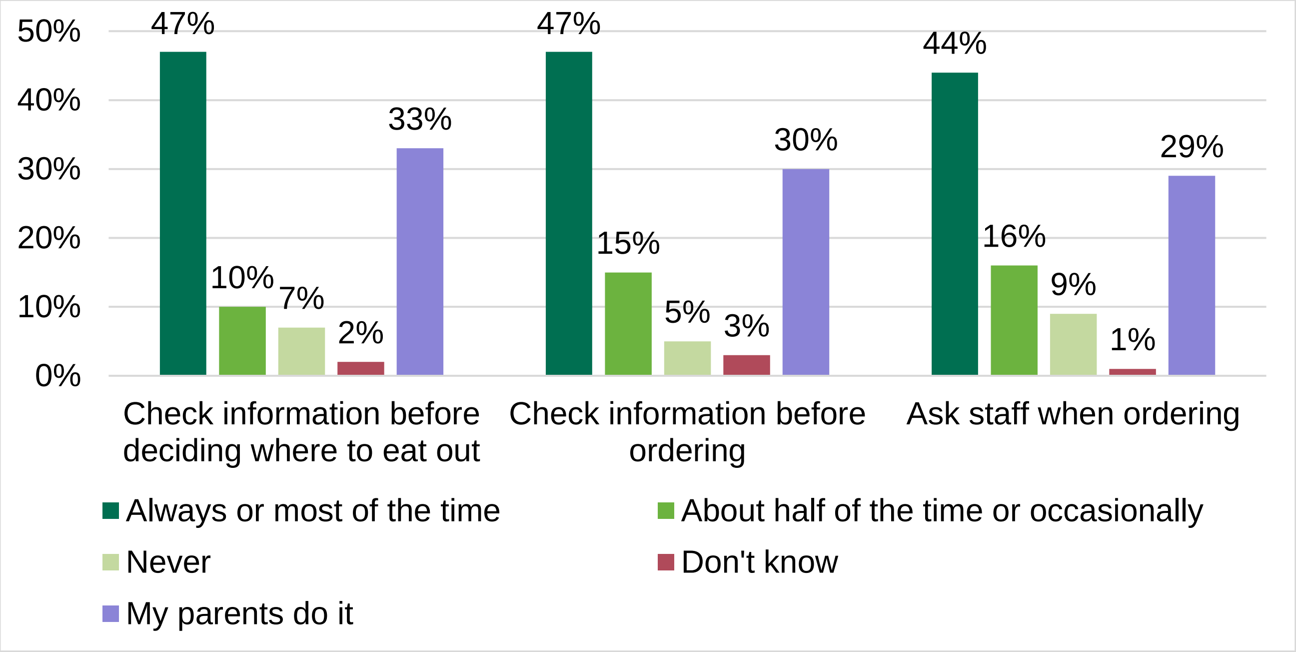
Across the hypersensitivities, child participants with food allergy most commonly ate out less than once a month (n = 24; 25%) and those with food intolerance (n = 23; 25%) most commonly ate out once or twice a week. However, there were no significant differences in how often children with different hypersensitivities eat out, with both groups on average eating out around once a month (*p* =.42). See Annex C Table 89.

Checking information when eating out

Children were asked how often they checked that there is information available that will allow them to identify foods that cause a bad or unpleasant physical reaction before deciding where to eat. They were also asked how often they review the available information, and how often they ask staff for information before ordering food.

Most children reported that they almost always reviewed information at each stage of eating out, but for many children, their caregiver was responsible for this (around 30% at each stage; see Figure 66).

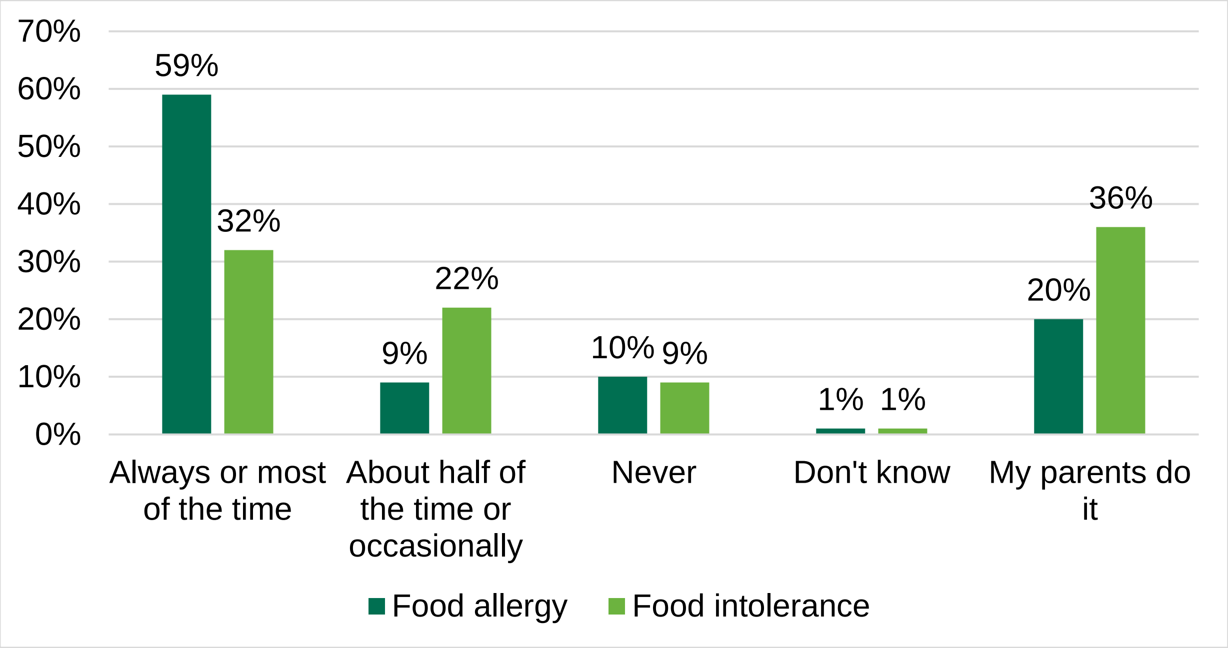
Figure 66: How often children review information when eating out



Base: All children; Check information before choosing where to eat out (237); Check information when ordering (236); Ask staff when ordering (235).

There were no significant differences in how often children with food allergy and food intolerance checked information was available before choosing where to eat out or reviewed available information before ordering food. However, there were significant differences for how often children ask members of staff for information about foods that may cause an adverse reaction, $t(122) = 2.13$, $p = .03$. Children with food allergy (mean = 3.9, SD = 1.4) asked for information significantly more often than children with food intolerance (mean = 3.4, SD = 1.4), on average reporting they asked for this most of the time (Figure 67).

Figure 67: How often children ask staff for information when eating out, by hypersensitivity

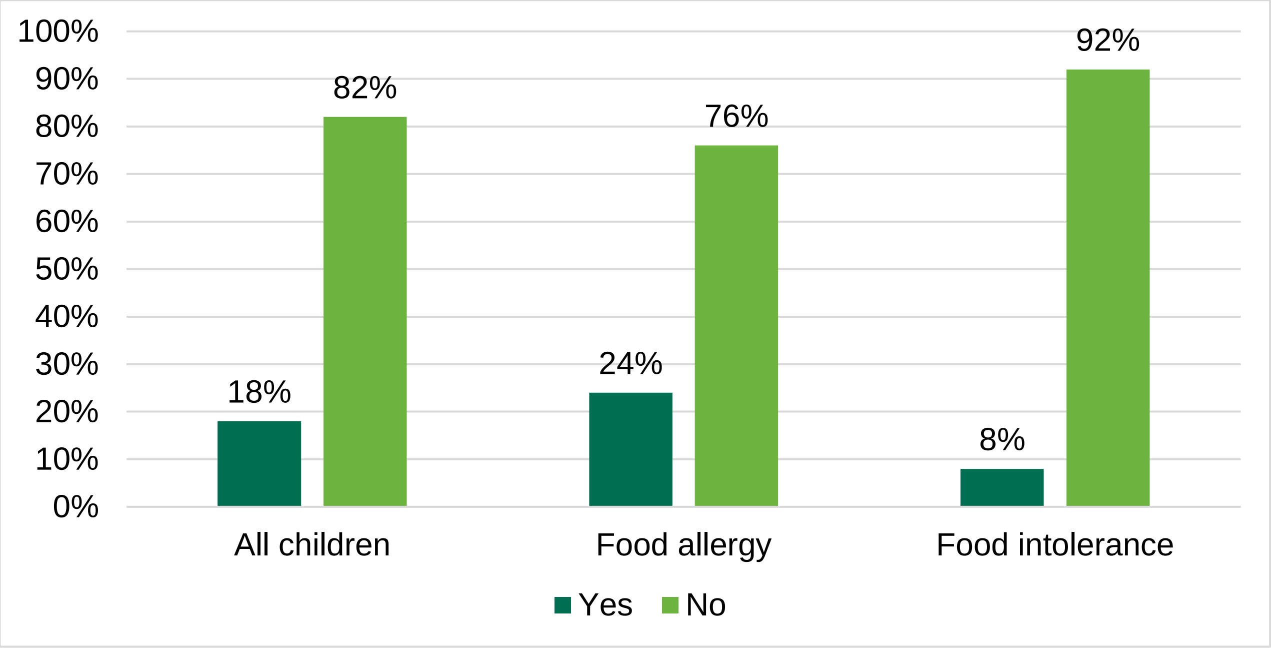


Base: Children with hypersensitivities; Food allergy (88); Food intolerance (88)

Participants were also asked how comfortable they felt asking a member of staff for information about food when eating out, because of a concern about experiencing a bad or unpleasant physical reaction. They were also asked how confident they were in the information provided when eating out. The majority of children reported being comfortable in asking staff for information (n = 130; 55% were very or fairly comfortable) and were confident in written (n = 132; 56% were very or fairly confident) and verbal information provided when eating out (n = 154; 65%). This was also true across hypersensitivities (Annex C Tables 90-92) and there were no significant differences observed by food hypersensitivity (all *ps*>.05).

Almost one in five (n = 41; 18%) of children reported they had been refused service because of their hypersensitivity (n = 184; 82% had not). Participants with food allergy (n = 21; 24%) were significantly more likely to report having been refused service than those with food intolerance (n =7; 8%), $\chi^2(1) = 8.4$, p = .004 (Figure 68).

Figure 68: Proportion of children refused service when eating out because of their reaction to food



Base: All children (225); Food allergy (86); Food intolerance (86)

Shopping

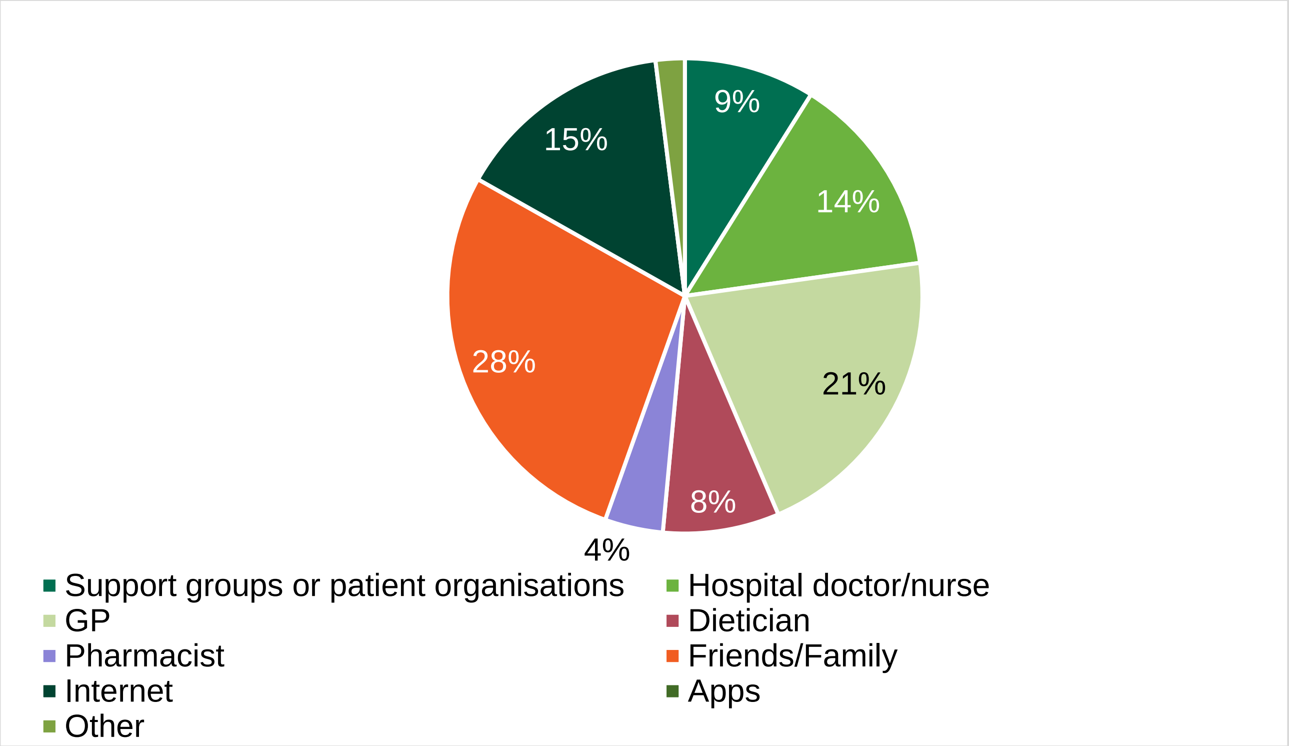
Children were asked how often they check information on food labels for ingredients that may cause a bad or unpleasant physical reaction. It was common for children to check labels for ingredients that would cause an adverse reaction ‘always or most of the time’ (53%; n = 132). Children were also asked how often they check labels on packaging for the possible presence of foods that may result in an adverse reaction (e.g. may contain). Fifty percent of children (n = 125) reported that they check for the possible presence of foods ‘always or most of the time’ (see Annex C Tables 93 and 94). It was also more common for those in the 8-12-year-olds sample to report that their parents checked labels for ingredients (n = 43; 40%) and for information on the possible presence of foods (n = 47; 44%) for them, compared to the 13-17-year-olds sample (n = 22; 18% and n = 24; 20% respectively).There were no significant differences in how often children with different hypersensitivities checked information on food labels (both *ps* >.05).

Sources of information

Children were asked about what sources of information they use to help manage their hypersensitivity (see Annex C Table 95). Participants could choose as many from the list that applied. Overall, one of the most frequently used sources of information for children was family and friends (n = 77; 29% of all responses). Of respondents reporting this, 45% (n = 35) were children with food allergy and 35% were children with intolerance (n = 27). Other popular sources of information for children were hospital doctors (n = 65, 24%) and GPs (n = 68; 25% of all children found these helpful). However, many children also reported self-managing their condition too (n = 67; 25%). Along with friends and family (n = 35, 34%), participants with food allergy most commonly reported using hospital doctors (n= 40, 39%) and GPs (n= 38, 37%) as sources of information to manage their condition, and those with food intolerance referred to GPs (n = 24; 24%) and the internet most (n = 20, 20%). For a full breakdown see Annex C Table 95.

The most helpful source of information reported across all children was friends/family (n = 64; 28%), followed by GPs (n = 49, 21%; see Figure 69). However, when children were split into the two age groups, the 13-17 sample (n = 112) were more likely to report friends/family (n = 28; 25%), the internet (n = 23, 21%) and GPs (n = 26; 23%) as the most useful source of information, whereas the 8-12 sample (n = 99) were most likely to find friends/family (n = 34, 34%), GPs (n = 21, 21%) and hospital doctors (n = 14, 14%) as the most useful sources of information. However, there were no significant associations for either group being more likely to report these sources of information as their most helpful sources, χ^2 (8) = 9.1, p = .33.

