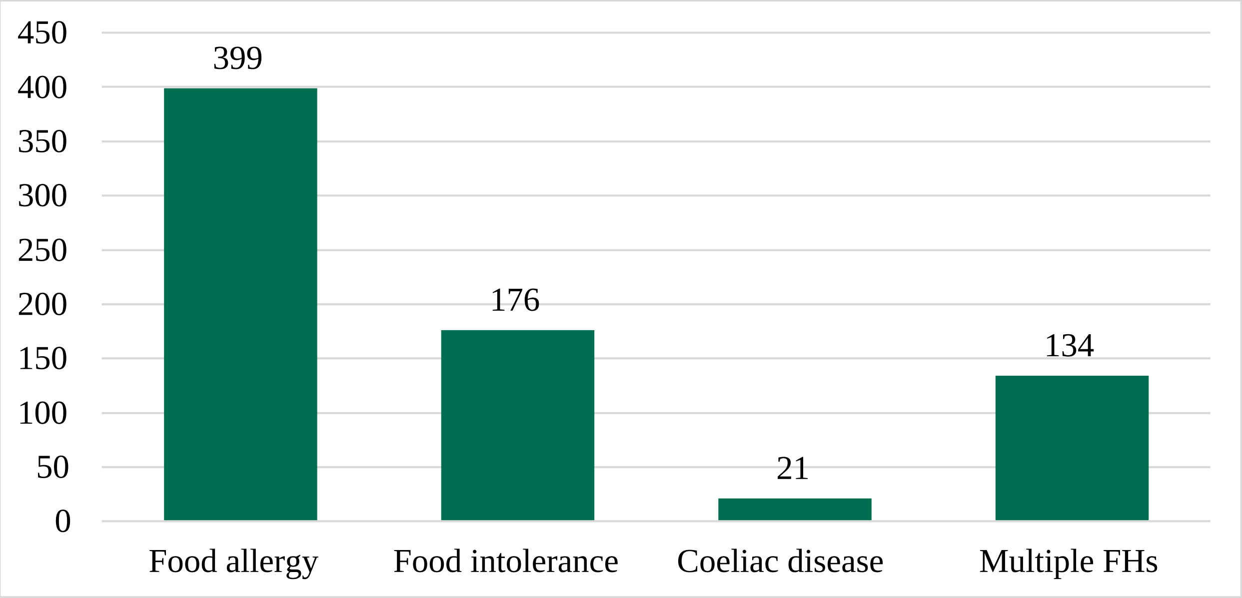
Part 2: Parents of children with food hypersensitivity

A total of 750 parents of children (under 18 years) with FH completed the survey, which included n= 20 reporting ‘Other’ or ‘Don’t know’ when asked to describe these reactions to food. These participants are not reported on in analysis as a subgroup but are included in the ‘all parents’ figures. From this total of 750 parents, 77 had also taken part in wave 1. For further detail please see pages 86-88 and Annex B, Table 47.

Prevalence of food hypersensitivities

The majority of parents reported children who had food allergy only (n = 399; 53%) followed by food intolerance only (n = 176; 23%). Fewer parents reported children with coeliac disease only (n = 21; 3%) or multiple hypersensitivities (for example, parents of one child with multiple food hypersensitivities or multiple children with different food hypersensitivities; n = 134; 18%) (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’ (730).

Profile of parent participants

Parents’ key characteristics

From a total of 750 parent participants, 78% (n = 580) of those reporting a child with a food hypersensitivity were female (22%; n = 167 were male; 1 reported ‘In another way’; 0.1%). The mean age of all parent participants was 37.1 years old (SD = 7.9), with a range from 18 to 62 years old. The majority of parents were of White British ethnicity (n = 607; 81%. See Annex B Table 28).

Parents of children with food allergy (mean age: 38.4 years old; SD = 7.6) were significantly older than those reporting children with a food intolerance (mean age: 34.6 years old; SD = 7.9) and multiple food hypersensitivities (mean age: 35.8; SD = 7.6; all ps <.008). There was no significant differences in age for parents of children coeliac disease (mean age: 40.6; SD = 8.1).
As with the whole sample, across all hypersensitivities, the majority of parents were of White British ethnicity (see Annex B Table 28 for a full breakdown). The most common region for all parents living with a child with a food hypersensitivity was London (n = 126, 17%). This was also true across the hypersensitivities, except for parents in the food intolerance group, who most commonly lived in the South East of England (n = 31; 18%; see Annex B Table 29 for a full breakdown).

