

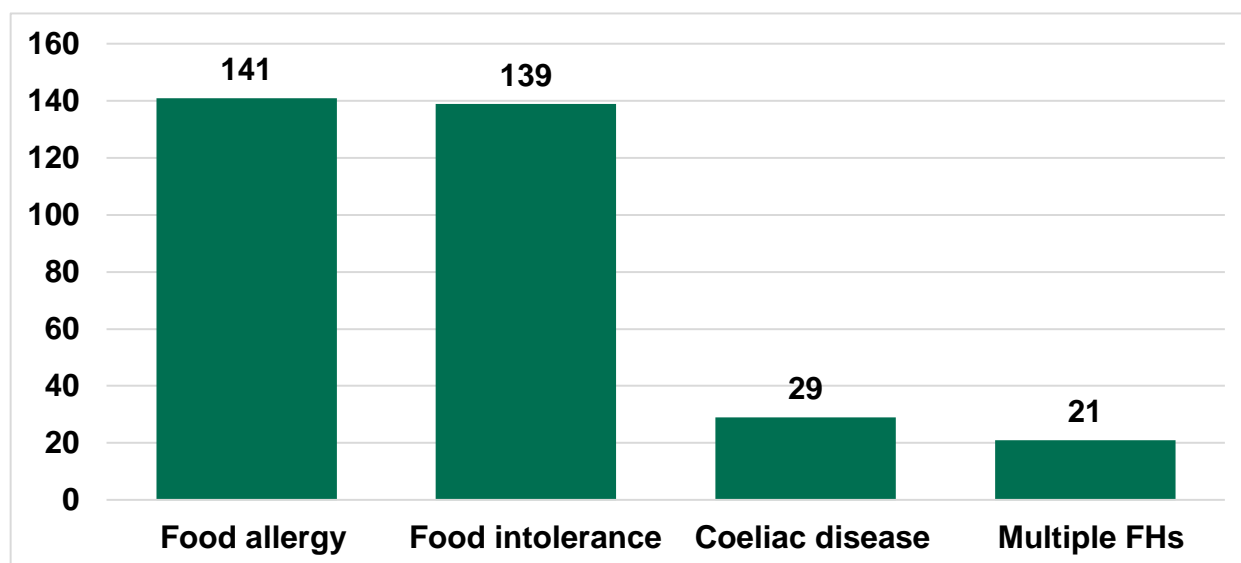
## Part 3: Children with food hypersensitivities

A total of 349 children aged 8-17 years with FH completed the survey, which included 19 reporting 'Other' conditions or 'Don't know' when asked to describe their reaction to food. These participants are not reported on in analysis as a subgroup but are included in the descriptive 'all children' figures. Key statistics and comparisons for all groups are reported on, however due to small numbers of those with coeliac disease ( $n = 29$ ) and multiple hypersensitivities ( $n = 21$ ), significance testing for these groups is not included. As only 15 children (3 8-12 year olds and 12 13-17 year olds) from wave 1 also took part in wave 2, comparisons across the two waves were not carried out for children.

### Prevalence of food hypersensitivities

Most of the child sample was made up of those with food allergy only (40%,  $n=141$ ) and food intolerance only (40%,  $n=139$ ). Group sizes for coeliac disease ( $n = 29$ ; 8%) and multiple hypersensitivities ( $n = 21$ ; 6%) were small (Figure 55).

**Figure 55: 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 (141); Food intolerance (139); Coeliac disease (29); Multiple FHs (21).

### Profile of child participants

#### Children's key characteristics

From a total of 267 children, 52% ( $n = 182$ ) of those reporting a food hypersensitivity were male (47%;  $n = 163$  were female). The mean age of all children was 12.6 years old ( $SD = 2.9$ ), with a range from 8 to 17 years old. The majority of children were from a White background ( $n = 300$ ;

86%. See Annex C Table 53).

More male child respondents reported each of the hypersensitivities than females, with the highest percentage of males reporting multiple hypersensitivities (n = 15 out of 21, 71%). As with the whole sample, across all hypersensitivities, the majority of children were of White British ethnicity (see Table 53 for a full breakdown).

The most common region for all children living with a food hypersensitivity was London (n = 50, 14%). This was also true for those reporting food allergy (n = 29; 21%), however for those with food intolerance, the most common region was the South East of England (n = 23; 17%). For children with coeliac disease the most common region was the North West of England (n = 5; 17%) and for children with multiple hypersensitivities the South East of England was the most common region (n = 6, 26%). See Annex C Table 54 for a full breakdown.

## **Other long-term conditions**

Children were asked if they had any other long-term physical or mental health conditions. Nineteen percent (n = 64) of the whole sample reported a long-term physical condition, 14% (n = 49) reported a mental health condition and 6% (n = 20) reported having both (60%, n = 207 did not have another long-term condition and 1%, n = 5 preferred not to say). Children with food allergy (n = 25; 18%) and intolerance (n = 23, 17%) were most likely to report having another long-term physical condition and children reporting a food intolerance were most likely to report having a mental health condition (n = 18, 13%).

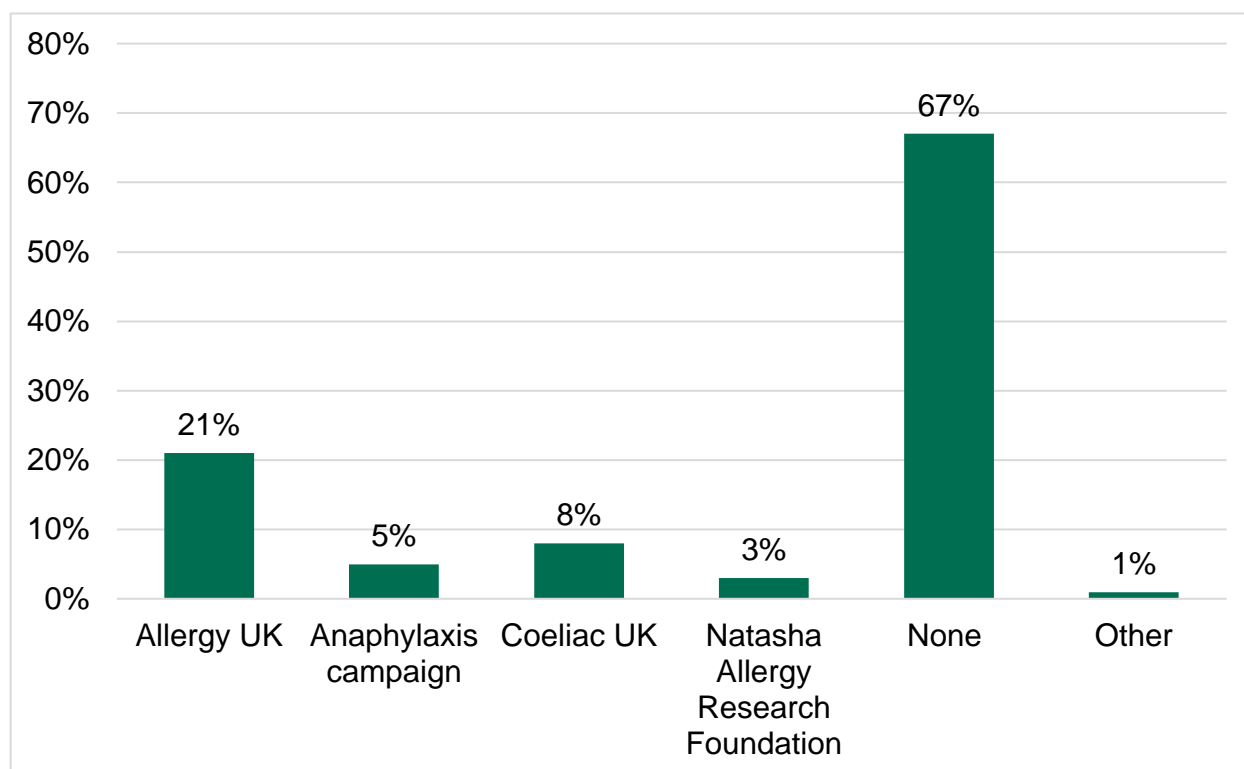
## **Patient organisation membership**

Children were asked to report on whether they were a member of any patient organisations and could choose as many as applied (hence percentages add up to more than 100%). The majority (67%, n = 233) were not members of any organisation (see Figure 54). However, for those who were members of organisations, the most common were Allergy UK (n = 74; 21%) and Coeliac UK (n = 27, 8%). Of those who reported belonging to Allergy UK, 61% (n = 45) were children from the food allergy group.