Figure 69: Most helpful sources of information for children



Base: All children (231)

Social situations

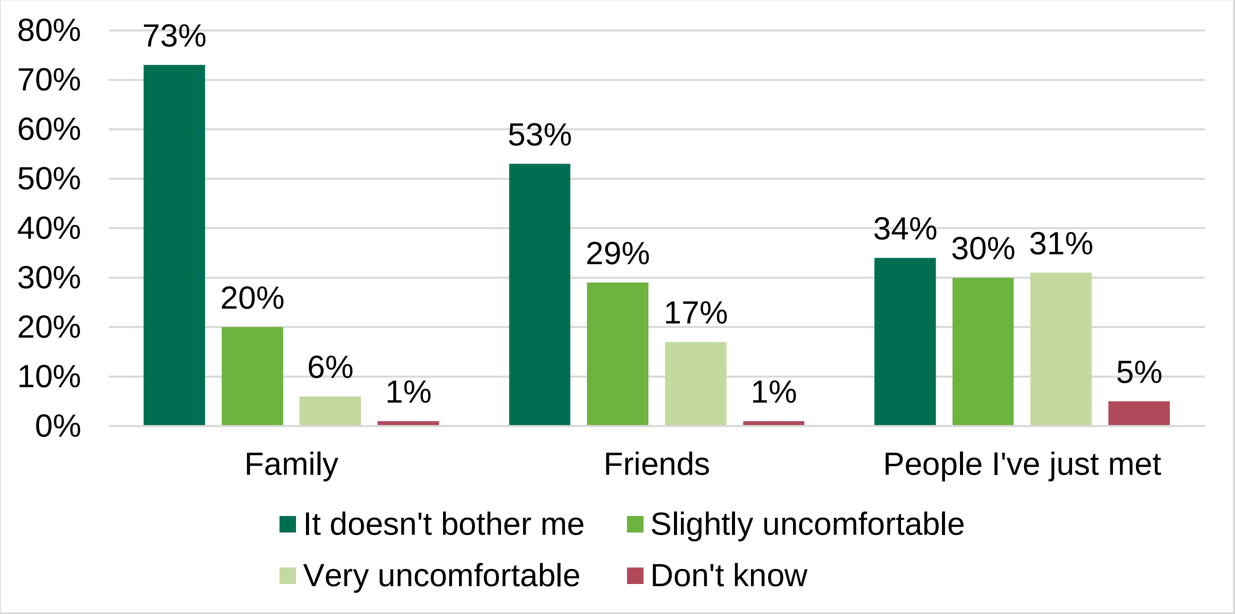
Children were asked how they felt about mentioning their food hypersensitivity or experiencing symptoms of a reaction in front of other people including friends, family and people they've just met. Most reported they were not bothered about mentioning their hypersensitivity in front of family (n = 174, 73%) and friends (n = 127, 53%). Children were equally divided about mentioning their hypersensitivity in front of people they had just met, with 34% reporting not being bothered by it, 30% feeling slightly uncomfortable and 31% very uncomfortable respectively (Figure 70).

Overall, children were less comfortable experiencing the symptoms of a reaction in social situations compared to mentioning their hypersensitivity. Sixty percent (n = 140) reported that it didn't bother them to experience symptoms of a reaction in front of their family. However, this decreased to 40% (n = 93) reporting this for experiencing symptoms in front of their friends, with 35% (n = 82) of respondents reporting being slightly uncomfortable. Children felt most uncomfortable about experiencing symptoms of a reaction in front of people they had just met (n = 97; 45% were very uncomfortable; Figure 71).

Most children with food allergy reported that it didn't bother them when mentioning their allergy in front of their family (76%) and friends (62%). However, this was slightly lower for those with food intolerance (67% for family and 49% for friends). While there were no significant differences between the two groups for mentioning their hypersensitivity in front of family, there was a significant difference for friends, *t*(170.1) = -2.3, *p* = .02, whereby children with food intolerance (mean = 1.7, SD = 0.8) felt significantly more uncomfortable mentioning their intolerance in front of friends, than children with food allergy (mean = 1.4, SD = 0.7).

Further, 43% of those with food intolerance felt very uncomfortable about mentioning their intolerance in front of people they'd just met, whereas this was true for only 16% of children with food allergy. Again this, difference was significant, *t*(167) = -4.2, *p* <.001, with children with food intolerance (mean = 2.2, SD = 0.8) feeling significantly more uncomfortable about mentioning their intolerance in front of people they'd just met, compared to children with food allergy (mean = 1.7, SD = 0.7; see Annex C Tables 97-99).

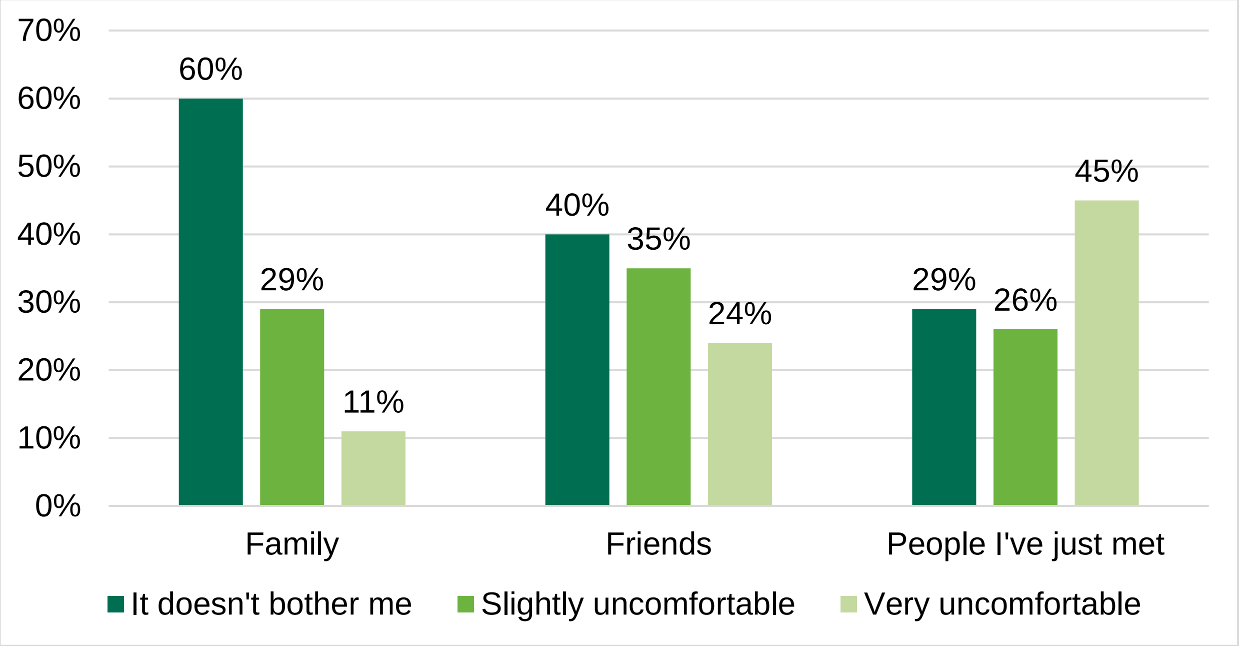
Figure 70: How comfortable children felt about mentioning their hypersensitivity in front of different groups



Base: All children; Family (240); Friends (240); People they've just met (230)

Children with food intolerance were most uncomfortable about experiencing symptoms of a reaction in front of people they had just met (49%). Children with food intolerance reported they were significantly more uncomfortable (mean = 2.3, SD = 0.8) experiencing symptoms of a reaction in front of people they'd just met, *t*(164) = -2.5, *p* =.01, than children with food allergy (mean = 2.0, SD = 0.9). There were no other significant differences for experiencing symptoms. See Annex C Tables 100-102.

Figure 71: How comfortable children felt about experiencing symptoms of a hypersensitive reaction in front of different groups



Base: All children; Family (233); Friends (231); People they've just met (214)

Quality of Life

Food hypersensitivity specific quality of life

Participants were asked to complete a health-related quality of life scale appropriate to the type of self-reported food hypersensitivity they reported for their first food. Those reporting a food allergy completed the Food Allergy Quality of Life Questionnaire (FAQLQ child or teen version), those reporting food intolerance completed Food Intolerance Quality of Life Questionnaire (FIQLQ child or teen version), and those reporting Coeliac Disease completed the CDDUX (a specific questionnaire for children of all ages with coeliac disease).

Children reporting multiple hypersensitivities completed the questionnaire appropriate to the first food they reported (e.g. if someone reported food allergy to their first food, intolerance to their second and third, they completed the FAQLQ). However, due to small numbers, results for those completing the CDDUX and those with multiple hypersensitivities are not reported here.

Quality of life in all children

The FAQLQ and FIQLQ are rated on a scale from 1 (least impact on quality of life) to 7 (most impact on quality of life). On both scales, the means were used (mean for each scale = 4, and reflects selected choice ‘moderately’), with high scores (closer to 7) indicating more impact upon quality of life. Children of different age groups completed age-appropriate scales. On average, teens and children with food allergy reported a mean of 4.8 out of 7, indicating they felt that their food allergy impacted their quality of life ‘moderately’ to ‘quite a bit’ compared to teens and children with food intolerance, who reported that their quality of life was impacted ‘moderately’ (4.3 out of 7; Table 3).

Table 3: Mean Quality of Life for each FH-specific scale, by age group

Respondent group	FAQLQ (Food allergy) N = 88	FIQLQ (Food intolerance) N = 84
All children Mean Total (SD)	4.8 (1.3)	4.3 (1.3)
8-12s Mean Total (SD)	4.4 (1.5)	3.9 (1.2)
13-17s Mean Total (SD)	5.1 (1.0)	4.6 (1.3)

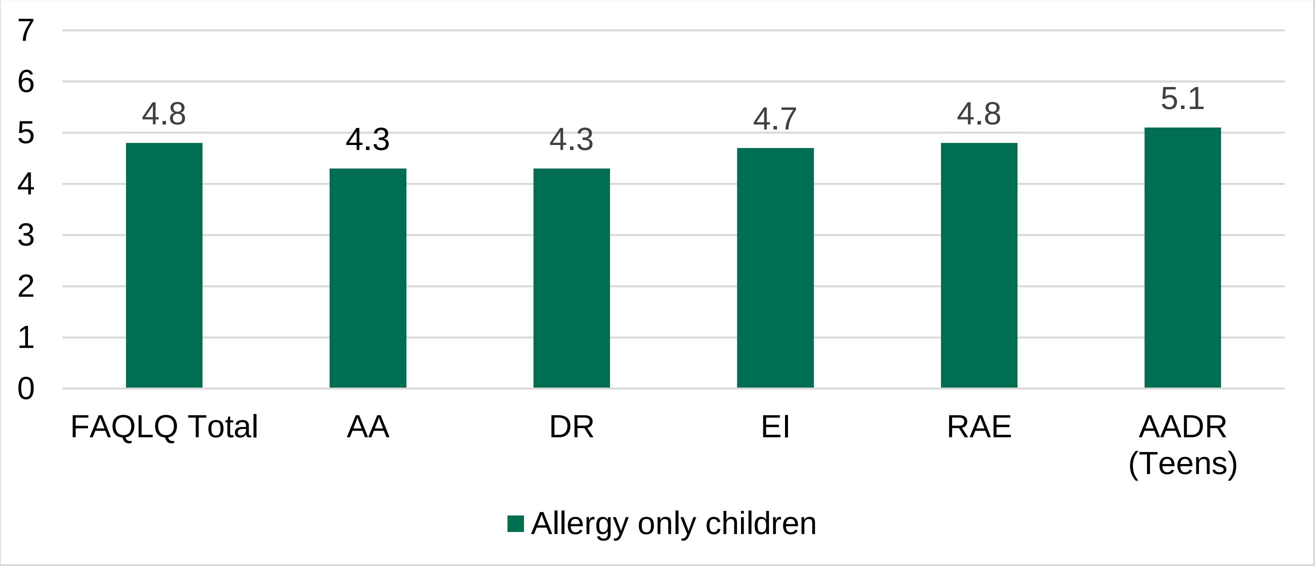
Quality of Life in children reporting allergy

The FAQLQ is comprised of the following sub-scales: Allergen Avoidance and Dietary Restrictions (AADR), relating to the impact of dietary and social limitations and allergy awareness behaviours (for example, checking whether you can eat something) to avoid an allergic reaction; Emotional Impact (EI), relating to the worries and concerns of having food allergy and of an allergic reaction; and Risk of Accidental Exposure (RAE), relating to the need for awareness of allergens in social situations and on packaging.

For each age group a different age-appropriate version of the FAQLQ was completed. Those aged 13-17 years completed the teen version and those aged 8-12 years completed the child version, which has separated Allergen Avoidance and Dietary Restrictions subscales. A total of 88 children completed the FAQLQ (of which all were from the allergy only group). Of those who completed the FAQLQ, 52 were from the 13-17 sample and 38 were from the 8-12 sample.

The impact on quality of life for all children (both age groups) with food allergy was above average (mean total = 4.8 out of 7, SD = 1.3), indicating quality of life was impacted 'moderately' to 'quite a bit'. Scores on the subscales for emotional impact (4.7 out of 7, reflecting choices 'moderate' impact or 'quite a bit' SD = 1.5) and risk of accidental exposure (mean = 4.8 out of 7 reflecting choices 'moderate' impact to 'quite a bit', SD = 1.5) were highest, reflecting that the worries and concerns around having food allergy and the awareness needed to check foods as a result of having allergy, were the areas which had the most impact on children's quality of life. For teens, the score on the allergy avoidance and dietary restrictions subscale (mean = 5.1 out of 7, SD = 1.3) were highest, indicating this had the most and 'quite a bit' of impact on quality of life for teenagers. Whereas, for 8–12-year-olds mean scores for the allergy avoidance subscale (related to allergy awareness behaviours; 4.3 out of 7) and dietary restrictions subscale (related to dietary limitations as a result of having food allergy; 4.3 out 7) were lower and indicated only moderate impact upon quality of life (Figure 72).

Figure 72: Mean FAQLQ scores for children reporting food allergy



Base: All children completing the FAQLQ in the food allergy only group (88)

Clinical factors correlated with children's FAQLQ scores included reported severity of their reactions (r = .53, p <.001), which was significantly positively correlated with impairment to children’s quality of life. Frequency of eating out was significantly negatively correlated (r = -.37, *p* =.01) with impairment to children’s quality of life. Additionally, frequency of checking available information when choosing where to eat out (r = .42) and reviewing this information before ordering food (r = .55) were significantly positively correlated with impaired quality of life in children with food allergy (both *p*s <.01).

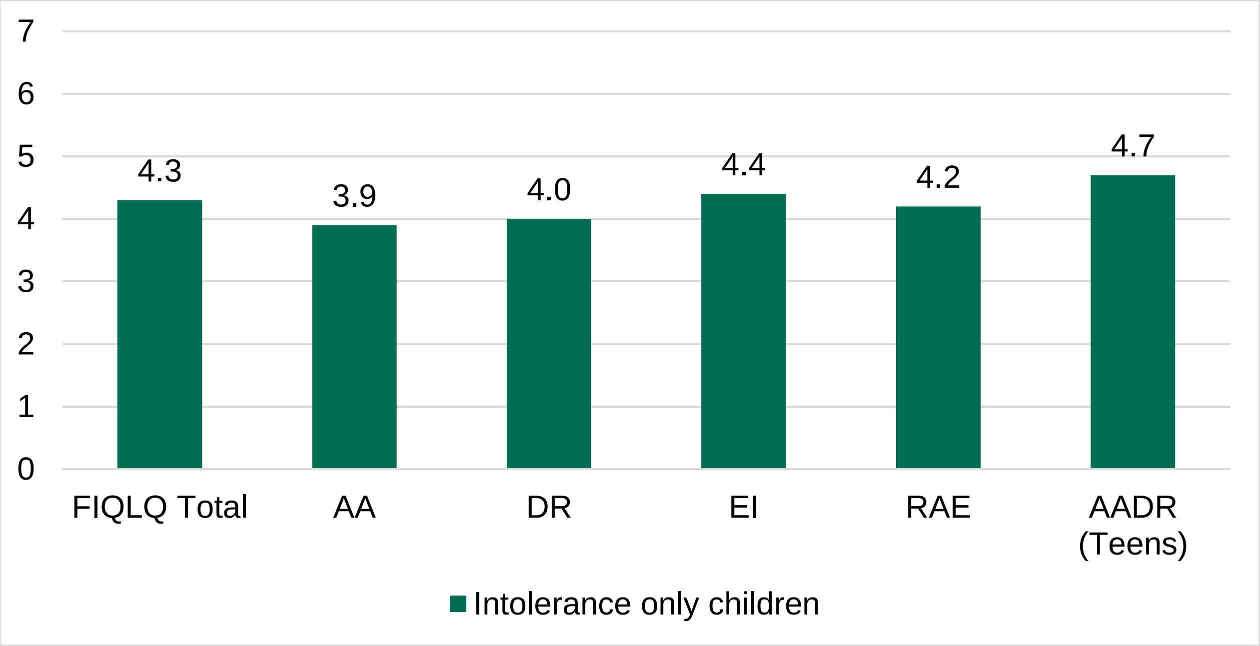
A regression model was run to see which of the variables described above might predict level of quality of life. All of the variables above which had a significant association with quality of life were included in the model (n=4 predictors). The overall model was significant (p<0.001) and 31% of the variance in quality of life was explained, indicating that 69% of the variance was due to other unknown factors. Greater self-reported severity significantly predicted poorer QoL (standardised beta 0.43). Greater frequency of eating out predicted better QoL (standardised beta 0.27). Severity rating was the strongest predictor of QoL. None of the other predictors were significant (standardised betas were -0.01 and 0.01, and confidence intervals for each predictor crossed zero).