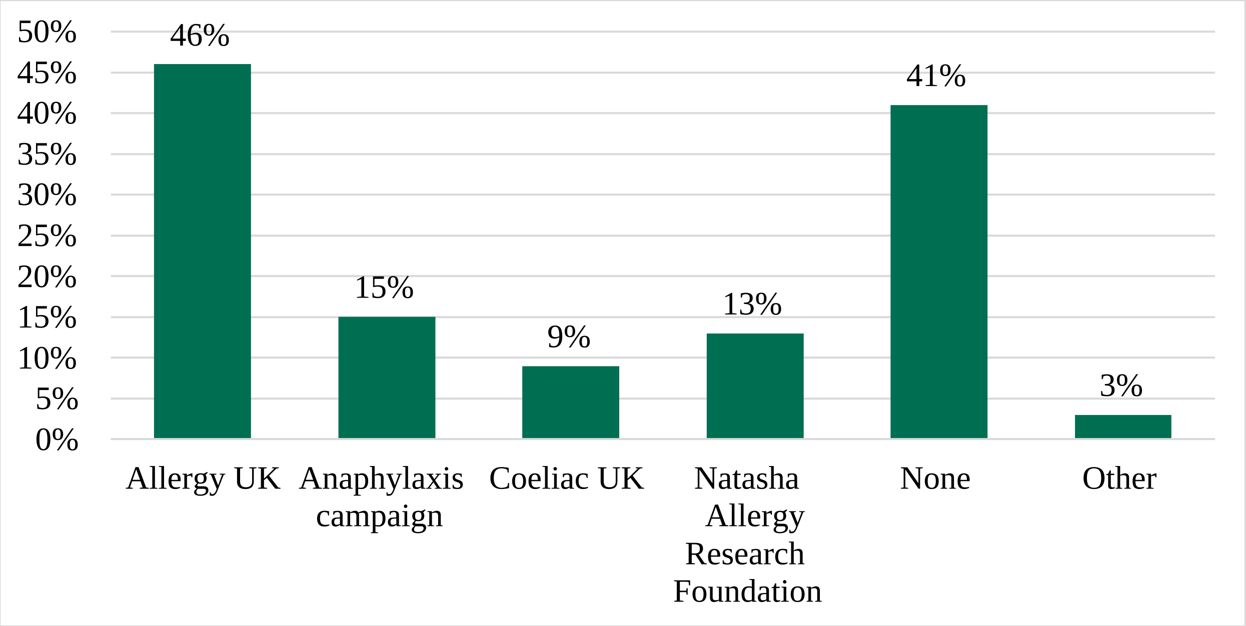
Fifty two percent (n = 388) of the sample were in full-time employment, 27% (n = 198) were in part-time employment but 17% (n = 124) were not working (for a full breakdown see Annex B Table 30). Across the hypersensitivities, children with multiple hypersensitivities had the highest percentage of parents in full-time employment (64%, n = 86), whilst children with coeliac disease had the highest percentage of parent respondents who were not working (24%; n = 5).

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 = 350; 48%) aged 0-17 years, and most commonly reported only one child (n = 567; 77%) 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. Whilst 41% (n = 306) were not members of any patient organisations, the most commonly reported organisation that parents belonged to was Allergy UK (46%; n = 334), followed by The Anaphylaxis Campaign (n = 115; 15%; see Figure 33). Of those reporting ‘Other’, this included support groups on social media, such as Facebook support groups (for example, gluten free/nut free/ allergy support groups); Facebook pages and websites of other patient organisations (for example, Cow’s Milk Protein Allergy support pages/groups; Mast Cell support groups).