## **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 (11% of all children reported this as one of the foods they reacted to), cereals (8%), eggs (8%) and peanuts (7%) were the most frequently reported foods. 'Other' foods included meat, pasta, bread, dairy, herbs and spices (for example, ginger), pulses, condiments and sauces (for example, tomato sauce) and pizza. Please see Annex C Table 55 for a full breakdown of foods reported by hypersensitivity.

### **Figure 56: Membership of patient organisation groups**



Base: All children (349)

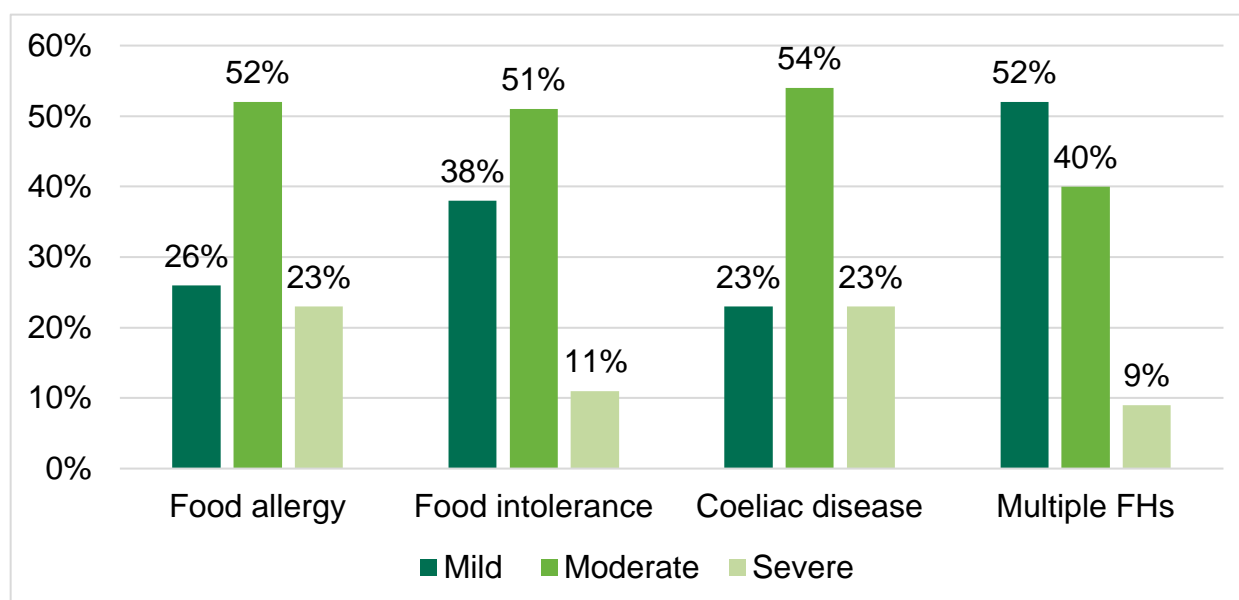
### Foods with an adverse reaction

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 = 349, 79%), with only 59 (13%) children reporting a second food and 32 (7%) reporting three foods. Across all foods reported (n = 440 - note this is not separate types of food but the number of foods reported in total by children), the most common food to result in an adverse reaction was milk (n = 78; 18%). Of those reporting a reaction to milk, 68% were children with food intolerance (n = 53). Peanuts were the most frequently reported food for those with food allergy (n = 45; 28%), tree nuts (n = 20; 13%) and fish (n = 19, 20%). In addition to milk (n = 53, 33%), cereals (n = 25; 16%) were also commonly reported by children with food intolerance. For a full breakdown of foods by hypersensitivity please see Annex C Table 56.

Children could categorise their reaction for each food they reported as food allergy (n = 182), food intolerance (n = 185), coeliac disease (n = 48), other or don't know (n = 25; not focussed on exclusively in this report).

For 16% (n = 70) of the reactions to food reported, children rated their reaction as severe, 49% (n = 213) rated their reactions as moderate and 35% (n = 152) as mild. Reactions reported by children as food allergy (n = 82; 52%), food intolerance (n = 81; 51%) and coeliac disease (n = 19; 54%) were most commonly rated as moderate and for those with multiple hypersensitivities as mild (n = 30; 52%). However, more reactions reported by children with food allergy (n = 36; 23%) were rated as severe compared to those with other hypersensitivities (Figure 57).

**Figure 57: Severity of reaction, by hypersensitivity**



Base: All reactions reported by children from hypersensitive groups (411): Food allergy (159); Food intolerance (159); Coeliac disease (35); Multiple hypersensitivities (58).

## 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 (52%) and coeliac disease (45%). However, for children with food allergy reactions (30%) and multiple hypersensitivities (26%), the most common symptoms experienced were breathing symptoms; Annex C Tables 57-59).

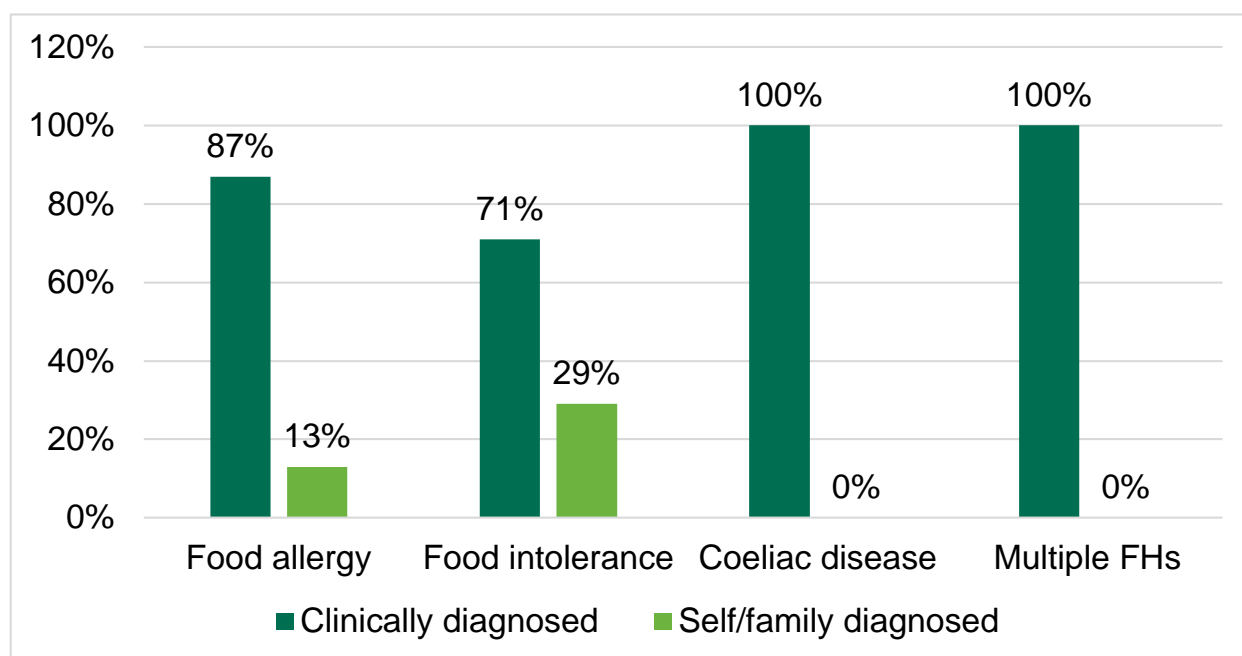
When asked to report the worst symptoms participants had ever had after eating the foods, the most severe symptoms for reactions experienced by all children (33%) and those reactions to foods reported by children with food intolerance (51%) and coeliac disease (36%), were gastrointestinal. However, for reactions reported by children with food allergy, the most frequently reported severe symptoms were skin symptoms (30%) and for children with multiple hypersensitivities, the most severe symptoms were both breathing and gastrointestinal (26% each; Annex C Table 60).