Quality of Life in children reporting food intolerance

For the FIQLQ, the subscales comprise of: Allergen Avoidance and Dietary Restrictions (AADR) relating to impact of the social and dietary limitations of having food intolerance; Emotional Impact (EI) relating to the worries and concerns about having food intolerance and an adverse reaction, and Risk of Accidental Exposure (RAE) relating to the impact of the need to check whether foods are suitable to eat in order to avoid an adverse reaction. As with the FAQLQ, two different scales were used for younger (8-12 years) and older children (13-17 years). A total of 84 children from the food intolerance only group completed the FIQLQ. Thirty eight of the 8-12 sample, and 47 of the 13-17 sample completed the FIQLQ.

Children (aged 8-17 years) with food intolerance reported ‘moderate’ quality of life (mean = 4.3 out of 7, SD = 1.3; see Figure 79). The most impact on quality of life was reported for the emotional impact subscale (mean = 4.4 out of 7, SD = 1.4), indicating that the worries and concerns experienced by children with food intolerance has ‘moderate’ impact on their quality of life. However, the highest impact on quality of life across all age groups was reported by 13-17 year-olds who scored an average of 4.7 out of 7 (SD = 1.3) on the AADR subscale, indicating that the social and dietary limitations and need to be aware of foods as a result of having food intolerance had ‘moderate’ to ‘quite a bit’ and the most impact on their quality of life. On average, children with food intolerance tended to have slightly better average QoL than those with food allergy (see Figure 73).

Figure 73: Mean FIQLQ scores for children with food intolerance



Base: All children completing the FIQLQ (84)

For children with food intolerance, the severity of their reaction was significantly positively correlated with impairment to their quality of life (r = .41, p<.001). Further, frequency of checking available information when choosing where to eat out (r = .29), reviewing information before ordering (r = .37) and asking staff for available information when eating out (r = .30) were all significantly positively correlated with impairment to quality of life (all ps <.05). Checking labels for the possible presence of foods that may cause an adverse reaction (r = .23, p =.047) when shopping was also significantly positively correlated to impairment of child participants’ quality of life.

A regression model was run to see which of the variables described above might predict level of quality of life. All of the variables above which had a significant association with quality of life were included in the model (n=5 predictors). The overall model was significant (p<0.05) and 10% of the variance in quality of life was explained, indicating that 90% of the variance was due to other unknown factors. Greater self-reported severity significantly predicted poorer QoL (standardised beta 0.33). None of the other predictors were significant (standardised betas ranged from -0.01 and -0.13 and confidence intervals for each predictor crossed zero).

Differences in Quality of Life by hypersensitivity

Comparisons in QoL scores were made for clinical vs self-diagnosed children where possible, gender of those reporting hypersensitivities, age group (8-12s vs 13-17s) and severity of reaction. Comparisons were made where numbers allowed for this. Where more than two groups are compared, a Bonferroni correction has been applied to the significance level of 0.05 (/3 in all cases), thus a new level of .016 was used for more than two comparisons.

Food allergy only

Of the food allergy only group, 64 children completed all questions of the FAQLQ.

Gender

For children reporting food allergy only, 35 females and 28 males completed the FAQLQ. There were no significant difference in the impact of food allergy upon quality of life between males (mean = 5.0, SD = 1.1) and females (mean = 4.7, SD = 1.4) with food allergy, $F(1) = 0.75$, $p = .39$, $\eta p^2 = .01$

Age

Of the children completing the FAQLQ, 23 were younger children (8-12) and 29 were older children (13-17). There was no significant difference in impact upon quality of life between the two age groups, $F(1) = 0.3$, $p = .60$, $\eta p^2 = .01$, (means: 8-12 year olds = 4.8, SD = 1.3; 13-17 year olds = 5.0, SD = 1.2) although this could be due to small numbers in both groups.

Severity

There were significant differences in impact on quality of life according to the self-reported severity of reaction, $F(2) = 11.8$, $p < .001$, $\eta p^2 = .28$. Participants reporting a mild reaction to their first food (n = 20, mean = 3.9, SD = 1.1) reported significantly less impact upon quality of life than those reporting a severe reaction, (n = 21, mean = 5.6, SD = 0.9), $t(39) = -5.7$, $p < .001$.

While those with a moderate reaction (n = 23, mean = 4.8, SD = 1.4) also reported less impact upon quality of life than children with a severe reaction, according to the new alpha level of .016, this was not significant, $t(42) = -2.2$, $p = .03$. Similarly, there was no significant difference in impact upon QoL between children who had mild and moderate reactions to their first food, $t(41) = -2.5$, $p = .02$. However, the numbers of those in each group were small and so these results should be taken with some caution.

Food intolerance only

Of the food intolerance only group, 75 children completed all questions of the FIQLQ.

Gender

Of those children with food intolerance who completed the FIQLQ, 34 were male, 42 were female. There were no significant differences in impact upon quality of life scores between males (mean = 4.3, SD = 1.4) and females (mean = 4.3, SD = 1.3), $F(1) = 0.01$, $p = .91$, $\eta p^2 = .00$.

Age

Of those who completed the FIQLQ, 28 children were aged 8-12 years, and 39 were aged 13-17 years. There were no significant differences in QoL scores between younger children (mean = 4.0, SD = 1.2) and older children (mean = 4.6, SD = 1.3), $F(1) = 3.8$, $p = .06$, $\eta p^2 = .06$, however, this may be due to small numbers of participants in each group.

Clinical diagnosis

Participants with a clinical diagnosis (n = 52, mean = 4.4, SD = 1.2) reported more impact upon quality of life than those who were self-diagnosed (n = 23, mean = 3.9, SD = 1.4), however this was not a significant difference $F(1) = 2.4$, $p = .12$, $\eta p^2 = .03$.

Coeliac disease only

For those in the coeliac group, 18 completed the CDDUX, however this was deemed too small a group to conduct sub-analysis on.

Multiple hypersensitivities

For children with multiple hypersensitivities, only 2 completed the FAQLQ, 1 completed the FIQLQ and 1 completed the CDDUX, thus this group was too small to make comparisons for.

Generic quality of life

Children with food hypersensitivity

Children aged 8-12 years completed the EQ-5D-3L. The mean quality of life scores on the VAS were similar for children with food allergy (n=28, mean = 83.25, SD = 16.88), and those with food intolerance (n=34, mean score = 83.88, SD = 12.92). Those with coeliac disease scored lower (n=5, mean = 80.80, SD = 14.55), but numbers in this group are extremely low and so results should be interpreted with caution. On the EQ-5D-3L sub-domains, Pain and Anxiety dimensions are markedly worse for the 8-12-year olds, than the other EQ5D dimensions.

Teens with food hypersensitivity

Children aged 13-17 years completed the EQ-5D-5L. The mean quality of life scores on the VAS were highest for teenagers with food allergy (n=53, mean = 81.32, SD = 16.69), followed by those with coeliac disease (n=12, mean = 76.08, SD = 16.56) and those with a food intolerance who scored lowest (n=48, mean score = 73.81, SD = 12.72). Numbers for coeliac disease are low and so results for this group should be interpreted with caution. On the EQ-5D-5L sub-domains, Pain and Anxiety dimensions are markedly worse for the 13-17-year olds, than the other EQ5D dimensions.

Conclusions

The first wave of this UK based survey has provided a wealth of data on the impact of FH on day-to-day activities and quality of life of adults and children. This survey was completed by nearly 2,000 people from all regions of the UK, aged from 8-86 years old. A wide variety of foods were reported which included the 14 allergens which are required by law to be listed as ingredients. Participants with clinically diagnosed as well as self-diagnosed FHs answered a range of questions about their reactions to food, including their behaviour when eating out, shopping, checking food labels, reacting to food in social situations and their quality of life.

Eating out

Participants were asked to report how often they ate out and how comfortable they were with various aspects of this activity, such as asking staff for information because of a concern about experiencing an adverse or unpleasant physical reaction. Across adults, parents and children, the majority reported that they check or review information at each stage of eating out (such as before choosing where to eat, and before ordering) to enable them to identify foods that may cause an unpleasant reaction. There were some differences across types of food hypersensitivity, with lower rates of reviewing available information before ordering food reported by adults with food intolerance and parents of children with food intolerance, compared to the other groups. Around half of adult and child participants, and the majority of parents were also comfortable asking staff for information when eating out because of a concern about experiencing a reaction.

The majority of adults reported being confident in written information provided by staff when eating out, but less than half reported feeling confident with verbal information. Adults with food intolerance reported being more confident in verbal information provided by staff than adults with food allergy. Similarly, the majority of parents were confident in both written and verbal information given, and parents of children with food intolerance were significantly more confident in verbal info provided by staff than parents of children with food allergy or coeliac disease. Over half of child respondents were very or fairly confident with verbal information provided by staff when eating out. Over half of the children were also very or fairly comfortable in asking staff for information. It is important that children learn to manage their FH as they grow older and become more independent of their parents. This data is therefore very encouraging although it might be influenced by the age of the child. Children aged 8 to 17 years took part and so it will be important to see if there are any age differences in further analysis of this data.

Around one in four adult respondents, and one in five parent and child respondents, reported being previously refused service because of their reactions to food. About one in ten adult and parent respondents had previously been asked to sign a disclaimer because of their or their child's reactions to food. It may therefore be important to investigate the ability and confidence in waiting staff in restaurants to provide suitable information for people with FH.

Shopping

Participants were asked how often they check information on food labels for ingredients, or the possible presence of food that may cause them a bad or unpleasant physical reaction, in various types of shops. Most adult and parent participants reported that they checked labels always or most of the time. There were some differences across groups with adults and parents of children with food intolerance tending to check less often than participants with other FHs. Children reported checking labels less often than adults or parents, but unsurprisingly reported that their parents tended to do this for them. Analysis by age needs to be conducted here to see if this is only the case for the younger children. Checking food labels is an important part of FH management and it is encouraging that participants reported doing this activity. It should be noted, however, that checking labels is a socially desirable answer and this may have affected the results, although it is impossible to tell by how much.

The level of confidence consumers have in being able to identify foods that cause a reaction is important to understand. Those affected by FH need to be confident that the information provided on labelling or otherwise will enable them to make the right decision regarding the safety of the food. In general, the majority of respondents expressed confidence that this information allows them to identify foods that cause a reaction, but this varied according to the place in which the food was being sold from. Adults and parents reported being more confident in information provided for food sold from in store supermarkets and online supermarkets compared to independent food shops and food markets/stalls. They were less confident in identifying food sold loose that could cause a reaction, compared to labelled food. Increasing confidence in identifying ingredients in food sold loose that cause a reaction is, therefore, important for those with FHs to enable them to feel able to purchase this type of food.

Sources of information

A range of information sources were reported by participants, with patient organisations being seen as most helpful for adults with food allergy and coeliac disease. Those with food intolerance stated the internet was most helpful. This may be because patient organisations such as Allergy UK, The Anaphylaxis Campaign and Coeliac UK appear to be less relevant for those with food intolerance, who also said family and friends were more helpful in comparison to the other FH groups. Compared to other FH groups, those with food allergy also reported that a hospital doctor was the most helpful source of information. This may reflect the lack of diagnostic tests for food intolerance, and a higher proportion of people in this group self-diagnosing.

Similar proportions of parents rated hospital doctors, GPs, patient organisations and the internet as most helpful, although parents of children with food allergy found hospital doctors the most helpful. Almost all parents reported a clinical diagnosis for their child and so it is not surprising they have had helpful information from healthcare practitioners.

Children reported family and friends to be the most helpful source of information, followed by hospital doctors and GPs. For older children (13-17-year olds), the internet was also cited as a helpful source of information. It is important therefore the family and friends are well informed about FH in order to ensure misinformation is not passed on. Likewise, it is important that people with FH are directed towards trustworthy internet sites, such as those run by patient organisations.

Social situations

Participants were asked how they felt about mentioning their food hypersensitivity or experiencing a reaction in front of others, including friends, family, work colleagues and people they've just met. Most adult, parent and child participants were comfortable talking about their FH or their child's FH to others, although understandably adults and children were less comfortable talking about it to people they had just met. This was slightly different for parents, with over half reporting that it would not bother them to talk about their child's FH to those they had just met.

Around half of adults reported they would be very uncomfortable experiencing a reaction in front of work colleagues or people they had just met. Similarly, most children said that experiencing a reaction in front of family would not bother them, but just under half would feel very uncomfortable in front of people they had just met. Interestingly, children with food intolerance reported that they would be more uncomfortable, compared to children with food allergy, in mentioning their food intolerance to friends and people they had just met, as well as experiencing symptoms of a reaction in front of people they had just met.

Reasons for these findings need further investigation. It is unclear whether participants feel embarrassed, lack confidence or do not want to be labelled by their FH, all of which have been reported in the literature (Cummings et al., 2010; DunnGalvin et al., 2009). It may also be that reasons are different for the different participant groups and for different age groups.

Quality of life

Participants were asked to complete a health-related quality of life scale appropriate to the type of self-reported FH they reported for their first food and a generic health related quality of life scale. All participants reported that their FH or their child's FH impacted their lives by 'quite a bit' or 'very much'. A number of clinical factors were related to quality of life. In particular, markers of FH severity were related to poorer quality of life across many of the groups, such as having another atopic condition (e.g. asthma or eczema), being prescribed an adrenaline auto-injector, having experienced anaphylaxis, being admitted to hospital, the number of foods they react to and self-reported severity. Self-reported or parental reported severity of FH was related to the level of quality of life as measured by the FH specific validated QoL scales. Severity also significantly predicted QoL for adults with any FH, and for children with food allergy or intolerance. Severity was the strongest predictor for adults with food intolerance and children with food allergy or food intolerance. The relationship between self-reported severity and QoL ratings from validated scales has been reported in previous studies in parents of children with peanut allergy (Acaster et al., 2020a, 2020b) and so asking about severity may be a good indicator of the impact of FH which can be completed very quickly by individuals and families.

FH specific QoL was related to eating out activities in meaningful ways. Being able to eat out more frequently was related to better QoL for adults with food allergy or coeliac disease, and for children with food allergy and parents of children with food intolerance. Being more comfortable asking staff for information about food, and higher confidence in the verbal or written information provided about food when eating out, were related to better quality of life in adults. However, a greater frequency with which participants had to check information at various stages of eating out was related to poorer QoL. This was the case for adults, parents of children and children themselves with food allergy or food intolerance but not those with coeliac disease. This is in keeping with the theory that checking behaviour creates a greater burden on the individual or parent, which has an impact on QoL. Being able to eat out and have confidence in the information provided, without feeling that checking information is a burden, therefore needs to be supported for those with FH.

In the regression models, frequency of checking information when eating out was a significant predictor for the adult food allergy group only. For many of the models a good proportion of variance in quality of life was explained but few or no individual predictors were significant. This may be due to multicollinearity in the data, with predictor variables correlating with each other. Further analysis should take this into account and control for the variance explained by clinical variables before entering variables related to eating out and reading of labels. The models for coeliac disease explained much less of the variance in quality of life. This can be partly explained by the smaller number of predictors entered into the models, but other factors not measured in the current study should be considered as possible contributors to quality of life in this group.

Adults, parents of children, and children themselves with food intolerance reported poorer generic quality of life than those with food allergy or coeliac disease. It is unclear why this might be. Many of those with food intolerance said it was self-diagnosed and so may not have had the benefit of advice and support from a healthcare practitioner. Those with food allergy and coeliac disease reported finding patient organisations very helpful whereas those with food intolerance relied more on the internet. This might also have had an impact on their QoL. Reasons for this finding require further investigation.

Across all groups generic quality of life related to pain, anxiety and depression was reportedly worse than other sub-domains such as usual activities, mobility or self-care. This is an interesting finding as you would not expect pain to be related to FH as symptoms are only experienced when the food is eaten by mistake. It may be related to other long-term conditions reported by respondents and this needs further investigation.

Limitations

There are some limitations to take into consideration in this report. For adults and parents there was a predominance of female respondents and so results may not always also apply to men. However, parents reported FHs for almost equal numbers of male and female children; similarly, the gender split was more equal for the child self-report survey. Across all surveys there was a predominance of participants with a White British background and results may be different for people from different ethnic backgrounds. Amongst adults, half the sample reported another long-term condition and a fifth reported having psychological therapy. Parents reported that a third of their children with FH also had another long-term condition, whilst almost a third of children reported this themselves. These other conditions could have an impact on daily life such as the ability to eat out and could have had an impact on the quality of life results. Further analysis of the data in this report could look at controlling for these variables in the analysis.