Figure 33: Membership of patient organisation groups

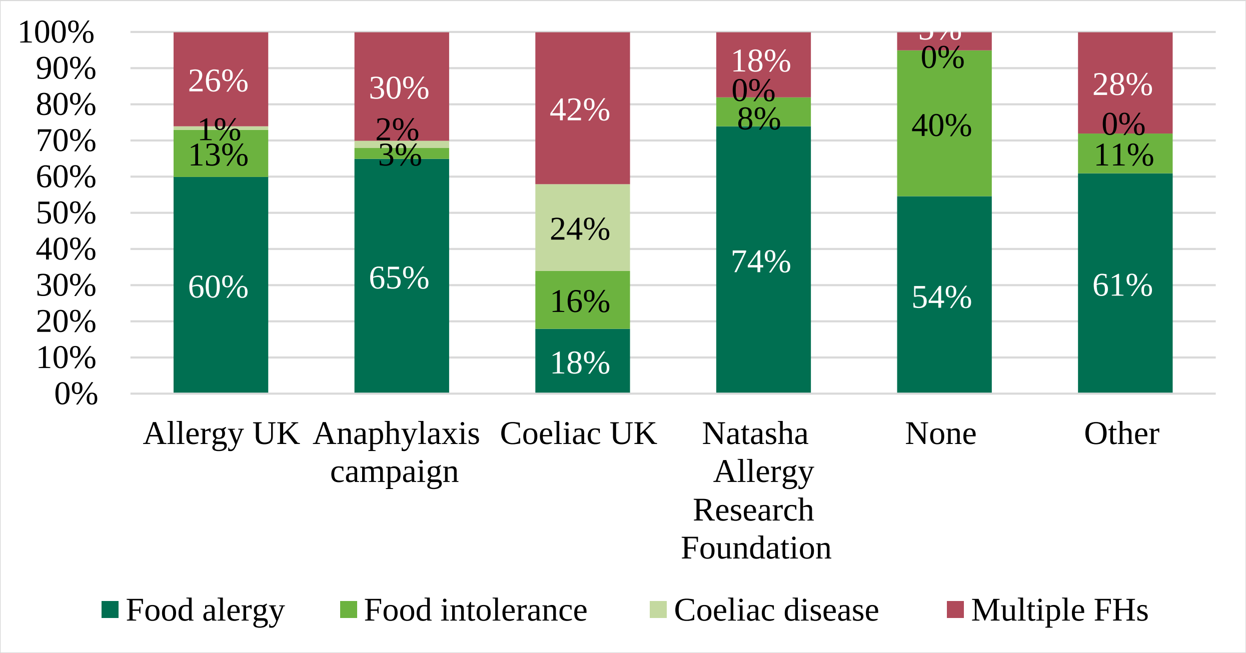


Base: All parents (750).

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 = 197; 49%); for parents of children with coeliac disease, the most subscribed to was Coeliac UK (n = 16; 76%); and for parents of children with multiple hypersensitivities the most subscribed to was Allergy UK (n = 86; 64%; Figure 34).

A majority of parents of children with food intolerance did not subscribe to any organisations (n = 120; 68%). A large proportion of parents of children with food allergy also reported not being a member of a support group or patient organisation (n = 162; 41%) in contrast to parents of children with coeliac disease (n = 0; 0%) and multiple hypersensitivities (n = 16; 12%; Figure 34).