Symptoms for most reactions ( $n = 178$ ; 41%) started between 5-30 minutes of children consuming their stated food. This was also reflected across the hypersensitivities except for reactions reported by children with coeliac disease, for whom the majority of reactions typically occurred after 30 minutes of consuming their stated food ( $n = 20$ ; 58%; Annex C Table 61).

## 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  $n = 349$ ; 83%). Across all hypersensitivities most participants reported their reaction as clinically diagnosed, however children in the food intolerance group also reported that 29% ( $n = 20$ ) of their reactions have been self or family-diagnosed (Figure 58).

**Figure 58: Diagnosis by hypersensitivity**

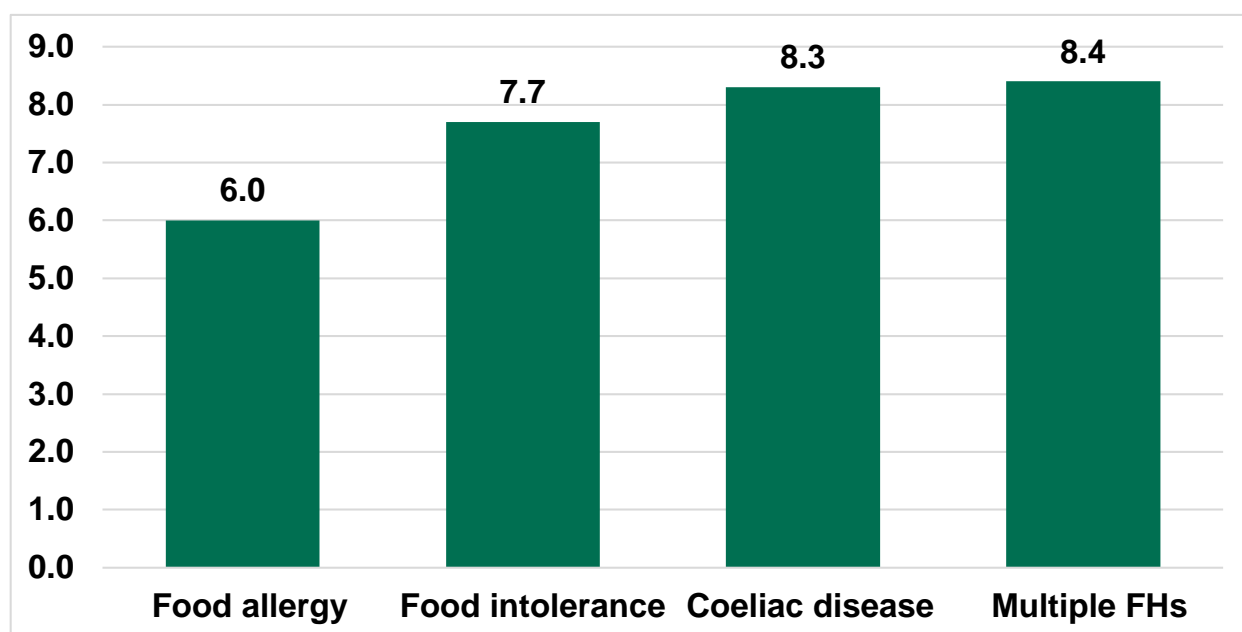


Base: All reactions to food given a diagnosis (378); Food allergy (154); Food intolerance (154); Coeliac disease (34); Multiple hypersensitivities (36)

The majority of all reactions to foods reported were diagnosed by a hospital doctor, nurse or a GP ( $n = 304$ , 73%). The most commonly reported diagnosis methods included noticing symptoms themselves ( $n = 111$ ; 21%), a blood test ( $n = 86$ , 16%) and healthcare professional's diagnosis ( $n = 82$ , 15%). For 20% ( $n = 105$ ) 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 62).

For 26% ( $n = 100$ ) 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 ([footnote 1](#)) was 7.2 years old ( $SD = 3.8$ ). Those with food allergy (mean = 6.0,  $SD = 3.4$ ) tended to start reacting to their first food at a significantly younger age than children reporting food intolerance (mean = 7.7,  $SD = 3.6$ ;  $p = .004$ ; Figure 59).

**Figure 59: Mean age (in years) children with each hypersensitivity were diagnosed for the first food they reported**



Base: All children with hypersensitivities (102); Food allergy (80); Food intolerance (65); Coeliac disease (19); Multiple hypersensitivities (9).

## About their reaction

While for 17% (n = 72) of all reactions to foods, children reported that they had not reacted to their first food in the previous 12 months, for 79% (n = 341) of reactions children reported that they had had a reaction (4%, n = 16 didn't know). For 21% of all reactions, children reported they had reacted once (n = 88) and for 25% that they had reacted twice (n = 107). Across hypersensitivities, 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 twice (n = 44; 28%); for food intolerance (n = 42; 27%) and coeliac disease (n = 9, 27%) it was most common to have experienced a reaction between 3-6 times. Participants with multiple hypersensitivities reported most commonly reacting once (n = 24, 41%) but 61% with multiple hypersensitivities reported reacting more frequently to foods (for example, 29% had reacted twice, 15% between 3-6 times and 7% 7-10 and more than 10 times; Annex C Table 63).

Children also reported where their stated reaction happened (for example, where they were when they first experienced symptoms of an adverse reaction). For the majority (58%, n = 237), their reactions occurred at home and this was also reflected across the hypersensitivities. However, for children in the multiple hypersensitivities group their reactions also commonly occurred at family and friends' houses (31%, n = 17%) and school (17%, n = 9) as well as at home (28%, n = 15) and work (11%, n = 6; see Annex C, Table 64). However, participants only reported where their reaction occurred and not where they consumed the stated food.

## Anaphylaxis

The total number of reactions reported by children who had ever experienced anaphylaxis was 145 (35%), of which 43% (n = 62) were reactions reported by those with food allergy and 31% (n = 45) were reactions reported by those with multiple hypersensitivities (Annex C, Table 66). For experience of anaphylaxis in the last 12 months, the total number of reactions was 98 (24%), with 33% and 36% of these being reported by children with food allergy and multiple hypersensitivities respectively, indicating these groups were most at risk of anaphylaxis in this sample (Annex C, Table 67). However, those with food intolerance (and coeliac disease also reported experience of anaphylaxis, which may indicate that participants may have misunderstood the question or miscategorised themselves, as this is not common for those with food intolerance or coeliac disease, thus these results should be taken with some caution.

Similarly, 38% (n = 166) of all children had been prescribed an adrenaline auto-injector, of which 45% (n = 74) were participants with food allergy and 30% (n = 50) were children with multiple hypersensitivities. However, 16% (n = 26) of these were also children reporting food intolerance and 7% (n = 11) were children with coeliac disease, again possibly reflecting that participants had either miscategorised themselves or misunderstood the question.

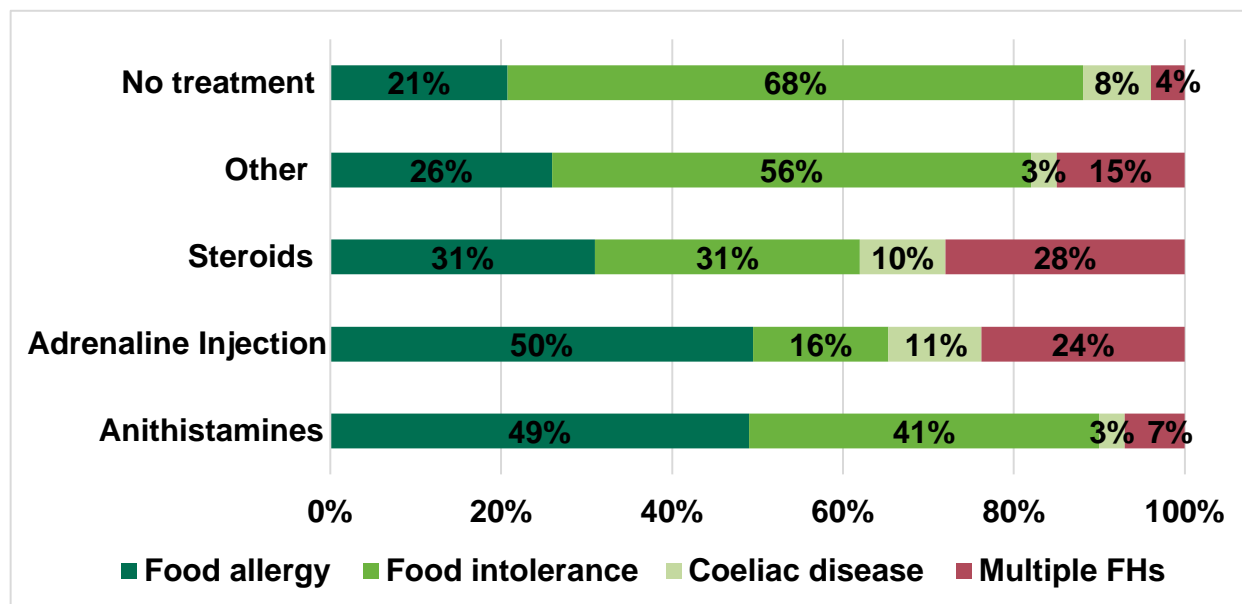
## Treatment

Participants were asked about the treatments they had received for the reactions to the food stated, including who treated them for the reaction. The majority of children across all reactions reported treating the reaction themselves (36%, n = 166) or being treated by someone else who was not medical (31%, n = 143). This was also true for those with food intolerance and coeliac disease, however for those with food allergy (31%, n = 51) and multiple hypersensitivities (47%, n = 32) participants also reported being treated by someone medical (Annex C, Table 65).