A wide variety of foods were reported, however, to avoid overburdening respondents, the survey only asked for specific details on up to three foods per participants (and for parents, for three foods per child in up to three children). This means that more detailed data is missing for those with hypersensitivity to more than three foods or more than three children with FH. This may have affected only a minor number of participants though, as across all groups the majority reported reacting to just one food.

Some groups reported symptoms that would not be expected. For example, a small number with self-reported coeliac disease or food intolerance reported anaphylaxis. A definition of anaphylaxis was given to participants and so confusion as to what the term meant may not be the cause of this. It is possible that some participants had undiagnosed food allergy which caused an anaphylactic reaction, but it is unlikely that such a severe reaction would have gone undiagnosed. It may also be the case that these participants misinterpreted their condition and had food allergy. Misunderstanding of the different FHs and erroneous self-diagnosis is common (Knibb, 2019). Indeed, over half of adults who reported their FH was a food intolerance in this survey stated that this was self-diagnosed. It may be possible to explore these issues further within the data and this is something to be aware of when collecting data for wave two.

When asked about eating out, participants were asked to report what they usually did and how they usually felt, however they completed surveys during the Covid-19 pandemic and restrictions on eating out were in place at that time. These restrictions were varied across the UK and varied over time, with a stricter lockdown and closure of restaurants coming into force in the last month of data collection. Participants may therefore have reported lower frequencies of eating out, but it is less clear if the restrictions would have affected ratings of other activities such as confidence in information provided by venues.

References

Acaster, S., Gallop, K., de Vries, J., Ryan, R., Vereda, A., Knibb, R.C. (2020a). Psychosocial and productivity impact of caring for a child with peanut allergy. *Allergy, Asthma and Clinical Immunology* 16, 83. https://doi.org/10.1186/s13223-020-00477-3

Acaster, S., Gallop, K., de Vries, J., Ryan, R., Vereda, A., Knibb, R.C. (2020b). Peanut Allergy impact on Productivity and Quality of life (PAPRIQUA): The psychosocial impact of peanut allergy in children. *Clinical and Experimental Allergy* 50, 1249-1257. https://doi.org/10.1111/cea.13727

Begen, F.M., Barnett, J., Payne, R., Gowland, M.H., DunnGalvin, A., Lucas J. (2018). Eating out with a food allergy in the UK: Change in the eating out practices of consumers with food allergy following introduction of allergen information legislation. *Clinical and Experimental Allergy*, 48, 317-324. https://doi.org/10.1111/cea.13072

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

Cummings AJ, Knibb RC, King RM & Lucas JS. (2010). The psychological impact of food allergy and food hypersensitivity in children, adolescents and their families: A review. *Allergy*, 65, 933-945. https://doi.org/10.1111/j.1398-9995.2010.02342.x

DunnGalvin A, Gaffney A. & Hourihane J. (2009). Developmental pathways in food allergy: a new theoretical framework. *Allergy*, 64, 560-8. https://doi.org/10.1111/j.1398-9995.2008.01862.x

Gallagher M, Worth A, Cunningham-Burley S, & Sheikh A. (2011). Epinephrine auto-injector use in adolescents at risk of anaphylaxis: a qualitative study in Scotland, UK. *Clinical and Experimental Allergy*, 41, 869-77. https://doi.org/10.1111/j.1365-2222.2011.03743.x

Knibb, R.C. (2019). Why do people mis-diagnose themselves with food hypersensitivity? An exploration of the role of biopsychosocial factors. *European Medical Journal*, 4(1), 30-37.

Morou Z, Tatsioni A, Dimoliatis IDK, Papadopoulos NG. (2014). Health-related quality of life in children with food allergy and their parents: A systematic review of the literature*. J Investigative Allergol Clin Immunol*, 24, 288-297.

Annex of Tables

Annex A: Adults with FHs

For the following tables, percentages may add up to more than 100, due to rounding. Additionally, '*' indicates below '0.5%'.

Table 4: Ethnicity by food hypersensitivity

Ethnicity	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple food hypersensitivities N (%)
White British/Irish	961 (95)	153 (91)	197 (92)	401 (98)	131 (97)
Mixed/multiple ethnicity	15 (1)	3 (2)	5 (2)	4 (1)	-
Asian (Indian, Chinese, Bangladeshi, Pakistani) background	21 (2)	6 (4)	8 (4)	2 (*)	2 (1)
Black British/African/Carribean	9 (1)	2 (1)	5 (2)	-	1 (1)
Arab	2 (*)	1 (1)	-	-	-
Other ethnic group	8 (1)	3 (2)	-	2 (*)	1 (1)
Total (N)	1,016	168	215	409	135

Table 5: Region by food hypersensitivity

Region	**All adults** **N (%)**	**Food allergy** **N (%)**	**Food intolerance** **N (%)**	**Coeliac disease** **N (%)**	**Multiple food hypersensitivities** **N (%)**
Scotland	91 (9)	17 (10)	17 (8)	43 (11)	7 (5)
Northern Ireland	12 (1)	3 (2)	3 (1)	5 (1)	-
Wales	44 (4)	10 (6)	7 (3)	16 (4)	5 (4)
North East of England	40 (4)	4 (2)	3 (1)	21 (5)	5 (4)
North West of England	109 (11)	14 (8)	17 (8)	48 (12)	10 (7)
Yorkshire and the Humber	68 (7)	6 (4)	17 (8)	31 (8)	11 (8)
East of England	95 (9)	13 (8)	21 (10)	40 (10)	15 (11)
East Midlands	74 (7)	10 (6)	12 (6)	31 (8)	11 (8)
West Midlands	87 (9)	12 (7)	22 (10)	31 (8)	14 (10)
London	113 (11)	33 (20)	24 (11)	27 (7)	20 (15)
South West of England	96 (9)	15 (9)	20 (9)	42 (10)	15 (11)

South East of England	185 (18)	30 (18)	52 (24)	73 (18)	22 (16)
Total (N)	1,014	167	215	408	135

Table 6: Employment status by food hypersensitivity

Employment	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple food hypersensitivities N (%)
Full-time	348 (34)	73 (44)	71 (33)	139 (34)	39 (29)
Part-time	154 (15)	37 (22)	31 (14)	60 (15)	18 (13)
Unemployed	31 (3)	4 (2)	10 (5)	5 (1)	2 (1)
Not working	123 (12)	20 (12)	36 (17)	31 (8)	21 (16)
Not working (retired)	273 (27)	16 (10)	52 (24)	145 (36)	40 (30)
Student	48 (5)	11 (7)	10 (5)	19 (5)	4 (3)
Other	33 (3)	6 (4)	4 (2)	9 (2)	10 (7)
Total (N)	1,010	167	214	408	134

Table 7: Other reasons for excluding foods from diet, by hypersensitivity

Reason for excluding foods	**All adults N (%)**	**Food allergy N (%)**	**Food intolerance N (%)**	**Coeliac disease N (%)**	**Multiple food hypersensitivities N (%)**
Vegan/vegetarian/pescatarian diet	116 (11)	14 (8)	34 (16)	45 (11)	15 (11)
Weight loss	60 (6)	10 (6)	23 (11)	17 (4)	5 (4)
Weight maintenance	31 (3)	4 (2)	7 (3)	10 (2)	4 (3)
Health reasons (unrelated to allergy)	88 (9)	8 (5)	27 (13)	33 (8)	8 (6)
Religious reasons	15 (1)	5 (3)	5 (2)	2 (*)	2 (1)
Other	44 (4)	5 (3)	8 (4)	15 (4)	9 (7)
Don’t exclude food	695 (68)	124 (73)	124 (57)	296 (72)	94 (70)
Total respondents (N)	1,019	170	216	409	135

Table 8: All foods reacted to (no limit on number of foods reported), by hypersensitivity

Food	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple food hypersensitivities N (%)
Celery	30 (1)	13 (2)	3 (1)	6 (1)	7 (1)
Cereals containing gluten (wheat, rye, barley or oats)	650 (22)	31 (4)	95 (19)	395 (59)	112 (16)
Crustaceans (such as prawns, crabs, scampi or lobsters)	70 (2)	20 (2)	14 (3)	10 (1)	22 (3)
Eggs	99 (3)	27 (3)	27 (5)	12 (2)	24 (3)
Fish	43 (1)	12 (1)	5 (1)	4 (1)	18 (3)
Lupin	20 (1)	9 (1)	1 (*)	2 (*)	6 (1)
Milk	249 (9)	30 (3)	81 (16)	51 (8)	75 (11)
Molluscs (such as mussels, snails, squid, whelks, clams or oysters)	62 (2)	16 (2)	12 (2)	12 (2)	18 (3)
Mustard	35 (1)	7 (1)	5 (1)	10 (1)	6 (1)
Peanuts	125 (4)	74 (9)	11 (2)	8 (1)	28 (4)
Tree nuts: Almonds	113 (4)	61 (7)	13 (3)	7 (1)	27 (4)
Tree nuts: Hazelnuts	107 (4)	60 (7)	8 (2)	7 (1)	28 (4)
Tree nuts: Brazil nuts	101 (3)	58 (7)	8 (2)	3 (*)	26 (4)
Tree nuts: Walnuts	101 (2)	59 (7)	9 (2)	3 (*)	26 (4)
Tree nuts: Cashew nuts	95 (3)	52 (6)	10 (2)	3 (*)	25 (4)

Food	**All adults N (%)**	**Food allergy N (%)**	**Food intolerance N (%)**	**Coeliac disease N (%)**	**Multiple food hypersensitivities N (%)**
Tree nuts: Pecans	90 (3)	54 (6)	6 (1)	2 (*)	25 (4)
Tree nuts: Macadamia nuts	93 (3)	54 (6)	8 (2)	3 (*)	25 (4)
Tree nuts: Pistachios	89 (3)	52 (6)	7 (1)	2 (*)	24 (3)
Sesame seed	36 (1)	13 (2)	6 (1)	1 (*)	14 (2)
Soybeans	76 (3)	17 (2)	13 (3)	14 (2)	28 (4)
Sulphur dioxide	72 (2)	16 (2)	22 (4)	11 (2)	18 (3)
Fruit	190 (7)	53 (6)	38 (8)	36 (5)	46 (7)
Vegetables	158 (5)	34 (4)	40 (8)	33 (5)	37 (5)
Other	198 (7)	44 (5)	51 (10)	33 (5)	37 (5)
Total (N)	2,902	866	493	668	702

Table 9: All foods resulting in adverse reactions, by hypersensitivity

Foods resulting in adverse reaction	**All foods reported by all adults N (%)**	**Food allergy N (%)**	**Food intolerance N (%)**	**Coeliac disease N (%)**	**Multiple FHs N (%)**
Celery	8 (1)	2 (1)	1 (*)	-	1 (*)
Cereals containing gluten (wheat, rye, barley or oats)	615 (45)	16 (6)	80 (30)	404 (95)	104 (31)

Foods resulting in adverse reaction	**All foods reported by all adults** **N (%)**	**Food allergy** **N (%)**	**Food intolerance** **N (%)**	**Coeliac disease** **N (%)**	**Multiple FHs** **N (%)**
Crustaceans (such as prawns, crabs, scampi or lobsters)	35 (3)	11 (4)	6 (2)	-	17 (5)
Eggs	51 (4)	17 (7)	17 (6)	-	13 (4)
Fish	22 (2)	6 (2)	3 (1)	-	9 (3)
Lupin	3 (*)	2 (1)	-	-	1 (*)
Milk	149 (11)	19 (7)	53 (20)	2 (*)	70 (21)
Molluscs (such as mussels, snails, squid, whelks, clams or oysters)	19 (1)	5 (2)	3 (1)	1 (*)	4 (1)
Mustard	7 (1)	3 (1)	2 (1)	-	-
Peanuts	80 (6)	57 (22)	6 (2)	1 (1)	15 (4)
Tree nuts	51 (4)	29 (11)	4 (1)	3 (1)	13 (4)
Sesame seed	7 (1)	3 (1)	2 (1)	-	2 (1)
Soybeans	17 (1)	8 (3)	2 (1)	-	5 (2)
Sulphur dioxide and sulphites	25 (2)	5 (2)	9 (3)	2 (*)	7 (2)
Fruit	75 (5)	30 (12)	12 (4)	1 (*)	23 (7)
Vegetables	64 (5)	17 (7)	22 (8)	1 (*)	15 (5)

Foods resulting in adverse reaction	All foods reported by all adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple FHs N (%)
Other	145 (11)	25 (10)	48 (18)	10 (2)	32 (10)
Total (N)	1,373	255	270	425	331

Table 10: All symptoms usually experienced for all foods reported, according to hypersensitivity group

Symptoms reported	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple food hypersensitivities N (%)
Breathing	1,136 (15)	564 (26)	147 (13)	67 (3)	310 (15)
Skin	1,258 (16)	567 (26)	134 (12)	176 (8)	337 (17)
Gastrointestinal	4,202 (54)	446 (20)	771 (68)	1,779 (81)	1,013 (50)
Mouth/throat/ear	783 (10)	449 (20)	52 (5)	42 (2)	278 (14)
Other	430 (6)	168 (8)	25 (2)	129 (6)	94 (5)
Total (N)	7,809	2,194	1129	2193	2,032

Table 11: Gastrointestinal symptoms for all foods reported, by hypersensitivity group

Gastrointestinal symptoms reported	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple food hypersensitivities N (%)
Bloated stomach	721 (17)	56 (13)	152 (20)	312 (18)	168 (17)
Abdominal pain/stomach cramps	830 (20)	100 (22)	161 (21)	328 (18)	202 (20)
Heart burn	212 (5)	24 (5)	49 (6)	79 (4)	48 (5)
Sickness/vomiting	442 (11)	104 (23)	58 (8)	166 (9)	99 (10)
Diarrhoea	670 (16)	64 (14)	114 (15)	295 (17)	169 (17)
Blood in stool	43 (1)	4 (1)	4 (1)	24 (1)	8 (1)
Dehydration	106 (3)	11 (2)	11 (1)	47 (3)	29 (3)
Loss of weight/malnutrition	173 (4)	8 (2)	12 (2)	119 (7)	30 (3)
Excessive wind	509 (12)	39 (9)	103 (13)	212 (12)	127 (13)
Irritable bowel symptoms	496 (12)	36 (8)	107 (14)	199 (11)	124 (12)
Total (N)	4,202	446	771	1,781	1,004

Table 12: Breathing symptoms and anaphylaxis experienced for all foods reported, by hypersensitivity group

Breathing symptoms reported	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple food hypersensitivities N (%)
Cough/sneezing	132 (10)	67 (10)	19 (13)	3 (4)	39 (12)
Runny nose	110 (9)	34 (5)	22 (15)	11 (16)	33 (10)
Irritable/ itchy nose	129 (10)	63 (9)	16 (11)	7 (10)	35 (10)
Congested nose	87 (7)	27 (4)	20 (14)	6 (9)	25 (7)
Wheezing	163 (13)	96 (14)	16 (11)	7 (10)	41 (12)
Tight chest	214 (17)	118 (18)	21 (14)	13 (19)	55 (16)
Breathless	202 (16)	106 (16)	22 (15)	17 (24)	52 (16)
Asthma	99 (8)	53 (8)	11 (7)	3 (4)	30 (9)
Anaphylaxis	133 (10)	104 (16)	-	3 (4)	25 (7)
Total (N)	1,269	668	147	70	335

Table 13: Most severe symptoms ever experienced for all foods reported, by hypersensitivity group

Most severe symptoms reported	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple food hypersensitivities N (%)
Breathing	606 (13)	320 (22)	73 (11)	29 (2)	157 (13)
Skin	738 (15)	366 (25)	67 (10)	76 (6)	206 (17)
Gastrointestinal	2,614 (54)	279 (19)	500 (72)	1,088 (83)	622 (52)
Mouth/throat/ear	540 (11)	324 (23)	34 (5)	24 (2)	147 (12)
Other	341 (7)	149 (10)	20 (3)	97 (7)	65 (5)
Total (N)	4,839	1,438	694	1,314	1,197

Table 14: Time period in which symptoms usually start, by hypersensitivity

Time symptoms usually start after eating the reported food	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple food hypersensitivities N (%)
Less than 5 mins	274 (20)	125 (50)	35 (13)	13 (3)	83 (25)
5 to 30 mins	371 (28)	69 (28)	95 (36)	97 (24)	84 (25)
30 mins to 1 hour	228 (17)	23 (9)	53 (20)	78 (19)	58 (18)
1 to 2 hours	164 (12)	13 (5)	32 (12)	78 (19)	33 (10)
More than 2 hours	197 (15)	7 (3)	42 (16)	93 (23)	48 (15)
Don’t know	104 (8)	13 (5)	6 (2)	50 (12)	24 (7)
Total (N)	1,338	250	263	409	330