Figure 34: Membership of patient organisations by hypersensitivity



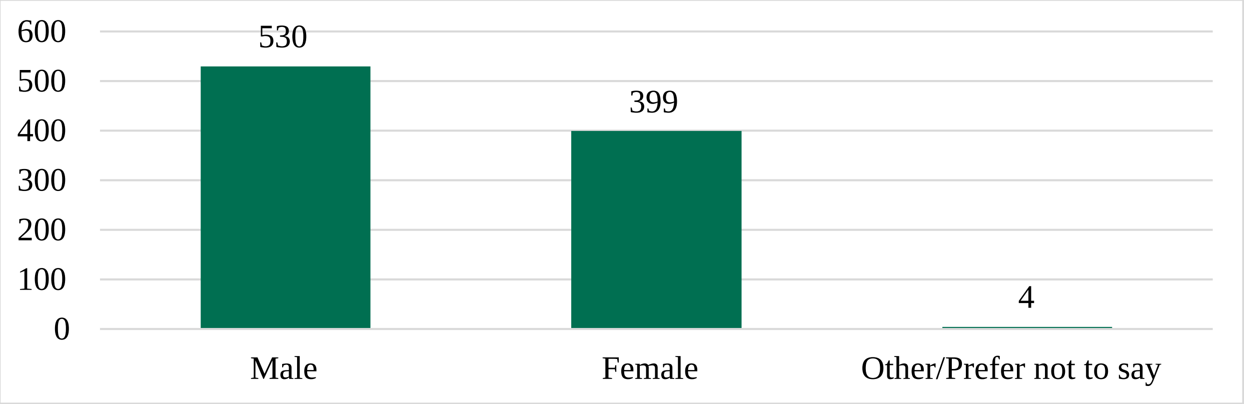
Base: All parents reporting children with a hypersensitivity (730): Food allergy (399); Food intolerance (176); Coeliac disease (21); Multiple FHs (134)

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 = 933), 57% of children with a food hypersensitivity were male and 43% were female (Figure 35).

Figure 35: Gender of all children reported by parent participants



Base: All children reported by parents, for gender (933); Male (530); Female (399); Other/Prefer not to say (4).

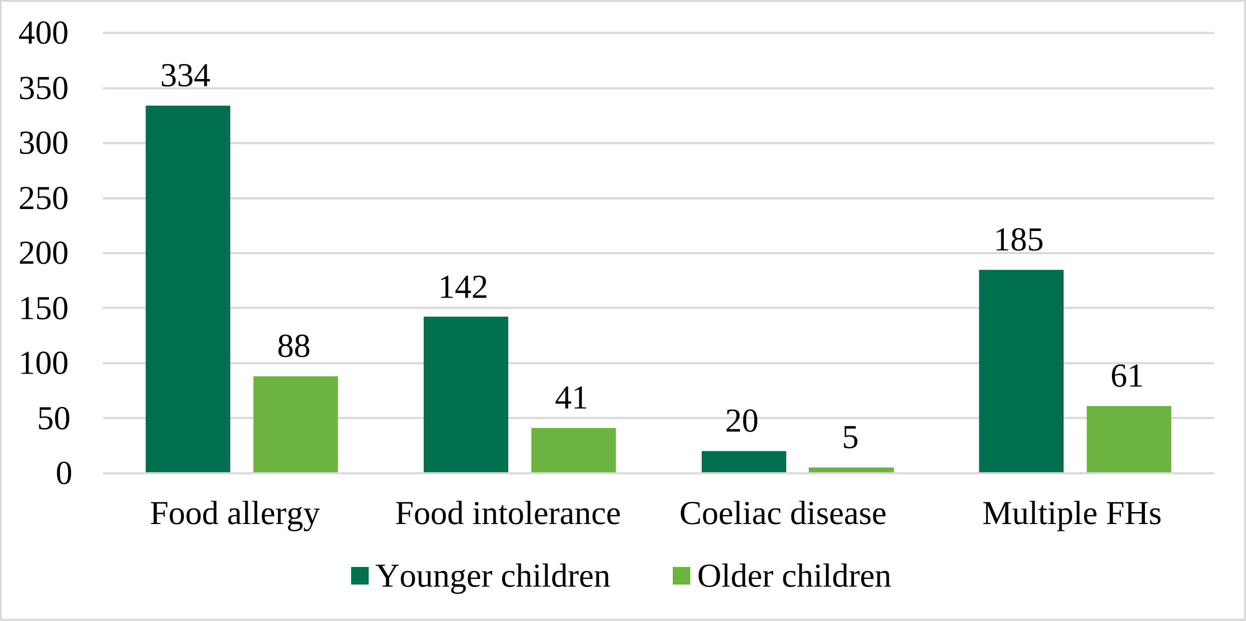
The mean age of all children reported was 7.7 years old (average SD = 4.8). Across all children, parents reported on 699 younger children (0-12 years old) and 198 older children (13-17 years old). The majority of parent participants reported that their children were of White British ethnicity (n = 729; 79%. See Annex B Table 31).