For treatments administered by a non-medical person, antihistamines were the most common treatment reported (n = 110; 35%), although 28% also reported not taking anything (see Figure

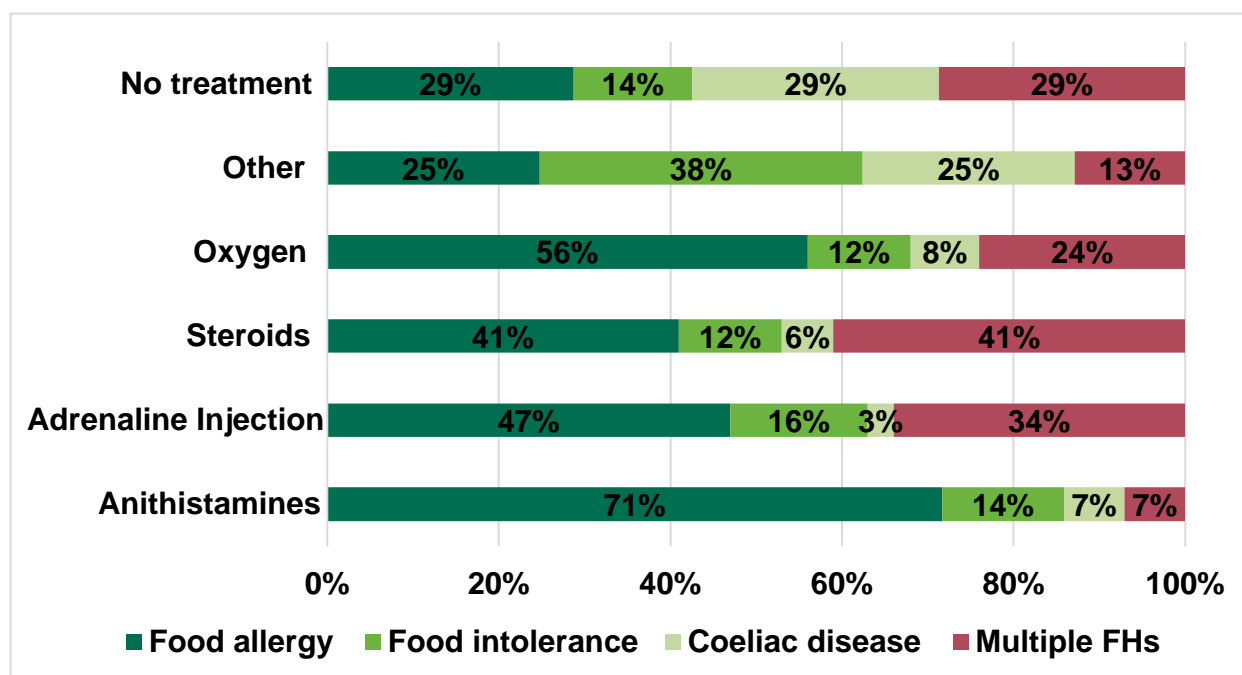
60). For treatments administered by a medical professional, the most common treatment was adrenaline injection (27%, n = 38), as well steroids (24%, n = 34). For both those given by a non-medical professional, as well as a medical professional, treatments were most commonly given for reactions reported by children with food allergy (see Figures 60 and 61).

**Figure 60: Treatments given by non medical person for all foods**



Base: All treatments for children with hypersensitivities (297); Food allergy (109); Food intolerance (134); Coeliac disease (18); Multiple hypersensitivities (36)

**Figure 61: Treatments given by medical professionals for all foods**



Base: All treatments for children with hypersensitivities (140); Food allergy (70); Food intolerance (21); Coeliac disease (11); Multiple hypersensitivities (38).

## Hospital admission

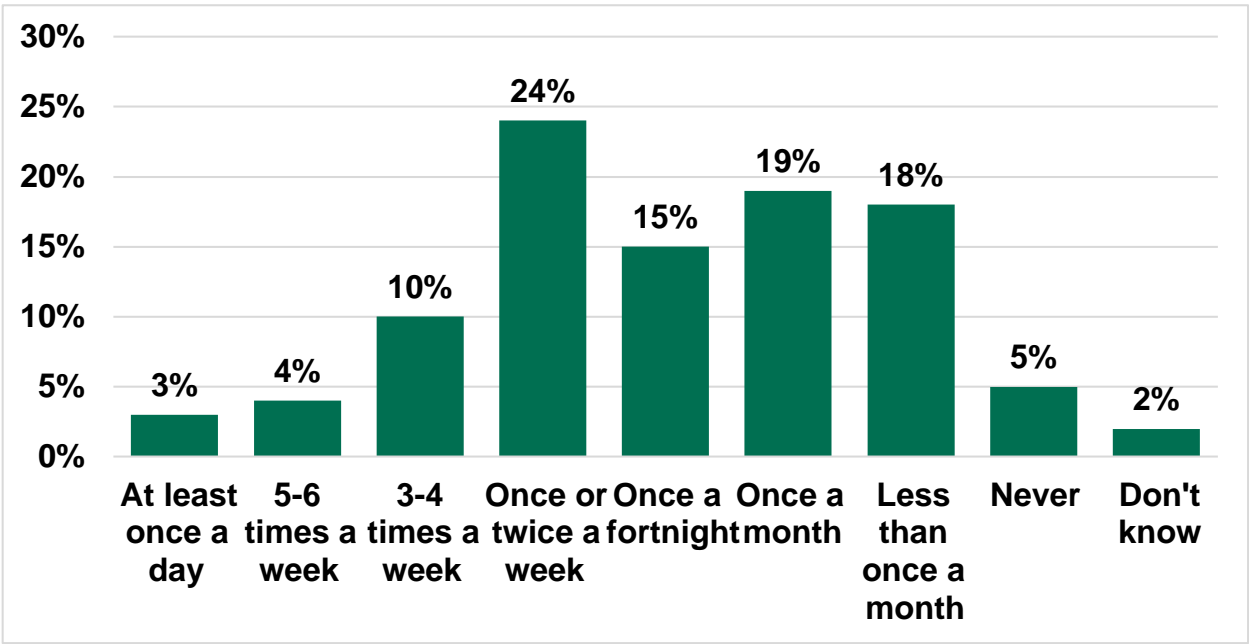
For 69% (n = 289) of the adverse reactions to foods reported, children had never had an ambulance called, and for 64% (n = 264) of reactions, children had never been admitted to hospital. For those that had been admitted to hospital (n = 149, 36% of all foods reported), 120 (81% of those who had been to hospital) were admitted the first time that they reacted. It was most common for children to report being admitted to hospital once (n = 44; 30%) or not to have been admitted in the last 12 months (n = 33; 23%). Across hypersensitivities, the group with the highest percentage of being admitted to hospital was children with food allergy (n = 61; 41% of all those being admitted), with 82% (n = 50) of these going the first time that they reacted. While 37% of children with food allergy had not been admitted in the last 12 months, 31% (n = 18) had been admitted once, as had 26% of children with food intolerance, 30% of children with coeliac disease and 29% of children with multiple hypersensitivities who had ever been admitted to hospital for their reaction (see Annex C, Tables 68 and 69).