Table 15: Diagnosis method, by hypersensitivity

Diagnosis method	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple food hypersensitivities N (%)
Healthcare professional's diagnosis	190 (11)	43 (12)	53 (18)	20 (4)	63 (16)
Skin prick test	151 (9)	98 (28)	14 (5)	1 (*)	38 (10)
Blood test (antibodies for allergy)	172 (10)	92 (26)	7 (2)	43 (8)	29 (7)
Food challenge	68 (4)	21 (6)	17 (6)	7 (1)	17 (4)
Blood test (antibodies for Coeliac disease)	345 (21)	5 (1)	3 (1)	273 (51)	61 (15)
Not formally diagnosed but noticed symptoms themselves (self)	323 (19)	41 (12)	132 (46)	9 (2)	105 (26)
Complementary/alternative Therapist	30 (2)	5 (1)	12 (4)	4 (1)	9 (2)
Don't know/can't remember	42 (3)	10 (3)	13 (5)	1 (*)	4 (1)
Other	343 (21)	41 (12)	36 (13)	180 (33)	72 (18)
Total (N)	1,664	356	287	538	398

Table 16: Diagnoses classed as ‘Other’, by hypersensitivity

‘Other’ diagnosis methods	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple food hypersensitivities N (%)
Endoscopy (incl. gastroscopy, colonoscopy)	118 (31)	1 (2)	4 (11)	95 (49)	17 (20)
Biopsy	73 (19)	1 (2)	2 (5)	54 (28)	15 (18)
Exclusion diet	19 (5)	3 (7)	6 (16)	2 (1)	7 (8)
Based on symptoms/reaction	44 (12)	23 (50)	2 (5)	4 (2)	14 (17)
Other	123 (33)	18 (39)	24 (63)	40 (21)	30 (36)
Total (N)	377	46	38	195	83

Table 17: Frequency of reactions to all foods in the previous 12 months

Frequency of reactions	**All adults N (%)**	**Food allergy N (%)**	**Food intolerance N (%)**	**Coeliac disease N (%)**	**Multiple food hypersensitivities N (%)**
Once	124 (9)	28 (12)	13 (5)	51 (12)	27 (8)
Twice	171 (13)	26 (11)	33 (13)	73 (18)	31 (10)
Between 3 and 6 times	226 (17)	32 (13)	55 (21)	72 (18)	52 (16)
Between 7 and 10 times	59 (4)	7 (3)	22 (8)	14 (3)	12 (4)
More than 10 times	204 (15)	22 (9)	71 (27)	41 (10)	55 (17)
I haven’t reacted to this food in the last year	425 (32)	114 (47)	48 (18)	119 (29)	117 (36)
Don’t know	112 (8)	14 (6)	19 (7)	39 (10)	27 (8)
Total (N)	1,321	243	261	409	321

Table 18: Frequency of hospital admissions, for all foods reported

Frequency of admission for those admitted to hospital	**All adults N (%)**	**Food allergy N (%)**	**Food intolerance N (%)**	**Coeliac disease N (%)**	**Multiple food hypersensitivities N (%)**
Once	68 (44)	29 (35)	5 (63)	19 (54)	11 (42)
Twice	34 (22)	17 (21)	3 (38)	7 (20)	7 (27)
Between 3 and 6 times	39 (25)	26 (32)	0	8 (23)	5 (19)
Between 7 and 10 times	6 (4)	6 (7)	0	0	0
More than10 times	6 (4)	4 (5)	0	0	2 (8)
Don’t know	2 (1)	0	0	1 (3)	1 (4)
Total (N)	155	82	8	35	26

Table 19: Frequency of eating out or getting food to take away from a restaurant or other food outlet, by hypersensitivity

Frequency	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
At least once a day	4 (*)	2 (1)	-	-	-
5-6 times a week	4 (*)	2 (1)	1 (*)	-	-
3-4 times a week	21 (2)	6 (4)	1 (*)	5 (1)	5 (4)
Once or twice a week	148 (15)	32 (20)	33 (16)	46 (12)	24 (18)
Once a fortnight	184 (19)	35 (22)	37 (18)	80 (20)	19 (14)
Once a month	188 (19)	24 (15)	43 (21)	89 (23)	17 (13)
Less than once a month	338 (35)	47 (30)	70 (34)	143 (36)	51 (38)
Never	86 (9)	10 (6)	21 (10)	32 (8)	18 (13)
Total (N)	973	158	206	395	134

Table 20: How comfortable adult respondents feel asking a member of staff for information about the food they are selling when eating out, by food hypersensitivity

Level of comfort asking for information	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Very or fairly comfortable	542 (61)	92 (63)	117 (64)	222 (61)	69 (59)
Not very or not at all comfortable	216 (24)	39 (27)	42 (23)	91 (25)	29 (25)
Varies from place to place	102 (12)	13 (9)	14 (8)	50 (14)	17 (15)
Don’t know	26 (3)	2 (1)	11 (6)	-	1 (1)
Total (N)	886	146	184	364	116

Table 21: Confidence that written information provided when eating out allows identification of foods that cause a bad or unpleasant physical reaction, by food hypersensitivity

Level of confidence in information provided	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Very or fairly confident	545 (62)	87 (60)	122 (66)	224 (62)	65 (56)
Not very or not at all confident	201 (23)	41 (28)	35 (19)	78 (21)	36 (31)
Varies from place to place	124 (14)	18 (12)	18 (10)	61 (17)	15 (13)
Don't know	15 (2)	-	9 (5)	-	-
Total (N)	885	146	184	363	116

Table 22: Frequency of checking labels for ingredients that cause a bad or unpleasant physical reaction when shopping for food

Frequency of checks	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Always or most of the time	82 (85)	134 (86)	142 (70)	387 (98)	125 (93)
About half of the time or occasionally	94 (10)	20 (13)	38 (19)	7 (2)	9 (7)
Never	48 (5)	2 (1)	24 (12)	-	-
Don’t know	2 (*)	-	-	-	-
Total (N)	968	156	204	394	134

Table 23: Frequency of checking labels for information on the possible presence of foods that will cause a bad or unpleasant physical reaction (for example, 'may contain').

Frequency of checks	**All adults N (%)**	**Food allergy N (%)**	**Food intolerance N (%)**	**Coeliac disease N (%)**	**Multiple hypersensitivities N (%)**
Always or most of the time	780 (81)	125 (80)	124 (61)	378 (96)	121 (90)
About half of the time or occasionally	113 (12)	22 (14)	45 (22)	14 (4)	12 (9)
Never	68 (7)	9 (6)	32 (16)	1 (*)	1 (1)
Don't know	3 (*)	-	1 (*)	-	-
Total (N)	964	156	202	393	134

Table 24: Confidence in the information provided on food labelling for food sold from in store supermarkets, by hypersensitivity

Confidence in information (in store supermarkets)	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Very or fairly confident	850 (88)	126 (81)	176 (86)	370 (94)	118 (88)
Not very or not at all confident	74 (8)	19 (12)	16 (8)	14 (4)	13 (10)
Varies from place to place	28 (3)	8 (5)	7 (3)	9 (2)	3 (2)
Don’t buy food there or don’t know	14 (1)	2 (1)	5 (2)	-	-
Total (N)	966	155	204	393	134

Table 25: Confidence in the information provided on food labelling for food sold from online supermarkets, by hypersensitivity

Confidence in information (online supermarkets)	All Adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Very or fairly confident	624 (66)	91 (59)	138 (69)	266 (69)	84 (64)
Not very or not at all confident	120 (13)	35 (23)	20 (10)	30 (8)	17 (13)
Varies from place to place	20 (2)	5 (3)	7 (3)	3 (1)	5 (4)
Don’t buy food there or don’t know	186 (20)	22 (14)	36 (18)	87 (23)	26 (20)
Total (N)	950	153	201	386	132

Table 26: Confidence in the information provided on food labelling for food sold from independent food shops, by hypersensitivity

Confidence in information (independent food shops)	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Very or fairly confident	596 (63)	88 (58)	126 (63)	259 (67)	75 (56)
Not very or not at all confident	194 (20)	38 (25)	42 (21)	66 (17)	32 (24)
Varies from place to place	81 (9)	16 (11)	14 (7)	35 (9)	14 (11)
Don’t buy food there or Don’t know	81 (9)	10 (7)	18 (9)	29 (7)	12 (9)
Total (N)	952	152	200	389	133

Table 27: Confidence in the information provided on food labelling for food sold from food markets/stalls, by hypersensitivity

Confidence in information (food markets/stalls)	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Very or fairly confident	228 (24)	35 (23)	59 (29)	82 (21)	23 (17)
Not very or not at all confident	467 (49)	84 (55)	91 (45)	195 (50)	62 (47)
Varies from place to place	73 (8)	8 (5)	12 (6)	39 (10)	11 (8)
Don’t buy food there or don’t know	186 (19)	25 (16)	39 (19)	74 (19)	37 (28)
Total (N)	954	152	201	390	133

Table 28: Confidence in identifying foods that cause a bad or unpleasant physical reaction when buying food sold loose from in store supermarkets

Confidence in identifying foods (in store supermarket)	All Adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Very or fairly confident	494 (51)	81 (52)	133 (66)	176 (45)	52 (39)
Not very or not at all confident	289 (30)	47 (30)	45 (22)	126 (32)	53 (40)
Varies from place to place	34 (4)	5 (3)	10 (5)	16 (4)	2 (1)
Don’t buy food there or don’t know	144 (15)	22 (14)	14 (7)	72 (18)	27 (20)
Total (N)	961	155	202	390	134

Table 29: Confidence in identifying foods that cause a bad or unpleasant physical reaction when buying food sold loose from online supermarkets

Confidence in identifying foods (online supermarkets)	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Very or fairly confident	397 (42)	70 (45)	113 (57)	134 (35)	42 (32)
Not very or not at all confident	259 (27)	42 (27)	39 (20)	116 (30)	38 (29)
Varies from place to place	17 (2)	2 (1)	6 (3)	6 (2)	3 (2)
Don’t buy food there or don’t know	278 (29)	41 (26)	42 (21)	131 (34)	49 (37)
Total (N)	951	155	200	387	132

Table 30: Confidence in identifying foods that cause a bad or unpleasant physical reaction when buying food sold loose from independent food shops

Confidence in identifying foods (independent food shops)	All Adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Very or fairly confident	377 (40)	60 (39)	103 (51)	135 (35)	38 (29)
Not very or not at all confident	328 (35)	60 (39)	58 (29)	132 (34)	55 (42)
Varies from place to place	77 (8)	14 (9)	14 (7)	36 (9)	11 (8)
Don’t buy food there or don’t know	167 (18)	20 (13)	26 (13)	84 (22)	27 (21)
Total (N)	949	154	201	387	131

Table 31: Confidence in identifying foods that cause a bad or unpleasant physical reaction when buying food sold loose from food markets/stalls, by hypersensitivity

Confidence in identifying foods (food markets/stalls)	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Very or fairly confident	232 (25)	40 (26)	68 (34)	69 (18)	22 (17)
Not very or not at all confident	421 (45)	71 (46)	75 (38)	183 (48)	62 (47)
Varies from place to place	71 (8)	11 (7)	16 (8)	34 (9)	8 (6)
Don’t buy food there or don’t know	221 (23)	33 (21)	40 (20)	98 (26)	39 (30)
Total (N)	945	155	199	384	131

Table 32: Sources of information used for advice on managing food hypersensitivities

Source of information	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Patient organisations	501 (49)	66 (39)	38 (18)	299 (73)	91 (67)
Hospital doctor/nurse	136 (13)	51 (30)	15 (7)	37 (9)	25 (19)
GP	143 (14)	33 (19)	29 (13)	49 (12)	24 (18)
Dietician	181 (18)	20 (12)	16 (7)	115 (28)	27 (20)
Pharmacist	33 (3)	10 (6)	7 (3)	4 (1)	8 (6)
Internet	340 (33)	48 (28)	65 (30)	148 (36)	59 (44)
Family/friends	112 (11)	26 (15)	23 (11)	37 (9)	15 (11)
Self-manage	410 (40)	72 (42)	120 (56)	120 (29)	48 (36)
Apps (e.g. Facebook support groups)	90 (9)	5 (3)	9 (4)	57 (14)	19 (14)
Other	40 (4)	5 (3)	5 (2)	19 (5)	11 (8)
Total respondents (N)	1,019	170	216	409	135

Table 33: Most helpful sources of information for advice on managing food hypersensitivities

Source of information	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Patient organisations	368 (40)	45 (30)	26 (15)	236 (62)	58 (46)
Hospital doctor/nurse	50 (5)	24 (16)	5 (3)	9 (2)	5 (4)
GP	53 (6)	19 (13)	17 (10)	8 (2)	2 (2)
Dietician	56 (6)	7 (5)	9 (5)	23 (6)	11 (9)
Pharmacist	15 (2)	6 (4)	7 (4)	-	1 (1)
Internet	224 (25)	30 (20)	75 (42)	67 (17)	26 (20)
Family/friends	64 (7)	11 (7)	24 (13)	6 (2)	4 (3)
Apps (e.g. Facebook support groups)	25 (3)	1 (1)	4 (2)	15 (4)	5 (4)
Other	58 (6)	9 (6)	11 (6)	19 (5)	15 (12)
Total (N)	913	152	178	383	127

Table 34: How comfortable adult respondents felt mentioning their hypersensitivity in front of family

Mentioning food hypersensitivities (family)	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
It doesn’t bother me	758 (79)	120 (78)	158 (78)	318 (81)	102 (77)
Slightly embarrassed or uncomfortable	157 (16)	29 (19)	36 (18)	60 (15)	21 (16)
Very embarrassed or uncomfortable	41 (4)	4 (3)	8 (4)	13 (3)	9 (7)
Don’t know	6 (1)	1 (1)	1 (*)	1 (*)	1 (1)
Total (N)	962	154	203	392	133

Table 35: How comfortable adult respondents felt mentioning their hypersensitivity in front of friends

Mentioning food hypersensitivities (friends)	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
It doesn't bother me	590 (61)	88 (58)	135 (66)	245 (63)	69 (51)
Slightly embarrassed or uncomfortable	306 (32)	57 (37)	57 (28)	126 (32)	52 (39)
Very embarrassed or uncomfortable	57 (6)	7 (5)	10 (5)	20 (5)	12 (9)
Don't know	8 (1)	1 (1)	2 (1)	1 (*)	1 (1)
Total (N)	961	153	204	392	134

Table 36: How comfortable adult respondents felt mentioning their hypersensitivity in front of work colleagues

Mentioning food hypersensitivities (work colleagues)	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
It doesn't bother me	393 (42)	71 (46)	85 (42)	158 (42)	47 (36)
Slightly embarrassed or uncomfortable	277 (29)	46 (30)	56 (28)	122 (32)	36 (28)
Very embarrassed or uncomfortable	172 (18)	33 (21)	29 (14)	67 (18)	29 (22)
Don't know	97 (10)	4 (3)	31 (15)	29 (8)	18 (14)
Total (N)	939	154	201	376	130

Table 37: How comfortable adult respondents felt mentioning their hypersensitivity in front of people they've just met

Mentioning food hypersensitivities (people you've just met)	All Adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
It doesn't bother me	322 (34)	57 (37)	70 (35)	133 (34)	41 (31)
Slightly embarrassed or uncomfortable	264 (28)	43 (28)	43 (21)	120 (31)	44 (33)
Very embarrassed or uncomfortable	309 (32)	49 (32)	70 (35)	121 (31)	47 (35)
Don't know	62 (6)	5 (3)	18 (9)	16 (4)	2 (2)
Total (N)	957	154	201	390	134

Table 38: How comfortable adult respondents felt experiencing symptoms of a reaction in front of family

Experiencing symptoms of a reaction (family)	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
It doesn't bother me	463 (48)	79 (51)	107 (53)	176 (45)	57 (43)
Slightly embarrassed or uncomfortable	286 (30)	35 (23)	65 (32)	124 (32)	39 (29)
Very embarrassed or uncomfortable	178 (19)	37 (24)	30 (15)	66 (17)	35 (26)
Don't know	34 (4)	4 (3)	1 (*)	23 (6)	3 (2)
Total (N)	961	155	203	389	134

Table 39: How comfortable adult respondents felt experiencing symptoms of a reaction in front of friends

Experiencing symptoms of a reaction (friends)	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
It doesn't bother me	304 (32)	60 (39)	75 (37)	100 (26)	30 (22)
Slightly embarrassed or uncomfortable	315 (33)	42 (27)	74 (37)	131 (34)	44 (33)
Very embarrassed or uncomfortable	299 (31)	50 (32)	51 (25)	131 (34)	54 (40)
Don't know	39 (4)	2 (1)	2 (1)	26 (7)	6 (4)
Total (N)	957	154	202	388	134

Table 40: How comfortable adult respondents felt experiencing symptoms of a reaction in front of work colleagues