Children with multiple hypersensitivities (mean age across all 3 children: 8.2; SD = 4.8) were typically reported by their parents to be older than those reporting a food intolerance (mean age: 6.3 years old; SD = 5.2), coeliac disease (mean age: 7.3 years old; SD = 4.2) or food allergy (mean age: 7.4; SD = 5.4; 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 multiple hypersensitivities (62% males; see Figure 37).

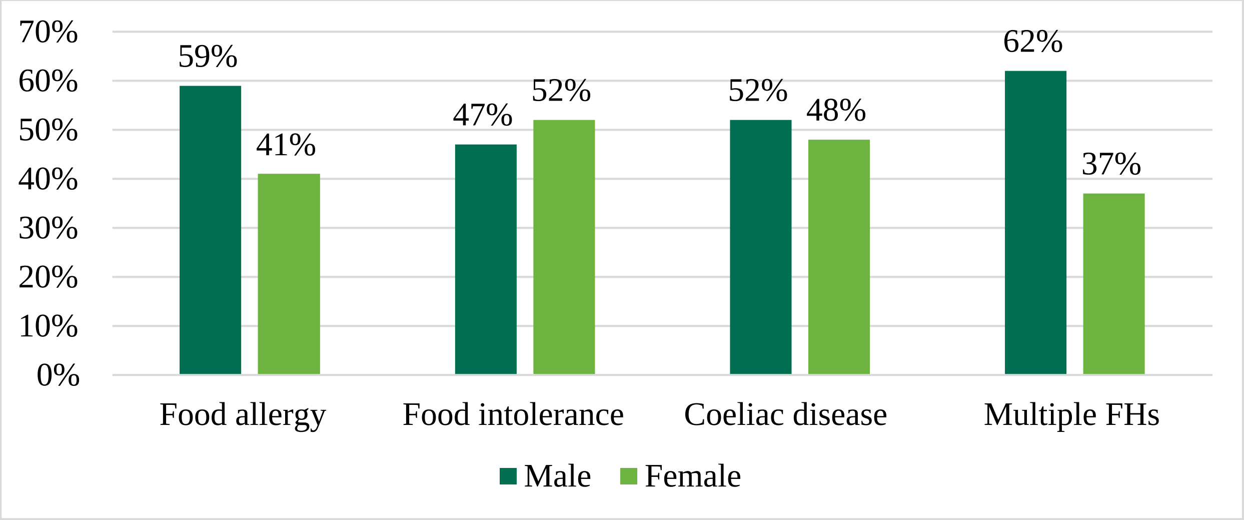
As with the overall sample, for ethnicity, across the hypersensitivities, the majority of children were of White British ethnicity (78%; see Annex Table 31).

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



Base: All children reported by parents in the hypersensitive groups (876): Younger children (0-12-year olds; 681); Older children (13-17-year olds;195)