## 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.

Children most frequently reported eating out between once or twice a week and less than once a month (n = 258; 76% of all children; Figure 62).

**Figure 62: How often participants eat out or get food to take away**



Base: All children (338).

Across the hypersensitivities, child participants with food allergy most commonly ate out once or twice a week (n = 36; 26%), those with food intolerance (n = 35; 26%) most commonly ate out once month, those with coeliac disease most commonly ate out once or twice a week or once a fortnight (n = 8, 27% each) and those with multiple hypersensitivities most commonly ate out 3-4 times a week (n = 6, 32%), indicating that those with food intolerance ate out less than children with other hypersensitivities. However, there were no significant differences in how often children with different hypersensitivities eat out, with both groups (food allergy and intolerance) on average eating out around once a month or fortnight (p =.13). See Annex C Table 70.

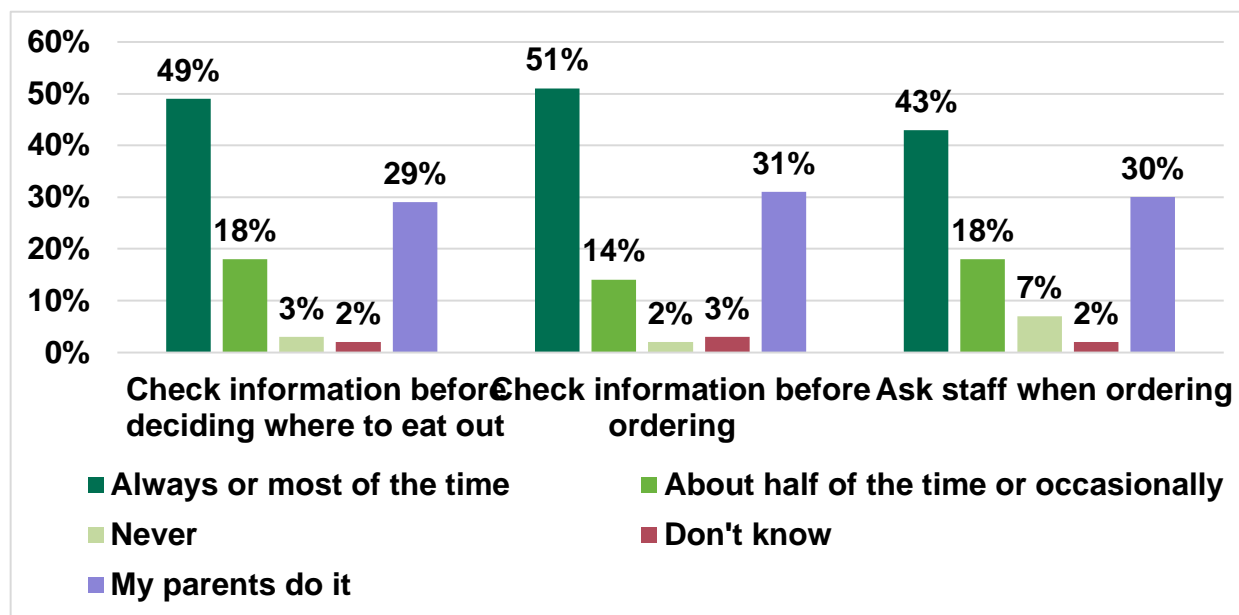
## Checking information when eating out



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 63).

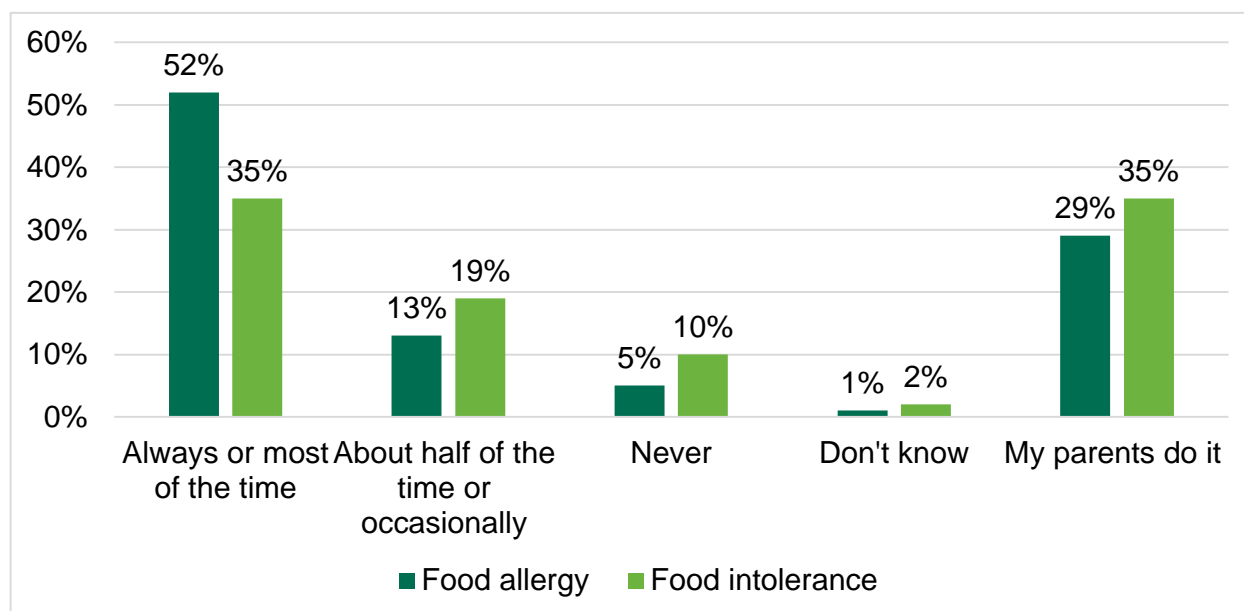
**Figure 63: How often children review information when eating out**



Base: All children; Check information before choosing where to eat out (321); Check information when ordering (317); Ask staff when ordering (315).

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 (both  $p > .05$ ). However, there were significant differences for how often children ask members of staff for information about foods that may cause an adverse reaction,  $t(150.9) = 2.61$ ,  $p = .01$ . Children with food allergy (mean = 3.9, SD = 1.2) asked for information significantly more often than children with food intolerance (mean = 3.4, SD = 1.5), on average reporting they asked for this most of the time (Figure 64).

**Figure 64: How often children ask staff for information when eating out, by hypersensitivity**



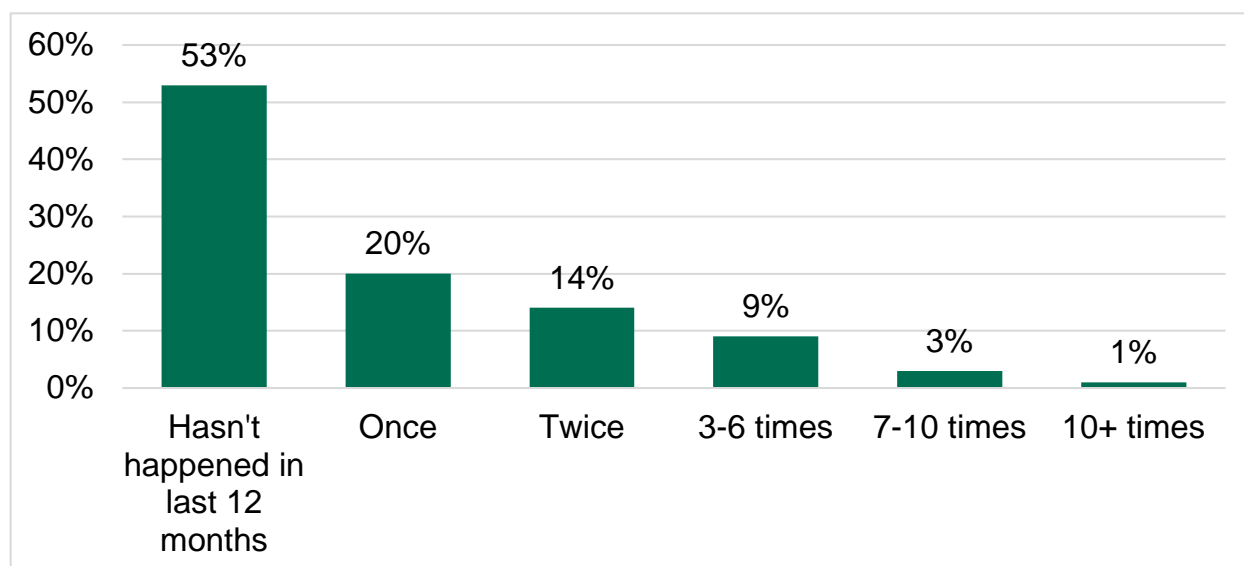
Base: Children with hypersensitivities; Food allergy (129); Food intolerance (124).