Experiencing symptoms of a reaction (work colleagues)	All adults N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
It doesn't bother me	187 (20)	42 (27)	50 (25)	56 (15)	16 (12)
Slightly embarrassed or uncomfortable	194 (21)	29 (19)	47 (23)	76 (20)	24 (18)
Very embarrassed or uncomfortable	438 (47)	77 (50)	83 (41)	188 (50)	68 (52)
Don't know	121 (13)	6 (4)	22 (11)	56 (15)	22 (17)
Total (N)	940	154	202	376	130

Table 41: How comfortable adult respondents felt experiencing symptoms of a reaction in front of people they've just met

Experiencing symptoms of a reaction (people you've just met)	**All adults N (%)**	**Food allergy N (%)**	**Food intolerance N (%)**	**Coeliac disease N (%)**	**Multiple hypersensitivities N (%)**
It doesn't bother me	155 (16)	36 (24)	42 (21)	41 (11)	17 (13)
Slightly embarrassed or uncomfortable	161 (17)	22 (14)	41 (20)	65 (17)	21 (16)
Very embarrassed or uncomfortable	544 (57)	89 (59)	102 (50)	231 (60)	90 (67)
Don't know	90 (9)	5 (3)	17 (8)	47 (12)	6 (4)
Total (N)	950	152	202	384	134

Table 42: Means for how comfortable adult respondents felt experiencing symptoms with different social circles

Experiencing symptoms	Food allergy Mean (SD)	Food intolerance Mean (SD)	Coeliac disease Mean (SD)	Multiple hypersensitivities Mean (SD)
Family	1.7 (0.8)	1.6 (0.7)	1.7 (0.8)	1.8 (0.8)
Friends	1.9 (0.9)	1.9 (0.8)	2.1 (0.8)	2.2 (0.8)
Work colleagues	2.2 (0.9)	2.2 (0.8)	2.4 (0.8)	2.5 (0.7)
People they've just met	2.4 (0.9)	2.3 (0.8)	2.6 (0.7)	2.6 (0.7)

Annex B – Parents of children with FHs

Table 43: Ethnicity of parent respondents by child's food hypersensitivity

Ethnicity	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple food hypersensitivities N (%)
White British/Irish	676 (86)	339 (86)	136 (88)	35 (90)	78 (83)
Mixed/multiple ethnicity	24 (3)	11 (3)	4 (3)	1 (3)	4 (4)
Asian (Indian, Chinese, Bangladeshi, Pakistani) background	52 (7)	26 (7)	9 (6)	3 (8)	6 (6)
Black British/African/Caribbean	24 (3)	11 (3)	5 (3)	-	4 (4)
Arab	6 (1)	1 (*)	1 (1)	-	2 (2)
Other ethnic group	5 (1)	4 (1)	-	-	-
Total (N)	787	392	155	39	94

Table 44: Region of parent respondents, by child's food hypersensitivity

Region	**All parents N (%)**	**Food allergy N (%)**	**Food intolerance N (%)**	**Coeliac disease N (%)**	**Multiple food hypersensitivities N (%)**
Scotland	70 (9)	32 (8)	21 (14)	3 (8)	9 (9)
Northern Ireland	18 (2)	7 (2)	5 (3)	1 (3)	2 (2)
Wales	33 (4)	11 (3)	7 (5)	2 (5)	6 (6)
North East of England	33 (4)	21 (5)	4 (3)	-	4 (4)
North West of England	87 (11)	40 (10)	23 (15)	2 (5)	9 (9)
Yorkshire and the Humber	60 (8)	28 (7)	11 (7)	2 (5)	9 (9)
East of England	38 (5)	22 (6)	9 (6)	2 (5)	2 (2)
East Midlands	58 (7)	26 (7)	10 (6)	5 (13)	5 (5)
West Midlands	74 (9)	34 (9)	10 (6)	6 (15)	14 (15)
London	140 (18)	68 (17)	23 (15)	6 (15)	23 (24)
South West of England	60 (8)	31 (8)	12 (8)	5 (13)	4 (4)
South East of England	120 (15)	75 (19)	20 (13)	5 (13)	8 (8)
Total (N)	791	395	155	39	95

Table 45: Parent respondent employment status, by child's hypersensitivity

Employment status	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple food hypersensitivities N (%)
Full-time	444 (57)	196 (50)	101 (66)	24 (63)	53 (59)
Part-time	176 (23)	106 (27)	24 (16)	10 (26)	17 (19)
Unemployed	19 (2)	10 (3)	5 (3)	-	1 (1)
Not working	112 (14)	67 (17)	20 (13)	3 (8)	14 (16)
Not working (retired)	3 (*)	1 (*)	-	-	1 (1)
Student	11 (1)	5 (1)	1 (1)	1 (3)	1 (1)
Other	10 (1)	6 (2)	1 (1)	-	3 (3)
Total (N)	775	391	152	38	90

Table 46: Ethnicity of children reported by parents, by child's hypersensitivity

Ethnicity	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple food hypersensitivities N (%)
White British/Irish	752 (81)	348 (80)	167 (86)	62 (85)	76 (76)
Mixed/multiple ethnicity	70 (8)	40 (9)	8 (4)	4 (5)	10 (10)
Asian (Indian, Chinese, Bangladeshi, Pakistani) background	53 (6)	29 (7)	10 (5)	5 (7)	4 (4)
Any other Asian background	3 (*)	2 (*)	1 (1)	-	-
Black British/African/Caribbean	29 (3)	12 (3)	6 (3)	1 (1)	4 (4)
Arab	13 (1)	2 (*)	2 (1)	1 (1)	6 (6)
Other ethnic group	3 (*)	3 (1)	-	-	-
Total (N)	923	436	194	73	100

Table 47: Other reasons for children excluding foods as reported by parents, by child's hypersensitivity

Reasons for excluding foods	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple food hypersensitivities N (%)
Vegan/vegetarian/ pescatarian diet	120 (13)	42 (10)	33 (17)	10 (14)	32 (32)
Weight loss	97 (10)	21 (5)	27 (14)	8 (11)	25 (25)
Weight maintenance	58 (6)	10 (2)	19 (10)	8 (11)	15 (15)
Health reasons (unrelated to allergy)	68 (7)	30 (7)	15 (8)	3 (4)	13 (13)
Religious reasons	32 (3)	15 (3)	5 (3)	4 (5)	2 (2)
Other	23 (2)	14 (3)	7 (4)	42 (58)	3 (3)
Don't exclude food	568 (61)	320 (73)	102 (52)	1 (1)	24 (24)
Total respondents (N)	932	439	195	73	101

Table 48: All foods (no limit on numbers reported) children of participants react to, by child's hypersensitivity

Food	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple food hypersensitivities N (%)
Celery	98 (3)	36 (2)	20 (5)	6 (5)	31 (11)
Cereals containing gluten (wheat, rye, barley or oats)	175 (6)	53 (3)	38 (10)	52 (42)	26 (9)
Crustaceans (such as prawns, crabs, scampi or lobsters)	84 (3)	37 (2)	18 (5)	6 (5)	18 (6)
Eggs	234 (8)	149 (7)	37 (10)	8 (7)	26 (9)
Fish	106 (4)	47 (2)	16 (4)	3 (2)	28 (9)
Lupin	35 (1)	14 (1)	7 (2)	2 (2)	9 (3)
Milk	252 (9)	133 (7)	76 (20)	7 (6)	21 (7)
Molluscs (such as mussels, snails, squid, whelks, clams or oysters)	38 (1)	23 (1)	9 (2)	2 (2)	3 (1)
Mustard	43 (1)	20 (1)	12 (3)	3 (2)	3 (1)
Peanuts	252 (9)	205 (10)	22 (6)	5 (4)	9 (3)
Tree nuts: Almonds	132 (4)	113 (6)	7 (2)	2 (2)	9 (3)
Tree nuts: Hazelnuts	165 (6)	132 (7)	8 (2)	3 (2)	16 (5)
Tree nuts: Brazil nuts	140 (5)	120 (6)	6 (2)	3 (2)	9 (3)
Tree nuts: Walnuts	151 (5)	129 (6)	8 (2)	2 (2)	9 (3)

Food	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple food hypersensitivities N (%)
Tree nuts: Cashew nuts	162 (6)	136 (7)	8 (2)	2 (2)	13 (4)
Tree nuts: Pecans	138 (5)	116 (6)	6 (2)	2 (2)	12 (4)
Tree nuts: Macadamia nuts	125 (4)	110 (5)	4 (1)	2 (2)	6 (2)
Tree nuts: Pistachios	151 (5)	130 (6)	7 (2)	2 (2)	11 (4)
Sesame seed	93 (3)	68 (3)	14 (4)	1 (1)	8 (3)
Soybeans	83 (3)	51 (3)	12 (3)	4 (3)	10 (3)
Sulphur dioxide	31 (1)	10 (*)	6 (2)	2 (2)	5 (2)
Fruit	115 (4)	85 (4)	12 (3)	1 (1)	7 (2)
Vegetables	55 (2)	42 (2)	6 (2)	1 (1)	2 (1)
Other	77 (3)	49 (2)	12 (3)	2 (2)	4 (1)
Total (N)	2,935	2,008	371	123	295

Table 49: All foods resulting in an adverse reaction, by child's hypersensitivity

All foods	All parents N (%)	Food allergy N (%)	Food intolerance (N%)	Coeliac disease N (%)	Multiple FHs N (%)
Celery	77 (6)	29 (4)	11 (4)	10 (10)	26 (9)
Cereals containing gluten (wheat, rye, barley or oats)	133 (10)	30 (5)	30 (12)	48 (48)	24 (9)
Crustaceans (such as prawns, crabs, scampi or lobsters)	41 (3)	11 (2)	12 (5)	-	13 (5)
Eggs	167 (12)	102 (16)	23 (9)	4 (4)	23 (8)
Fish	67 (5)	23 (4)	16 (6)	2 (2)	21 (8)
Lupin	19 (1)	1 (*)	1 (*)	4 (4)	7 (3)
Milk	204 (15)	100 (15)	66 (26)	2 (2)	22 (8)
Molluscs (such as mussels, snails, squid, whelks,	17 (1)	5 (1)	5 (2)	1 (1)	1 (*)

All foods	All parents N (%)	Food allergy N (%)	Food intolerance (N%)	Coeliac disease N (%)	Multiple FHs N (%)
clams or oysters)					
Mustard	33 (2)	13 (2)	9 (4)	1(1)	3 (1)
Peanuts	169 (12)	137 (21)	14 (5)	1 (1)	11 (4)
Tree nuts	256 (18)	102 (16)	33 (13)	21 (21)	100 (36)
Sesame seed	41 (3)	27 (4)	3 (1)	1 (1)	5 (2)
Soybeans	32 (2)	14 (2)	8 (3)	2 (2)	3 (1)
Sulphur dioxide and sulphites	18 (1)	4 (1)	3 (1)	-	4 (1)
Fruit	53 (4)	31 (5)	5 (2)	-	5 (2)
Vegetables	23 (2)	10 (2)	9 (4)	1(1)	2(1)
Other	49 (4)	18 (3)	8 (4)	2 (2)	8 (3)
Total (N)	1,399	657	256	100	278

Table 50: All symptoms usually experienced by all children reported by parent respondents, according to child’s hypersensitivity

Symptoms reported	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple food hypersensitivities N (%)
Breathing	2,110 (27)	1,283 (29)	283 (25)	101 (19)	346 (24)
Skin	2,056 (26)	1,344 (30)	209 (18)	100 (18)	314 (22)
Gastrointestinal	1,970 (25)	882 (20)	433 (38)	236 (43)	336 (24)
Mouth/throat/ear	1,054 (13)	673 (15)	102 (9)	41 (8)	198 (14)
Other	751 (9)	316 (7)	107 (9)	65 (12)	224 (16)
Total (N)	7,941	4,498	1,134	543	1,418

Table 51: Gastrointestinal symptoms for all foods reported, by child's hypersensitivity

Gastrointestinal symptoms reported	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple food hypersensitivities N (%)
Bloated stomach	250 (13)	107 (12)	68 (16)	35 (14)	24 (7)
Abdominal pain/stomach cramps	408 (21)	225 (26)	77 (18)	47 (18)	52 (15)
Heart burn	133 (7)	30 (3)	30 (7)	12 (5)	52 (15)
Sickness/vomiting	385 (20)	224 (25)	62 (14)	34 (13)	50 (15)
Diarrhoea	316 (16)	136 (15)	79 (18)	35 (14)	53 (16)
Blood in stool	100 (5)	21 (2)	20 (5)	14 (5)	41 (12)
Dehydration	62 (3)	15 (2)	13 (3)	9 (4)	23 (7)
Loss of weight/malnutrition	68 (3)	19 (2)	9 (2)	41 (16)	16 (5)
Excessive wind	144 (7)	65 (7)	40 (9)	14 (5)	16 (5)
Irritable bowel symptoms	104 (5)	40 (5)	35 (8)	14 (5)	9 (3)
Total (N)	1,970	882	433	255	336

Table 52: Breathing symptoms and anaphylaxis experienced by all children reported on for all foods, by child's hypersensitivity

Breathing symptoms reported	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple food hypersensitivities N (%)
Cough/sneezing	394 (17)	233 (16)	43 (15)	17 (16)	75 (20)
Runny nose	335 (14)	143 (10)	68 (23)	17 (16)	78 (21)
Irritable/ itchy nose	284 (12)	133 (9)	58 (20)	16 (15)	69 (18)
Congested nose	183 (8)	88 (6)	27 (9)	22 (21)	38 (10)
Wheezing	293 (13)	206 (14)	32 (11)	8 (8)	38 (10)
Tight chest	245 (10)	181 (12)	26 (9)	10 (10)	24 (6)
Breathless	242 (10)	194 (13)	20 (7)	9 (9)	12 (3)
Asthma	134 (6)	105 (7)	9 (3)	2 (2)	12 (3)
Anaphylaxis	232 (10)	183 (12)	13 (4)	4 (4)	29 (8)
Total (N)	2,342	1,466	296	105	375

Table 53: Most severe symptoms ever experienced across all foods reported, by child's hypersensitivity

Most severe symptoms reported	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple food hypersensitivities N (%)
Breathing	1,274 (24)	638 (23)	230 (26)	75 (18)	300 (24)
Skin	1,318 (25)	763 (28)	163 (19)	71 (17)	274 (21)
Gastrointestinal	1,299 (24)	470 (17)	297 (34)	174 (42)	303 (24)
Mouth/throat/ear	748 (14)	617 (22)	87 (10)	39 (9)	186 (15)
Other	665 (13)	277 (10)	91 (10)	55 (13)	213 (17)
Total (N)	5,304	2,765	868	414	1,276

Table 54: Time period in which symptoms usually start, by child's hypersensitivity

Time symptoms usually start after eating the reported foods	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple food hypersensitivities N (%)
Less than 5 mins	423 (33)	329 (52)	29 (12)	8 (9)	47 (18)
5 to 30 mins	360 (28)	155 (25)	85 (36)	21 (23)	85 (32)
30 mins to 1 hour	235 (18)	47 (7)	55 (24)	33 (35)	84 (32)
1 to 2 hours	97 (7)	19 (3)	29 (12)	13 (14)	31 (12)
More than 2 hours	77 (6)	31 (5)	23 (10)	9 (10)	11 (4)
Don't know	107 (8)	46 (7)	12 (5)	9 (10)	7 (3)
Total (N)	1299	627	233	93	265

Table 55: Diagnosis method for all foods, by child's food hypersensitivity

Diagnosis method	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple food hypersensitivities N (%)
Healthcare professional's diagnosis	241 (15)	134 (15)	54 (23)	12 (10)	39 (13)
Skin prick test	434 (27)	318 (36)	37 (16)	8 (7)	62 (21)
Blood test (antibodies for allergy)	326 (20)	220 (25)	24 (10)	16 (14)	62 (21)
Food challenge	179 (11)	80 (9)	39 (17)	10 (9)	38 (13)
Blood test (antibodies for coeliac disease)	98 (6)	9 (1)	14 (6)	40 (35)	33 (11)
Not formally diagnosed but noticed symptoms	126 (8)	34 (4)	41 (18)	11 (10)	26 (9)
Complementary alternative therapist	43 (3)	7 (1)	7 (3)	10 (9)	15 (5)
Don't know/can't remember	75 (5)	13 (1)	12 (5)	1 (1)	8 (3)
Other	91 (6)	70 (8)	4 (2)	7 (6)	7 (2)
Total (N)	1,613	885	232	115	290