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

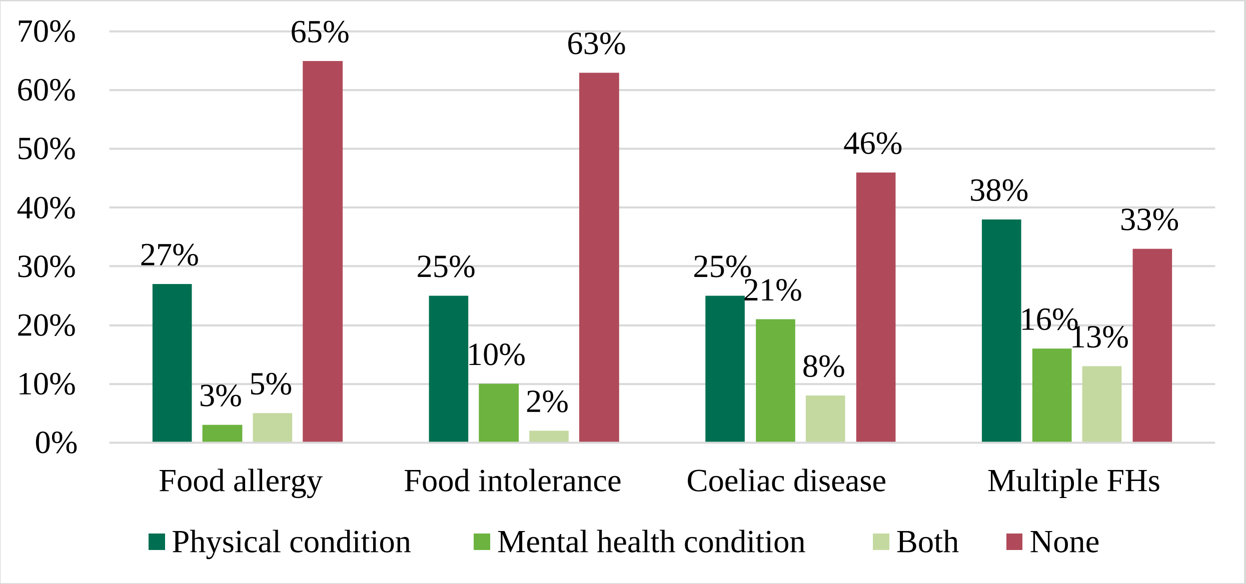


Base: All children reported by parents in the hypersensitive groups (907): Food allergy (429); Food intolerance (184); Coeliac disease (25); Multiple FHs (269).

Other long-term conditions

Parents reported that 30% (n = 267) of children had another physical long-term condition, 8% (n = 76) had a mental health condition and 7% (n = 66) had both a mental health and physical condition. Parents reported that children with multiple hypersensitivities had higher percentages for all these conditions compared to the other hypersensitive groups, apart from parents of children with coeliac disease, who reported higher proportion of mental health conditions (21%; Figure 38).

Figure 38: Other long-term conditions by hypersensitivity



Base: All children with other conditions (880); Food allergy (412); Food intolerance (182); Coeliac disease (24); Multiple FHs (262).

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.

When asked to initially report all foods their children react to, milk (n = 352, 12%), eggs (n = 317, 10%) and peanuts (n = 236, 8%) were the most frequently reported foods, with peanuts most common for those reporting their child's reaction as food allergy (n = 173, %), eggs for those with children with food intolerance (n = 106, 29%), cereals for children with coeliac disease (n = 19, 42%), as well as for children with multiple hypersensitivities (n = 88, 11%). Please see Annex B Table 32 for a full breakdown of frequencies of foods reported by hypersensitivity.