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 ( $n = 179$ ; 56% were very or fairly comfortable) and were confident in written ( $n = 198$ ; 63% were very or fairly confident) and verbal information provided when eating out ( $n = 188$ ; 59%). This was also true across hypersensitivities (Annex C Tables 71-73).

However on a scale from 1 (Not at all) to 4 (Very comfortable), children with food allergy (mean = 3.0, SD = 0.9) reported being significantly more comfortable asking for available information than those with food intolerance (mean = 2.7, SD = 0.9,  $t(212) = 1.98$ ,  $p = .049$ ). Further, there were significant differences for how confident children were in verbal information provided by staff when eating out, with children with food allergy (mean = 3.0, SD = 0.9) being more confident in this than those with food intolerance (mean = 2.6, SD 0.8;  $t(207) = 2.58$ ,  $p = .01$ ). There were no significant differences observed by food hypersensitivity for confidence in written information ( $p > .05$ ).

Participants also reported how often they had been offered a food which may cause a bad or unpleasant reaction in the last 12 months, when eating out, despite checking available information. For the majority, this hadn't happened ( $n = 169$ , 53%) but for those who had been offered a food which may cause an adverse reaction in the past 12 months, despite checking available information ( $n = 150$ ; 47%), this was most likely to have happened once ( $n = 65$ , 20%; see Figure 65 and Annex C Table 74). This was the same across hypersensitivities, except for children in the multiple hypersensitivities group who reported that they had most frequently experienced being offered food which may cause an adverse reaction twice ( $n = 8$ ; 44%).

**Figure 65: How often children have been offered an allergen in the last 12 months**



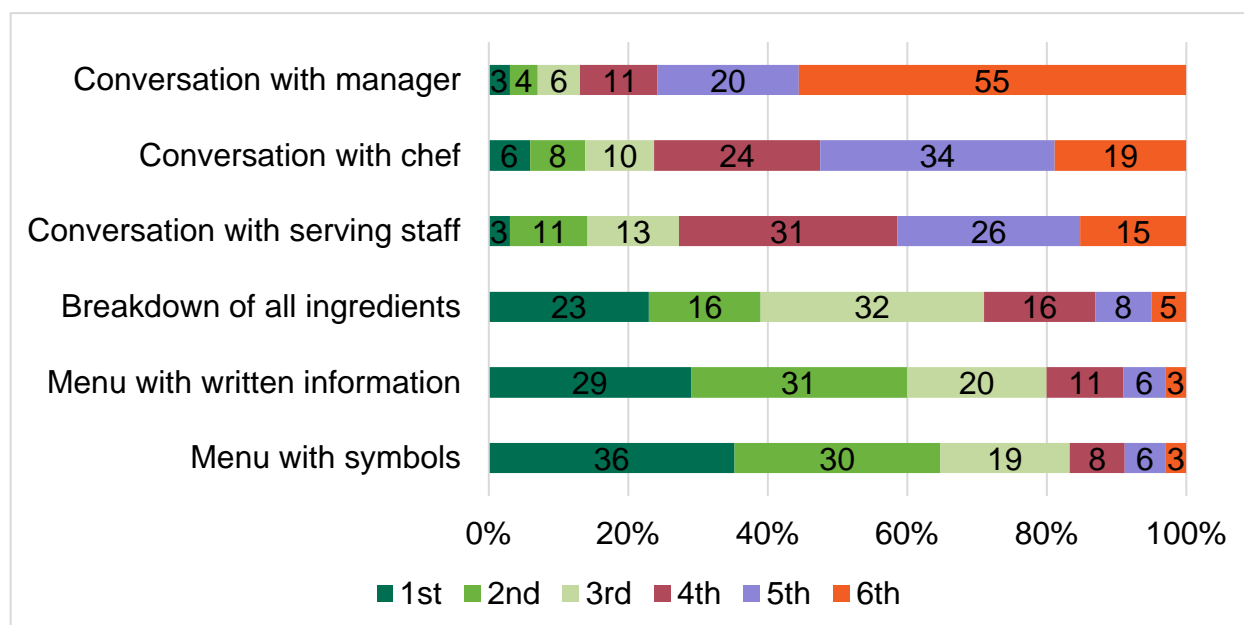
Base all children (319).

When reporting the sources of information they found most useful when checking available information allergen information when eating out, children rated menus with symbols indicating allergens in each dish as most useful ( $n = 113$ , 36% rated this as their most useful source of information). The second most helpful was menus with written allergen information ( $n = 97$ , 31%) and the third most helpful was a breakdown of all ingredients in a dish on menus ( $n = 102$ , 32%; see Figure 66).

This was also true across hypersensitivities with children with food allergy and multiple hypersensitivities rating the menus with symbols indicating allergens and written information on menus as equally useful. However, children with food intolerance rated menus with written allergen information ( $n = 40$ , 31%) as most helpful and menus with symbols indicating allergens as second helpful ( $n = 44$ , 35%).

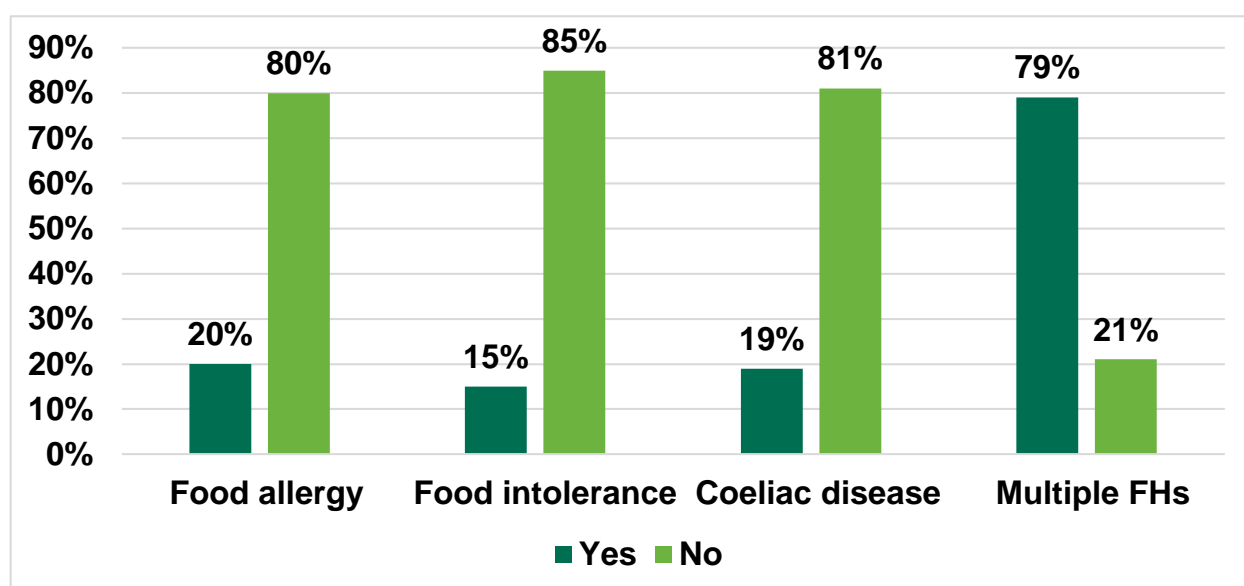
More than one in five ( $n = 71$ ; 22%) of children reported they had been refused service because of their hypersensitivity ( $n = 257$ ; 78% had not). Although within those who had multiple hypersensitivities the majority reported having been refused service ( $n = 15$ , 79%), of those who had been refused service, children with food allergy ( $n = 26$ ; 40%) were significantly more likely to report having been refused service than those with other hypersensitivities,  $\chi^2(3) = 41.97$ ,  $p < .001$ , reflecting the larger sample size of children with food allergy (Figure 67).