Table 56: Frequency of reactions to first food in the previous 12 months

Frequency of reactions	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple food hypersensitivities N (%)
Once	263 (20)	134 (21)	53 (23)	16 (16)	78 (30)
Twice	259 (20)	90 (14)	59 (25)	26 (26)	65 (25)
Between 3 and 6 times	160 (12)	59 (9)	38 (16)	17 (17)	38 (14)
Between 7 and 10 times	52 (4)	13 (2)	11 (5)	5 (5)	19 (7)
More than 10 times	59 (5)	23 (4)	25 (11)	9 (9)	1 (*)
They haven't reacted to this food in the last year	427 (33)	282 (45)	38 (16)	19 (19)	58 (22)
Don't know	79 (6)	26 (4)	10 (4)	7 (7)	5 (2)
Total (N)	1,299	627	234	99	264

Table 57: Frequency of parents' households eating out or getting food to takeaway, by child's hypersensitivity

Frequency	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
At least once a day	22 (3)	6 (2)	5 (4)	-	10 (13)
5-6 times a week	23 (3)	6 (2)	6 (5)	1 (3)	8 (10)
3-4 times a week	38 (6)	7 (2)	7 (5)	-	15 (19)
Once or twice a week	106 (16)	56 (17)	22 (17)	4 (11)	8 (10)
Once a fortnight	135 (20)	66 (19)	33 (25)	7 (19)	15 (19)
Once a month	123 (18)	67 (20)	26 (20)	7 (19)	7 (9)
Less than once a month	154 (23)	88 (26)	25 (19)	16 (43)	12 (15)
Never	63 (9)	37 (11)	7 (5)	2 (5)	4 (5)
Don't know	16 (2)	6 (2)	1 (1)	-	-
Total (N)	680	339	132	37	79

Table 58: How comfortable parent respondents feel about asking a member of staff for information about the food they are selling when eating out, because of a concern about their child's food hypersensitivity, by child's hypersensitivity

Level of comfort asking for information	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Very or fairly comfortable	449 (73)	230 (77)	98 (78)	24 (69)	49 (66)
Not very or not at all comfortable	106 (17)	46 (15)	19 (15)	5 (14)	22 (30)
Varies from place to place	35 (6)	18 (6)	6 (5)	5 (14)	2 (3)
Don't know	22 (4)	4 (1)	2 (2)	1 (3)	1 (1)
Total (N)	612	298	125	35	74

Table 59: Confidence that written information provided when eating out allows the identification of foods that cause their child a bad or unpleasant physical reaction, by child's food hypersensitivity

Level of confidence in information provided	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Very or fairly confident	397 (65)	190 (64)	92 (74)	21 (60)	45 (62)
Not very or not at all confident	138 (23)	70 (24)	25 (20)	7 (20)	21 (29)
Varies from place to place	55 (9)	34 (11)	6 (5)	6 (17)	5 (7)
Don't know	20 (3)	3 (1)	2 (2)	1 (3)	2 (3)
Total (N)	610	297	125	35	73

Table 60: Confidence that information provided verbally by staff when eating out allows the identification of foods that cause their child a bad or unpleasant physical reaction, by child's food hypersensitivity

Level of confidence in information provided verbally by staff	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Very or fairly confident	345 (57)	152 (51)	90 (73)	14 (40)	42 (58)
Not very or not at all confident	176 (29)	101 (34)	20 (16)	15 (43)	24 (33)
Varies from place to place	63 (10)	40 (13)	9 (7)	5 (14)	5 (7)
Don't know	24 (4)	4 (1)	4 (3)	1 (3)	2 (3)
Total (N)	608	297	123	35	73

Table 61: Frequency of checking labels for ingredients that cause their child a bad or unpleasant physical reaction when shopping for food, by child's food hypersensitivity

Frequency of checks	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Always or most of the time	528 (78)	297 (88)	93 (71)	32 (86)	60 (77)
About half of the time or occasionally	100 (15)	32 (10)	31 (24)	4 (11)	13 (17)
Never	25 (4)	4 (1)	5 (4)	-	2 (3)
Don't know	22 (3)	3 (1)	2 (2)	1 (3)	3 (4)
Total (N)	675	336	131	37	78

Table 62: Frequency of checking labels for information on the possible presence of foods that may cause a bad or unpleasant physical reaction (e.g. ‘may contain), by child’s food hypersensitivity

Frequency of checks	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Always or most of the time	501 (74)	277 (83)	90 (69)	31 (84)	57 (73)
About half of the time or occasionally	119 (18)	42 (13)	34 (26)	5 (14)	15 (19)
Never	32 (5)	13 (4)	5 (4)	-	4 (5)
Don’t know	22 (3)	3 (1)	2 (2)	1 (3)	2 (3)
Total (N)	674	335	131	37	78

Table 63: Confidence in the information provided on food labelling for food sold from in store supermarkets, by child's hypersensitivity

Confidence in information (in store supermarkets)	**All parents N (%)**	**Food allergy N (%)**	**Food intolerance N (%)**	**Coeliac disease N (%)**	**Multiple hypersensitivities N (%)**
Very or fairly confident	518 (77)	266 (79)	96 (73)	35 (95)	55 (71)
Not very or not at all confident	90 (13)	46 (14)	21 (16)	-	14 (18)
Varies from place to place	43 (6)	20 (6)	9 (7)	2 (5)	5 (6)
Don't buy food there or don't know	22 (3)	3 (1)	5 (4)	-	4 (5)
Total (N)	673	335	131	37	78

Table 64: Confidence in the information provided on food labelling for food sold from online supermarkets, by child's hypersensitivity

Confidence in information (online supermarkets)	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Very or fairly confident	443 (67)	230 (70)	89 (68)	32 (89)	39 (51)
Not very or not at all confident	135 (20)	63 (19)	23 (18)	-	30 (39)
Varies from place to place	42 (6)	21 (6)	11 (8)	2 (6)	4 (5)
Don't buy food there or don't know	44 (7)	15 (5)	7 (5)	2 (6)	4 (5)
Total (N)	664	329	130	36	77

Table 65: Confidence in the information provided on food labelling for food sold from independent shops, by child's hypersensitivity

Confidence in information (independent food shops)	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Very or fairly confident	354 (53)	173 (52)	77 (60)	22 (61)	35 (46)
Not very or not at all confident	191 (29)	100 (30)	30 (23)	9 (25)	26 (34)
Varies from place to place	68 (10)	40 (12)	17 (13)	3 (8)	5 (7)
Don't buy food there or Don't know	51 (8)	18 (5)	5 (4)	2 (6)	10 (13)
Total (N)	664	331	129	36	76

Table 66: Confidence in the information provided on food labelling for food sold from food markets/stalls, by child's hypersensitivity

Confidence in information (Food markets/stalls)	**All parents N (%)**	**Food allergy N (%)**	**Food intolerance N (%)**	**Coeliac disease N (%)**	**Multiple hypersensitivities N (%)**
Very or fairly confident	229 (35)	94 (28)	61 (48)	8 (22)	23 (30)
Not very or not at all confident	286 (43)	158 (48)	44 (34)	21 (58)	36 (47)
Varies from place to place	57 (9)	28 (8)	14 (11)	3 (8)	6 (8)
Don't buy food there or don't know	90 (14)	50 (15)	9 (7)	4 (11)	11 (14)
Total (N)	662	330	128	36	76

Table 67: Confidence in identifying foods that cause a bad or unpleasant physical reaction when buying food sold loose from in store supermarkets, by child's hypersensitivity

Confidence in identifying foods (in store supermarkets)	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Very or fairly confident	332 (49)	138 (41)	84 (65)	18 (50)	36 (46)
Not very or not at all confident	211 (31)	120 (36)	35 (27)	10 (28)	27 (35)
Varies from place to place	39 (6)	24 (7)	6 (5)	2 (6)	3 (4)
Don't buy food there or don't know	89 (13)	52 (16)	5 (4)	6 (17)	12 (15)
Total (N)	671	334	130	36	78

Table 68: Confidence in identifying foods that cause a bad or unpleasant physical reaction when buying food sold loose from online supermarkets, by child's hypersensitivity

Confidence in identifying foods (online supermarkets)	**All parents N (%)**	**Food allergy N (%)**	**Food intolerance N (%)**	**Coeliac disease N (%)**	**Multiple hypersensitivities N (%)**
Very or fairly confident	315 (47)	138 (42)	78 (60)	17 (47)	34 (44)
Not very or not at all confident	208 (31)	114 (35)	36 (28)	8 (22)	27 (35)
Varies from place to place	31 (5)	15 (5)	9 (7)	1 (3)	4 (5)
Don't buy food there or don't know	110 (17)	62 (19)	6 (5)	10 (28)	13 (17)
Total (N)	664	329	129	36	78

Table 69: Confidence in identifying foods that cause a bad or unpleasant physical reaction when buying food sold loose from independent shops, by child's hypersensitivity

Confidence in identifying foods (independent food shops)	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Very or fairly confident	262 (39)	112 (34)	71 (55)	10 (28)	25 (32)
Not very or not at all confident	248 (37)	126 (38)	45 (35)	17 (47)	31 (40)
Varies from place to place	50 (8)	29 (9)	9 (7)	4 (11)	5 (6)
Don't buy food there or don't know	104 (16)	64 (19)	4 (3)	5 (14)	16 (21)
Total (N)	664	331	129	36	77

Table 70: Confidence in identifying foods that cause a bad or unpleasant physical reaction when buying food sold loose from food markets/stalls, by child's hypersensitivity

Confidence in identifying foods (food markets/stalls)	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Very or fairly confident	211 (32)	81 (25)	54 (42)	8 (22)	27 (35)
Not very or not at all confident	274 (42)	153 (47)	52 (40)	17 (47)	27 (35)
Varies from place to place	47 (7)	21 (6)	11 (9)	1 (3)	9 (12)
Don't buy food there or don't know	125 (19)	72 (22)	12 (9)	10 (28)	14 (18)
Total (N)	657	327	129	36	77

Table 71: Sources of information used for advice on managing their child's food hypersensitivity

Source of information	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Patient organisations	251 (32)	163 (41)	22 (14)	22 (56)	35 (37)
Hospital doctor/nurse	272 (34)	190 (48)	29 (19)	9 (23)	29 (31)
GP	218 (27)	103 (26)	67 (43)	8 (21)	16 (17)
Dietician	145 (18)	71 (18)	24 (15)	15 (38)	24 (25)
Pharmacist	60 (8)	24 (6)	19 (12)	1 (3)	6 (6)
Internet	218 (27)	129 (33)	34 (22)	9 (23)	19 (20)
Family/friends	97 (12)	51 (13)	22 (14)	4 (10)	6 (6)
Self-manage	115 (15)	54 (14)	20 (13)	11 (28)	7 (7)
Apps (e.g. Facebook support groups)	13 (2)	8 (2)	2 (1)	1 (3)	2 (2)
Other	27 (3)	18 (5)	4 (3)	2 (5)	-
Total respondents (N)	793	396	156	39	95

Table 72: Most helpful sources of information for advice on managing food hypersensitivities

Source of information	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
Patient organisations	120 (18)	76 (23)	6 (5)	16 (46)	18 (23)
Hospital doctor/nurse	136 (21)	95 (29)	14 (11)	2 (6)	14 (18)
GP	132 (20)	49 (15)	44 (35)	3 (9)	14 (18)
Dietician	63 (10)	24 (7)	20 (16)	5 (14)	11 (14)
Pharmacist	28 (4)	9 (3)	4 (3)	-	8 (10)
Internet	110 (17)	51 (16)	22 (17)	6 (17)	10 (13)
Family/friends	36 (6)	8 (2)	13 (10)	-	1 (1)
Apps (e.g. Facebook support groups)	6 (1)	3 (1)	1 (1)	1 (3)	-
Other	22 (3)	13 (4)	3 (2)	2 (6)	1 (1)
Total (N)	653	328	127	35	77

Table 73: How comfortable parent respondents feel mentioning their child's hypersensitivity in front of family, by child's hypersensitivity

Mentioning food hypersensitivities (family)	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
It doesn't bother me	479 (72)	261 (79)	92 (71)	29 (81)	43 (54)
Slightly embarrassed or uncomfortable	120 (18)	45 (14)	27 (21)	4 (11)	27 (34)
Very embarrassed or uncomfortable	45 (7)	17 (5)	9 (7)	3 (8)	7 (9)
Don't know	23 (3)	7 (2)	2 (2)	-	2 (3)
Total (N)	667	330	130	36	79

Table 74: How comfortable parent respondents feel mentioning their child's hypersensitivity in front of friends, by child's hypersensitivity

Mentioning food hypersensitivities (friends)	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
It doesn't bother me	428 (65)	234 (72)	85 (66)	28 (78)	32 (41)
Slightly embarrassed or uncomfortable	152 (23)	63 (19)	32 (25)	7 (19)	28 (36)
Very embarrassed or uncomfortable	58 (9)	23 (7)	10 (8)	1 (3)	15 (19)
Don't know	22 (3)	6 (2)	2 (2)	-	3 (4)
Total (N)	660	326	129	36	78

Table 75: How comfortable parent respondents feel mentioning their child's hypersensitivity in front of work colleagues, by child's hypersensitivity

Mentioning food hypersensitivities (Work colleagues)	**All parents N (%)**	**Food allergy N (%)**	**Food intolerance N (%)**	**Coeliac disease N (%)**	**Multiple hypersensitivities N (%)**
It doesn't bother me	422 (64)	237 (72)	85 (66)	27 (75)	33 (42)
Slightly embarrassed or uncomfortable	137 (21)	59 (18)	25 (19)	4 (11)	28 (35)
Very embarrassed or uncomfortable	69 (10)	18 (5)	15 (12)	3 (8)	15 (19)
Don't know	36 (5)	14 (4)	4 (3)	2 (6)	3 (4)
Total (N)	664	328	129	36	79

Table 76: How comfortable parent respondents feel mentioning their child's hypersensitivity in front of people they've just met, by child's hypersensitivity

Mentioning food hypersensitivities (people you've just met)	All parents N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple hypersensitivities N (%)
It doesn't bother me	375 (57)	210 (64)	75 (58)	25 (69)	24 (31)
Slightly embarrassed or uncomfortable	161 (24)	70 (21)	37 (29)	6 (17)	30 (39)
Very embarrassed or uncomfortable	81 (12)	32 (10)	11 (9)	4 (11)	19 (25)
Don't know	43 (7)	14 (4)	6 (5)	1 (3)	4 (5)
Total (N)	660	326	129	36	77

Annex C – Children (8-17 years) with FHs

Table 77: Ethnicity, by food hypersensitivity

Ethnicity	All children N (%)	Food allergy N (%)	Food intolerance N (%)
White British/Irish	230 (86)	85 (83)	88 (89)
Mixed/multiple ethnicity	19 (7)	9 (9)	6 (6)
Asian (Indian, Chinese, Bangladeshi, Pakistani) background	10 (4)	4 (4)	3 (3)
Black British/African/Caribbean	5 (2)	2 (2)	2 (2)
Arab	1 (*)	1 (1)	-
Other ethnic group	1 (*)	1 (1)	-
Total (N)	266	102	99

Table 78: Region by food hypersensitivity

Region	All children N (%)	Food allergy N (%)	Food intolerance N (%)
Scotland	15 (6)	4 (4)	5 (5)
Northern Ireland	8 (3)	4 (4)	2 (2)
Wales	17 (6)	4 (4)	10 (10)
North East of England	13 (5)	9 (9)	2 (2)
North West of England	29 (11)	9 (9)	13 (13)
Yorkshire and the Humber	20 (8)	8 (8)	6 (6)
East of England	24 (9)	6 (6)	12 (12)
East Midlands	21 (8)	11 (11)	7 (7)
West Midlands	23 (9)	7 (7)	10 (10)
London	27 (10)	17 (17)	4 (4)
South West of England	36 (14)	12 (12)	12 (12)
South East of England	33 (12)	11 (11)	16 (16)
Total (N)	266	102	99

Table 79: Other reasons for excluding foods, by hypersensitivity

Reasons for excluding food	All children N (%)	Food allergy N (%)	Food intolerance N (%)
Vegan/vegetarian/ pescatarian diet	30 (11)	11 (11)	14 (14)
Health reasons (unrelated to allergy)	32 (12)	15 (15)	11 (11)
Religious reasons	15 (6)	5 (5)	4 (4)
Other	8 (3)	-	5 (5)
Don’t exclude food	188 (70)	72 (71)	69 (69)
Total respondents (N)	267	102	100

Table 80: All foods child respondents reacted to (no limit on numbers reported), by hypersensitivity