**Figure 66: Rank of most useful sources of information for children, when eating out**



Base: All children (318)

**Figure 67: Proportion of children refused services when eating out because of their reaction to food**



Base: All children (309); Food allergy (132); Food intolerance (131); Coeliac disease (27); Multiple hypersensitivities (19).

## 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 (for example, 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 4.3 out of 7, and teens and children with food intolerance reported a mean of 4.2 out of 7, indicating that both groups felt that their food allergy or intolerance impacted their quality of life 'moderately' to 'quite a bit' (Table 3).

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

Respondent group	FAQLQ (Food allergy) N = 131	FIQLQ (Food intolerance) N = 139
All children Mean total (SD)	4.3 (1.4)	4.2 (1.4)
8-12s Mean total (SD)	4.0 (1.5)	4.2 (1.4)
13-17s Mean Total (SD)	4.7 (1.3)	4.2 (1.4)
Out of a possible total of:	7	7

## 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.

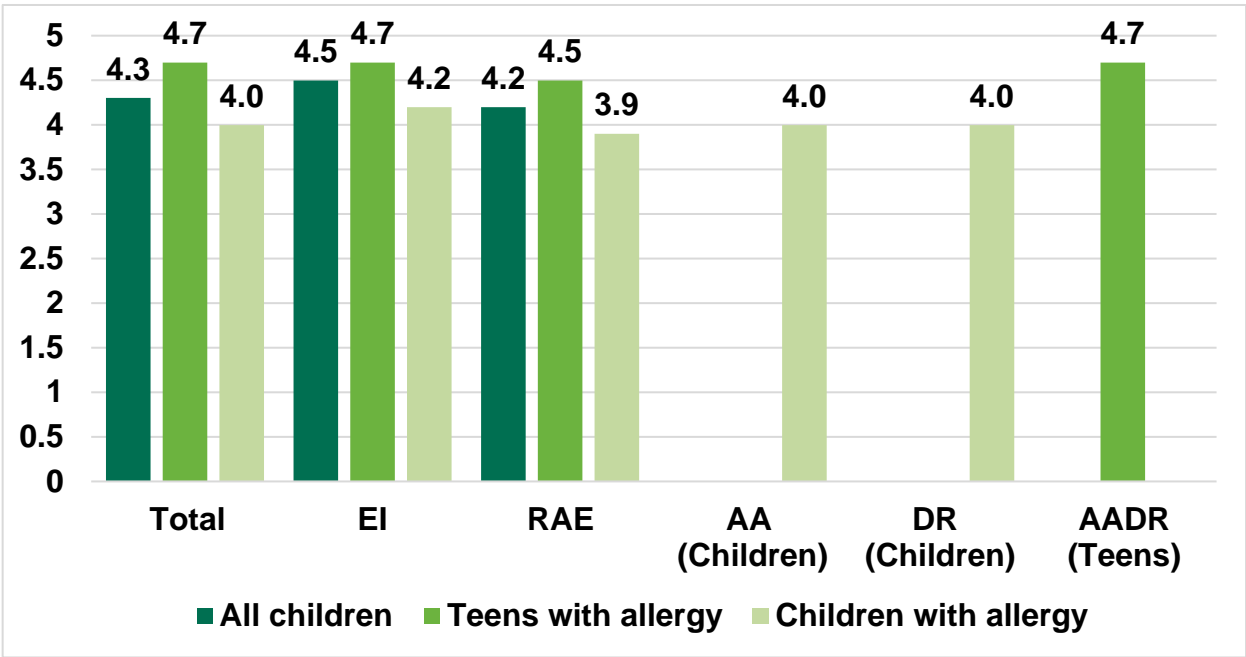
For each age group a different age-appropriate version of the FAQLQ was completed. Those aged 13-17 years completed the teen version and those aged 8-12 years completed the child version, which has separated Allergen Avoidance and Dietary Restrictions subscales. A total of 131 children completed the FAQLQ, of which 128 were from the allergy only group (and 3 with multiple hypersensitivities however these will not be reported on). Of those who completed the FAQLQ, 68 were from the 13-17 sample and 63 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 = 4.3 out of 7, SD = 1.4), indicating quality of life was impacted 'moderately'. However, the total and subscale scores for teens were higher than those reported by children (see Figure 68), with the subscales for emotional impact (4.7 out of 7, reflecting choices 'moderate' impact or 'quite a bit' SD = 1.4) and allergen avoidance and dietary restrictions (mean = 4.7 out of 7 reflecting choices 'moderate' impact to 'quite a bit', SD = 1.3) reflecting that the worries and concerns around having food allergy and the restrictions and allergy awareness behaviours associated with it were the areas which had the most impact on teenagers' quality of life. For children, the score on the emotional impact subscale (mean = 4.2 out of 7, SD = 1.7) was highest, indicating that worries and concerns around having food allergy had the most and 'moderate' impact on quality of life for younger children (Figure 68).

Differences in clinical factors for younger childrens' and teenagers' FAQLQ scores were not examined as subgroups were too small. However, reported severity of younger childrens' reactions ( $r = .31$ ,  $p = .02$ ) and teenagers' reactions ( $r = .57$ ,  $p < .001$ ), were significantly positively correlated with impairment to children's quality of life. Frequency of eating out ( $r = -.31$ ,  $p = .03$ )

and confidence in verbal information when eating out ( $r = -.46$ ,  $p = .002$ ) were both significantly negatively correlated with impairment to younger children’s quality of life. However, frequency of reviewing information before ordering food when eating out ( $r = .39$ ,  $p = .02$ ) and asking staff for available information when eating out ( $r = .44$ ,  $p = .004$ ) were significantly positively correlated with impaired quality of life in teenagers with food allergy.

**Figure 68: Mean FAQLQ scores for children reporting food allergy**



Base: All children completing the FAQLQ in the food allergy only group (128); Teens (13-17s; 68); Children (8-12s; 63).

A regression model was run for both younger children and older children to see which of the variables described above might predict impairment to quality of life. For younger children, the variables above which had a significant association with quality of life were included in the model ( $n = 3$  predictors). The overall model was significant ( $p = .02$ ) and 24% of the variance in quality of life was explained, indicating that 76% of the variance was due to other unknown factors. Confidence in verbal information was the only significant predictor of quality of life, indicating that greater confidence predicted lower impairment to younger children’s quality of life (standardised beta = - 0.42). None of the other predictors were significant (standardised betas were -0.06 and 0.16, and confidence intervals for each predictor crossed zero).

For older children (teenagers), the three significant variables above were entered into the model to see which predicted impairment to quality of life. The overall model was significant ( $p < .001$ ) and 42% of the variance in quality of life was explained, indicating that 58% of the variance was due to other unknown factors. Only self-reported severity of reaction was a significant predictor of impairment to quality of life, indicating that greater severity predicted more impairment to teenager’s quality of life (standardised beta = 0.51). None of the other predictors were significant (standardised betas were 0.10 and 0.24 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