All foods reacted to	All children N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple food hypersensitivities N (%)
Celery	13 (2)	7 (2)	5 (3)	-	-
Cereals containing gluten (wheat, rye, barley or oats)	52 (8)	10 (3)	19 (11)	18 (82)	3 (8)
Crustaceans (such as prawns, crabs, scampi or lobsters)	18 (3)	8 (2)	7 (4)	-	1 (3)
Eggs	54 (8)	23 (6)	24 (14)	-	1 (3)
Fish	25 (4)	14 (4)	6 (3)	-	1 (3)
Lupin	5 (1)	-	2 (1)	-	-
Milk	80 (12)	25 (7)	45 (26)	1 (5)	2 (5)
Molluscs (such as mussels, snails, squid, whelks, clams or oysters)	10 (2)	5 (1)	3 (2)	1 (5)	-
Mustard	11 (2)	2 (1)	7 (4)	-	1 (3)
Peanuts	54 (8)	38 (11)	9 (5)	-	3 (8)

All foods reacted to	**All children N (%)**	**Food allergy N (%)**	**Food intolerance N (%)**	**Coeliac disease N (%)**	**Multiple food hypersensitivities N (%)**
Tree nuts: Almonds	30 (5)	21 (6)	4 (2)	-	3 (8)
Tree nuts: Hazelnuts	28 (4)	21 (6)	3 (2)	-	3 (8)
Tree nuts: Brazil nuts	34 (5)	25 (7)	3 (2)	-	2 (5)
Tree nuts: Walnuts	32 (5)	23 (6)	5 (3)	-	3 (8)
Tree nuts: Cashew nuts	30 (5)	23 (6)	3 (2)	-	2 (5)
Tree nuts: Pecans	23 (4)	18 (5)	1 (1)	-	3 (8)
Tree nuts: Macadamia nuts	27 (4)	20 (6)	2 (1)	-	4 (11)
Tree nuts: Pistachios	28 (4)	21 (6)	2 (1)	-	3 (8)
Sesame seed	19 (3)	12 (3)	2 (1)	-	2 (5)
Soybeans	9 (1)	6 (2)	2 (1)	-	-
Sulphur dioxide	7 (1)	2 (1)	3 (2)	1 (5)	-
Fruit	29 (4)	17 (5)	6 (3)	1 (5)	-
Vegetables	13 (2)	7 (2)	4 (2)	-	-
Other	21 (3)	8 (2)	7 (4)	-	-
Total (N)	652	356	174	22	37

Table 81: All foods resulting in adverse reactions, by food hypersensitivity

Food resulting in adverse reaction	All children N (%)	Food allergy N (%)	Food intolerance N (%)	Coeliac disease N (%)	Multiple Food Hypersensitivities N (%)
Celery	10 (3)	5 (4)	4 (4)	-	-
Cereals containing gluten (wheat, rye, barley or oats)	40 (13)	4 (1)	15 (14)	18 (100)	1 (10)
Crustaceans (such as prawns, crabs, scampi or lobsters)	13 (4)	5 (4)	5 (5)	-	-
Eggs	34 (11)	11 (9)	16 (15)	-	1 (10)
Fish	19 (6)	11 (9)	4 (4)	-	-
Lupin	5 (2)	1 (1)	2 (2)	-	-
Milk	65 (21)	19 (15)	39 (36)	-	-
Molluscs (such as mussels, snails, squid, whelks,	5 (2)	2 (2)	2 (2)	-	1 (10)

Food resulting in adverse reaction	**All children N (%)**	**Food allergy N (%)**	**Food intolerance N (%)**	**Coeliac disease N (%)**	**Multiple Food Hypersensitivities N (%)**
clams or oysters)					
Mustard	3 (1)	-	2 (2)	-	-
Peanuts	39 (13)	31 (25)	2 (2)	-	2 (20)
Tree nuts	28 (9)	18 (14)	3 (3)	-	4 (40)
Sesame seed	3 (1)	2 (2)	-	-	-
Soybeans	3 (1)	-	1 (1)	-	-
Sulphur dioxide and sulphites	5 (2)	-	2 (2)	-	1 (10)
Fruit	14 (5)	7 (6)	2 (2)	-	-
Vegetables	4 (1)	1 (1)	1 (1)	-	-
Other	23 (7)	8 (6)	9 (8)	-	-
Total (N)	310	125	109	18	10

Table 82: All symptoms usually experienced for all foods, according to hypersensitivity group

Symptoms	All children N (%)	Food allergy N (%)	Food intolerance N (%)
Breathing	454 (26)	288 (31)	106 (21)
Skin	391 (22)	256 (28)	73 (15)
Gastrointestinal	598 (34)	155 (17)	274 (54)
Mouth/throat/ear	212 (12)	155 (17)	28 (6)
Other	122 (7)	68 (7)	22 (4)
Total N	1,777	922	503

Table 83: Gastrointestinal symptoms experienced for all foods reported, according to hypersensitivity

Gastrointestinal symptoms reported	**All children N (%)**	**Food allergy N (%)**	**Food intolerance N (%)**
Bloated stomach	103 (17)	19 (12)	58 (21)
Abdominal pain/stomach cramps	139 (23)	37 (24)	68 (25)
Heart burn	29 (5)	12 (8)	10 (4)
Sickness/vomiting	88 (15)	34 (22)	23 (8)
Diarrhoea	104 (17)	27 (17)	51 (19)
Blood in stool	16 (3)	3 (2)	7 (3)
Dehydration	13 (2)	3 (2)	7 (3)
Loss of weight/malnutrition	22 (4)	4 (3)	5 (2)
Excessive wind	39 (7)	9 (6)	19 (7)
Irritable bowel symptoms	45 (8)	7 (5)	26 (9)
Total (N)	598	155	274

Table 84: Breathing symptoms and anaphylaxis experienced for all foods reported, according to hypersensitivity

Breathing symptoms reported	All children N (%)	Food allergy N (%)	Food intolerance N (%)
Cough/sneezing	66 (13)	42 (13)	14 (13)
Runny nose	60 (12)	33 (10)	20 (18)
Irritable/ itchy nose	53 (11)	32 (10)	18 (17)
Congested nose	29 (6)	12 (4)	10 (9)
Wheezing	66 (13)	43 (13)	12 (11)
Tight chest	83 (17)	56 (17)	18 (17)
Breathless	65 (13)	49 (15)	9 (8)
Asthma	31 (6)	21 (7)	5 (5)
Anaphylaxis	40 (8)	33 (10)	3 (3)
Total (N)	493	321	109

Table 85: Most severe symptoms ever experienced for all foods, by hypersensitivity group

Most severe symptoms reported	All children N (%)	Food allergy N (%)	Food intolerance N (%)
Breathing	268 (23)	155 (26)	65 (20)
Skin	253 (22)	158 (26)	58 (18)
Gastrointestinal	398 (34)	120 (20)	157 (49)
Mouth/throat/ear	152 (13)	108 (18)	23 (7)
Other	104 (9)	60 (10)	17 (5)
Total (N)	1,175	601	320

Table 86: Time period in which symptoms usually start, by hypersensitivity

Time symptoms usually start after eating the reported food	All children N (%)	Food allergy N (%)	Food intolerance N (%)
Less than 5 mins	68 (22)	47 (38)	12 (12)
5 to 30 mins	111 (37)	41 (33)	46 (45)
30 mins to 1 hour	68 (22)	20 (16)	26 (25)
1 to 2 hours	18 (6)	4 (3)	9 (9)
More than 2 hours	18 (6)	5 (4)	5 (5)
Don’t know	20 (7)	7 (6)	4 (4)
Total (N)	303	124	102

Table 87: Diagnosis method, by hypersensitivity

Diagnosis method	All children N (%)	Food allergy N (%)	Food intolerance N (%)
Healthcare professional's diagnosis	61 (16)	24 (13)	30 (26)
Skin prick test	63 (16)	47 (26)	8 (7)
Blood test	70 (18)	43 (23)	14 (12)
Food challenge	33 (8)	18 (10)	9 (8)
Blood test – (antibodies for coeliac disease)	25 (6)	2 (1)	3 (3)
No formally diagnosed but noticed symptoms themselves	54 (14)	12 (7)	27 (24)
Caregiver told me I reacted to it	61 (16)	27 (15)	20 (18)
Don't know/can't remember	12 (3)	4 (2)	2 (2)
Other	12 (3)	7 (4)	1 (1)
Total (N)	391	184	114

Table 88: Frequency of reactions to all foods in the previous 12 months

Frequency of reactions	All children N (%)	Food allergy N (%)	Food intolerance N (%)
Once	62 (21)	29 (25)	9 (9)
Twice	53 (18)	18 (16)	23 (23)
Between 3 and 6 times	52 (17)	12 (11)	20 (20)
Between 7 and 10 times	18 (6)	7 (6)	6 (6)
More than 10 times	28 (9)	2 (2)	19 (19)
I haven’t reacted to this food in the last year	63 (21)	41 (36)	11 (11)
Don’t know	22 (7)	5 (4)	10 (10)
Total (N)	298	114	98

Table 89: Frequency of eating out or getting food to take away from a restaurant or other food outlet, by hypersensitivity

Frequency	**All children** N (%)	**Food allergy** N (%)	**Food intolerance** N (%)
At least once a day	5 (2)	3 (3)	2 (2)
5-6 times a week	7 (3)	5(5)	2 (2)
3-4 times a week	12 (5)	3 (3)	5 (6)
Once or twice a week	55 (22)	19 (20)	23 (25)
Once a fortnight	46 (18)	15 (16)	19 (21)
Once a month	48 (19)	18 (19)	17 (19)
Less than once a month	61 (24)	24 (25)	20 (22)
Never	13 (5)	7 (7)	2 (2)
Don't know	5 (2)	2 (2)	1 (1)
Total (N)	252	96	91

Table 90: How comfortable child respondents feel asking a member of staff for information about the food they are selling when eating out, by food hypersensitivity

Level of comfort asking for information	All children N (%)	Food allergy N (%)	Food intolerance N (%)
Very or fairly comfortable	130 (55)	58 (66)	46 (52)
Not very or not at all comfortable	80 (34)	25 (28)	30 (34)
Varies from place to place	15 (6)	1 (1)	7 (8)
Don’t know	12 (5)	4 (5)	6 (7)
Total (N)	237	88	88

Table 91: Confidence that written information provided when eating out allows identification of foods that cause a bad or unpleasant physical reaction, by food hypersensitivity

Level of confidence in information provided	**All children** **N (%)**	**Food allergy** **N (%)**	**Food intolerance** **N (%)**
Very or fairly confident	132 (56)	51 (58)	52 (58)
Not very or not at all confident	70 (30)	26 (30)	23 (26)
Varies from place to place	21 (9)	6 (7)	7 (8)
Don’t know	14 (6)	5 (6)	7 (8)
Total (N)	237	88	89

Table 92: Confidence that information provided verbally by staff when eating out allows identification of foods that cause a bad or unpleasant physical reaction, by hypersensitivity

Level of confidence in information provided	All children N (%)	Food allergy N (%)	Food intolerance N (%)
Very or fairly confident	154 (65)	65 (74)	55 (62)
Not very or not at all confident	41 (17)	12 (14)	14 (16)
Varies from place to place	27 (11)	8 (9)	12 (13)
Don’t know	15 (6)	3 (3)	8 (9)
Total (N)	237	88	89

Table 93: Frequency child respondents check labels for ingredients that will cause a bad or unpleasant physical reaction

Frequency of checks	All children N (%)	Food allergy N (%)	Food intolerance N (%)
Always or most of the time	132 (53)	57 (60)	41 (45)
About half of the time or occasionally	31 (12)	11 (12)	12 (13)
Never	15 (6)	3 (3)	6 (7)
Don’t know	4 (2)	1 (1)	2 (2)
My parents do it for me	68 (27)	23 (24)	30 (33)
Total (N)	250	95	91

Table 94: Frequency child respondents check labels for information on the possible presence of foods that will cause a bad or unpleasant physical reaction (for example, ‘may contain’)

Frequency of checks	All children N (%)	Food allergy N (%)	Food intolerance N (%)
Always or most of the time	125 (50)	52 (55)	42 (47)
About half of the time or occasionally	27 (11)	14 (15)	11 (12)
Never	19 (8)	5 (5)	6 (7)
Don’t know	4 (2)	2 (2)	1 (1)
My parents do it for me	74 (30)	22 (23)	30 (33)
Total (N)	249	95	90

Table 95: Sources of information used for advice on managing food hypersensitivity, by hypersensitivity

Source of information	All children N (%)	Food allergy N (%)	Food intolerance N (%)
Patient organisations	38 (14)	16 (6)	7 (7)
Hospital doctor/nurse	65 (24)	40 (39)	19 (19)
GP	68 (25)	38 (37)	24 (24)
Dietician	29 (11)	11 (11)	8 (8)
Pharmacist	16 (6)	5 (5)	9 (9)
Internet	48 (18)	19 (19)	20 (20)
Family/friends	77 (29)	35 (34)	27 (27)
Self-manage	67 (25)	15 (15)	26 (26)
Apps (for example, Facebook support groups)	1 (*)	-	-
Other	3 (1)	2 (2)	-
Total respondents (N)	267	102	100

Table 96: Most helpful sources of information for advice on managing food hypersensitivities

Source of information	All children N (%)	Food allergy N (%)	Food intolerance N (%)
Patient organisations	20 (9)	7 (8)	5 (6)
Hospital doctor/nurse	32 (14)	19 (21)	11 (13)
GP	49 (21)	23 (25)	19 (23)
Dietician	18 (8)	2 (2)	9 (11)
Pharmacist	9 (4)	3 (3)	4 (5)
Internet	34 (15)	13 (14)	15 (18)
Family/friends	64 (28)	22 (24)	20 (24)
Apps (e.g. Facebook support groups)	1 (*)	-	-
Other	4 (2)	2 (2)	1 (1)
Total (N)	231	91	84

Table 97: How comfortable child respondents feel mentioning their hypersensitivity in front of family, by hypersensitivity

Mentioning food hypersensitivities (family)	All children N (%)	Food allergy N (%)	Food intolerance N (%)
It doesn't bother me	174 (73)	70 (76)	59 (67)
Slightly embarrassed or uncomfortable	49 (20)	16 (17)	23 (26)
Very embarrassed or uncomfortable	14 (6)	6 (7)	6 (7)
Don't know	3 (1)	-	-
Total (N)	240	92	88

Table 98: How comfortable child respondents feel mentioning their hypersensitivity in front of friends, by hypersensitivity

Mentioning food hypersensitivities (friends)	All children N (%)	Food allergy N (%)	Food intolerance N (%)
It doesn't bother me	127 (53)	58 (62)	43 (49)
Slightly embarrassed or uncomfortable	70 (29)	24 (26)	27 (31)
Very embarrassed or uncomfortable	40 (17)	9 (10)	18 (20)
Don't know	3 (1)	2 (2)	-
Total (N)	240	93	88

Table 99: How comfortable child respondents feel mentioning their hypersensitivity to people they've just met, by hypersensitivity

Mentioning food hypersensitivities (people you've just met)	All children N (%)	Food allergy N (%)	Food intolerance N (%)
It doesn't bother me	79 (34)	43 (48)	23 (26)
Slightly embarrassed or uncomfortable	69 (30)	28 (31)	24 (28)
Very embarrassed or uncomfortable	71 (31)	14 (16)	37 (43)
Don't know	11 (5)	4 (4)	3 (3)
Total (N)	230	89	87

Table 100: How comfortable child respondents feel experiencing symptoms of a reaction in front of family, by hypersensitivity

Experiencing symptoms of a reaction (family)	All children N (%)	Food allergy N (%)	Food intolerance N (%)
It doesn't bother me	140 (60)	59 (66)	49 (55)
Slightly embarrassed or uncomfortable	68 (29)	20 (22)	32 (36)
Very embarrassed or uncomfortable	25 (11)	11 (12)	8 (9)
Total (N)	233	90	89

Table 101: How comfortable children respondents feel experiencing symptoms of a reaction in front of friends, by hypersensitivity

Experiencing symptoms of a reaction (friends)	All children N (%)	Food allergy N (%)	Food intolerance N (%)
It doesn’t bother me	93 (40)	44 (48)	29 (33)
Slightly embarrassed or uncomfortable	82 (35)	25 (27)	36 (41)
Very embarrassed or uncomfortable	56 (24)	22 (24)	22 (25)
Total (N)	231	91	87

Table 102: How comfortable child respondents feel experiencing symptoms of a reaction in front of people they’ve just met, by hypersensitivity

Experiencing symptoms of a reaction (people you’ve just met)	All children N (%)	Food allergy N (%)	Food intolerance N (%)
It doesn’t bother me	61 (29)	32 (39)	17 (20)
Slightly embarrassed or uncomfortable	56 (26)	21 (26)	26 (31)
Very embarrassed or uncomfortable	97 (45)	29 (35)	41 (49)
Total (N)	214	82	84

Food Standards Agency
food.gov.uk

For enquiries about this publication, contact the Food Standards Agency.

Project reference: FS430406

Follow us on Twitter:
@foodgov

Find us on Facebook:
facebook.com/FoodStandardsAgency