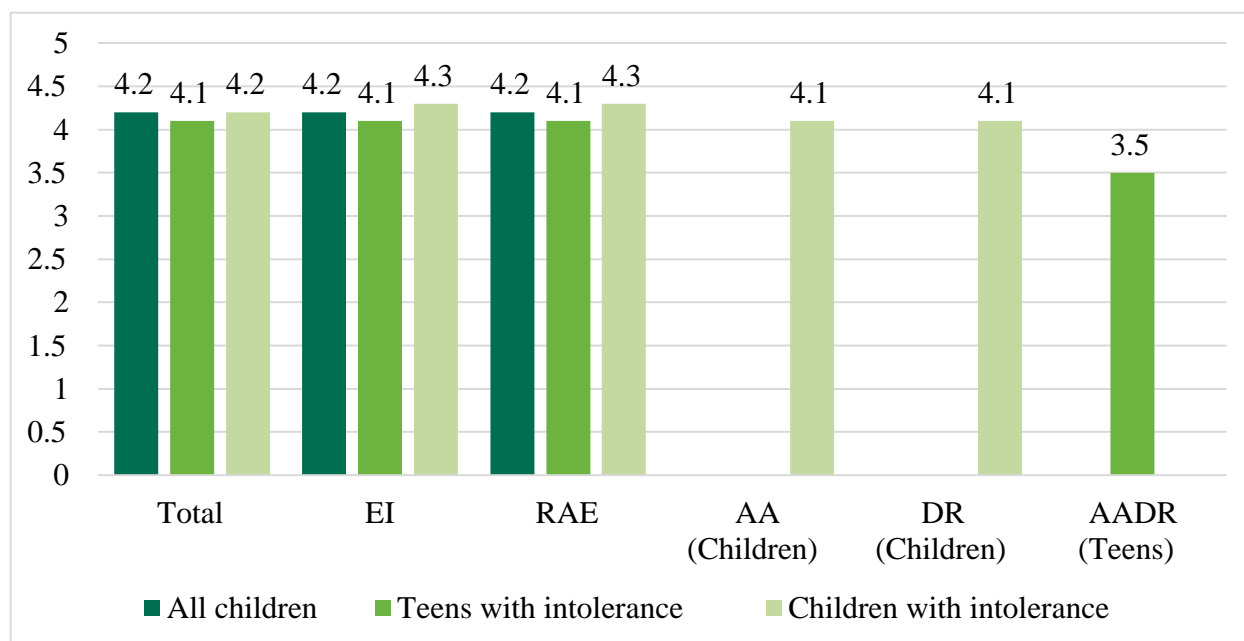
are suitable to eat in order to avoid an adverse reaction. As with the FAQLQ, two different scales were used for younger (8-12 years) and older children (13-17 years). A total of 130 children from the food intolerance only group completed the FIQLQ (a further 9 were from the multiple hypersensitivities group). Seventy one of the 8-12 sample, and 59 of the 13-17 sample completed the FIQLQ.

Children (aged 8-17 years) with food intolerance reported 'moderate' quality of life (mean = 4.2 out of 7, SD = 1.4) with scores across the subscales for both teens and children reflecting this (see Figure 66). Younger children reported slightly higher scores and more impact on quality of life across subscales, especially for the emotional impact subscale (mean = 4.3 out of 7, SD = 1.5) and risk of accidental exposure subscales, indicating that the worries and concerns experienced by children with food intolerance and the need to check foods to avoid a reaction has the most and 'moderate' impact on their quality of life.

For 13-17 year-olds scores indicated that food intolerance had a moderate impact on quality of life across the subscales, except for the AADR subscale, which teens reported an average of 3.5 out of 7 (SD = 1.3), indicating that the social and dietary limitations and need to be aware of foods as a result of having food intolerance 'slightly' affected quality of life and had the least 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 69).

For children and teenagers with food intolerance, the severity of their reaction was significantly positively correlated with impairment to their quality of life for both younger children ( $r = .32$ ,  $p = .02$ ) and teenagers ( $r = .40$ ,  $p = .003$ ). Further, frequency of checking available information when choosing where to eat out was also significantly positively correlated with impairment to childrens' ( $r = .48$ ,  $p = .004$ ) and teenagers' ( $r = .41$ ,  $p = .01$ ) quality of life. For younger children, how comfortable they were in asking staff for available information when eating out ( $r = .37$ ,  $p = .02$ ), and for teenagers' frequency of checking available information before ordering ( $r = .45$ ,  $p = .004$ ) when eating out were both significantly positively correlated with impairment to quality of life.

**Figure 69: Mean FIQLQ scores for children with food intolerance**



Base: All children completing the FIQLQ in the food intolerance only group (130); Teens with intolerance (13-17s; 59); Children with intolerance (8-12s; 71).

A regression model was run for both younger and older children to see which of the variables described above might predict level of quality of life. For younger children (aged 8 -12), the variables above which had a significant association with quality of life were included in the model ( $n=3$  predictors). The overall model was significant ( $p=0.02$ ) and 31% of the variance in quality of

life was explained, indicating that 69% of the variance was due to other unknown factors. Higher frequency of checking available information before choosing where to eat out significantly predicted more impairment to quality of life (standardised beta 0.36). None of the other predictors were significant (standardised betas ranged from 0.13 and 0.34 and confidence intervals for each predictor crossed zero).

For older children (aged 13-17), the three significant variables above were also entered into the model. The overall model was significant ( $p < 0.05$ ) and explained 25% of the variance in impairment to quality of life, indicating that 75% of the variance was due to unknown factors. However, none of the predictors were significant in predicting impairment to quality of life (all standardised betas ranged from 0.11 to 0.31 and confidence intervals for each predictor crossed zero).

## **Differences in Quality of Life by hypersensitivity**

For these key comparisons, data for children and teenagers was combined, to ensure numbers in subgroups were sufficient to carry out the analysis. Comparisons in QoL scores were made for 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, 102 children completed all questions of the FAQLQ.

#### **Gender**

For children reporting food allergy only, 53 males and 36 females completed the FAQLQ (as well as 2 who identified 'in another way' and 1 who preferred not to say, however these were excluded for these analyses only). There were no significant difference in the impact of food allergy upon quality of life between males (mean = 4.5, SD = 1.5) and females (mean = 4.1, SD = 1.3) with food allergy,  $t(97) = 1.23$ ,  $p = .22$ .

#### **Age**

Of the children completing the FAQLQ, 54 were younger children (8-12) and 48 were older children (13-17). Older children reported significantly more impact upon quality of life (mean = 4.7, SD = 1.3), compared to younger children (mean = 4.0, SD = 1.5)  $t(100) = 2.39$ ,  $p = .02$ .

#### **Severity**

There were significant differences in impact on quality of life according to the self-reported severity of reaction,  $F(2) = 11.1$ ,  $p < .001$ ,  $\eta^2 = .18$ . Participants reporting a severe reaction to their first food ( $n = 25$ , mean = 5.3, SD = 1.2) reported significantly more impact upon quality of life than those reporting a mild reaction, ( $n = 23$ , mean = 3.5, SD = 1.1),  $t(46) = 5.25$ ,  $p < .001$  and a moderate reaction ( $n = 54$ , mean = 4.3, SD = 1.4,  $t(77) = 3.15$ ,  $p = .002$ . However, the numbers of those in the mild and severe groups were small and so these results should be taken with some caution.

### **Food intolerance only**

Of the food intolerance only group, 106 children completed all questions of the FIQLQ.



## **Gender**

Of those children with food intolerance who completed the FIQLQ, 54 were male, 52 were female. Females (mean = 4.4, SD = 1.4) reported significantly higher impairment to quality of life than males (mean = 3.9, SD = 1.3),  $t(104) = 2.01$ ,  $p = .047$ .

## **Age**

Of those who completed the FIQLQ, 52 children were aged 8-12 years, and 54 were aged 13-17 years. There were no significant differences in QoL scores between younger children (mean = 4.2, SD = 1.3) and older children (mean = 4.1, SD = 1.4),  $t(104) = 0.27$ ,  $p = .79$ .

## **Severity**

As the numbers of those reporting a severe reaction were too small ( $n = 13$ ) comparisons were only made for mild ( $n = 33$ ) and moderate ( $n = 60$ ) reactions. Those reporting moderate reactions (mean = 4.2, SD = 1.3) had significantly more impact upon quality of life than those reporting mild reactions (mean = 3.6, SD = 1.3),  $t(91) = 2.13$ ,  $p = .04$ .

## **Coeliac disease only**

For those in the coeliac group, 28 completed the CDDUX, however this was deemed too small a group to conduct sub-analysis on.

## **Multiple hypersensitivities**

For children with multiple hypersensitivities, only 3 completed the FAQLQ, 9 completed the FIQLQ and 4 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 ( $n = 51$ , mean = 83.27, SD = 16.47), and those with food intolerance ( $n = 70$ , mean score = 82.03, SD = 16.59). Those with coeliac disease scored lower ( $n = 10$ , mean = 75.60, SD = 20.46), but numbers in this group are 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. For each dimension scores for wave 2 were worse than scores for wave 1, indicating poorer QoL.

### **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 ( $n = 80$ , mean = 80.00, SD = 19.4), followed by those with food intolerance ( $n = 61$ , mean = 77.10, SD = 21.20) and those with coeliac disease who scored lowest ( $n = 19$ , mean score = 70.10, SD = 16.30). 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. For each dimension scores for wave 2 were worse than scores for wave 1, indicating poorer QoL.

No other comparisons have been made between wave 1 and 2 for children and teens as numbers are too low for meaningful analysis.

1. Comparisons were not made for foods two and three, due to small numbers in these groups