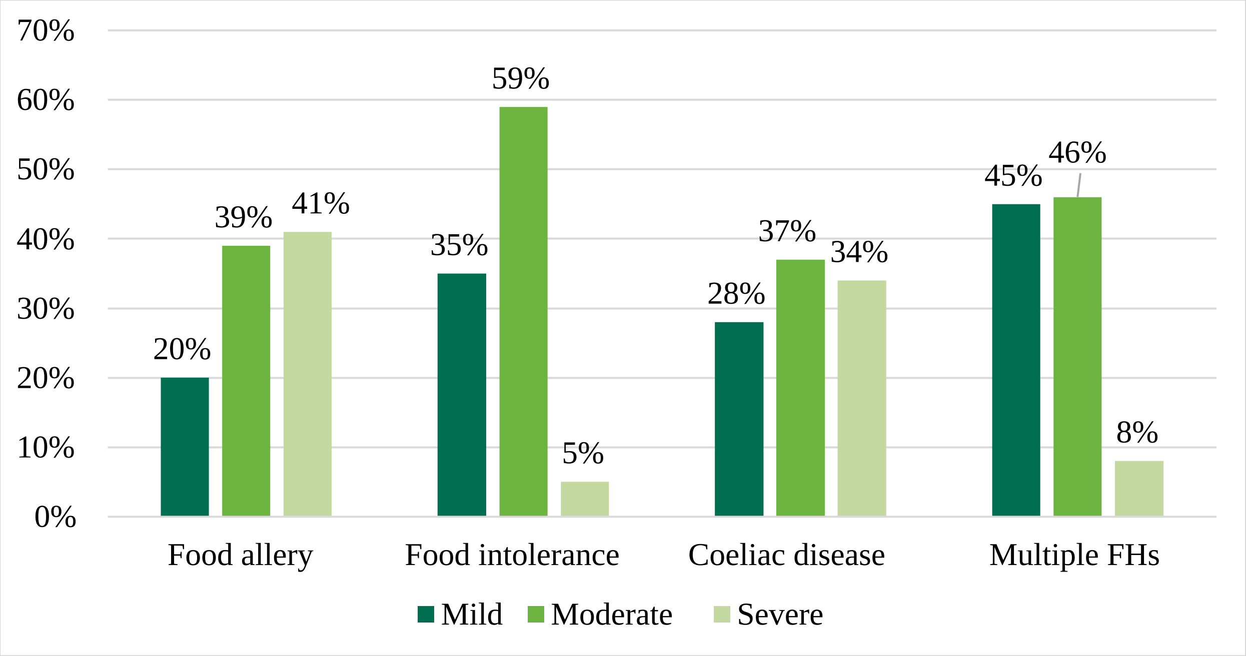
Foods with adverse reactions

When asked to report on three foods in detail, parents reported a total of 1,523 foods that their children reacted to (please note this is not separate types of food but the number of foods reported in total by parents). Parents reported their child's reaction as food allergy (n = 792; 52%), food intolerance (n = 453; 30%), coeliac disease (n = 209; 14%), other or don't know (n = 69; 5% 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 = 298; 20%), milk (n = 296; 19%), eggs (n = 215; 14%) and peanuts (n = 142; 9%). The majority of those reporting a reaction to tree nuts (64%; n = 190) was those with multiple hypersensitivities, whereas the majority reporting a reaction to peanuts (78%; n = 111) and egg (50%; n = 107) were those with food allergy. Milk was also commonly reported by parents of children with food allergy (45%; n =133) and for parents of children with food intolerance (30%; n = 90). Other foods included cheese, bread, onions/garlic, condiments, and tea. For a full breakdown of foods by hypersensitivity please see Annex B Table 33.

Across all three children and all foods, parents rated their child's condition as mild (total number of reactions reported by parents (n = 492), moderate (n = 665) or severe (n = 330). Parents of children with food allergy were most likely to report their reaction as severe (41%), whereas parents of children with food intolerance (59%), coeliac disease (37%) and multiple hypersensitivities were most likely to report their reaction as moderate (46%; Figure 39).

Figure 39: Severity of reaction to foods, by hypersensitivity



Base: All reactions reported on by parents for children in hypersensitivity groups (1,447): Food allergy (604); Food intolerance (204); Coeliac disease (29); Multiple FHs (610).

Symptoms

Parent participants reported that their children experienced a wide range of symptoms, which were grouped into breathing (for example, coughing/sneezing, wheezing, breathless), skin (for example,, rash, itchy, dry skin, swelling of face, eczema), gastrointestinal (for example, abdominal pain, sickness/vomiting/diarrhoea, loss of weight), mouth/throat/ear symptoms (for example, tingling/itching, tight throat, tongue swelling) and other reactions (for example, 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 gastrointestinal symptoms (28%; n = 2795), of which 38% (n = 1076) were reactions reported by parents of children with multiple hypersensitivities. For children with food intolerance (48%; n = 506) and coeliac disease (58%; 69) the most common symptoms experienced were also gastrointestinal. For parents of children with food allergy, the most common symptom type experienced was breathing symptoms (30%; n = 1401; Annex B Tables 34-36).

The most severe symptoms experienced to all foods were gastrointestinal symptoms (28%; 2090), of which 45% (n = 944) were reported by parents of children with multiple hypersensitivities. For parents of children with food intolerance (49%, n = 364) and coeliac disease (53%, n = 41) the most common severe symptoms were gastrointestinal) and for parents of children with food allergy, the most common severe symptoms were skin symptoms (28%, n = 808; Annex B Table 37).
Most parents reported that their child's symptoms started between 5 to 30 minutes (n = 480; 33%) after ingesting the stated food and this was also true for those with food intolerance (n = 95; 48%). However, for those with coeliac disease (n = 12; 45%) and multiple hypersensitivities (n = 317, 51%) symptoms more frequently occurred after 30 minutes and for those with food allergy, symptoms most commonly started within 5 minutes (n = 282, 49%; Annex B Table 38).

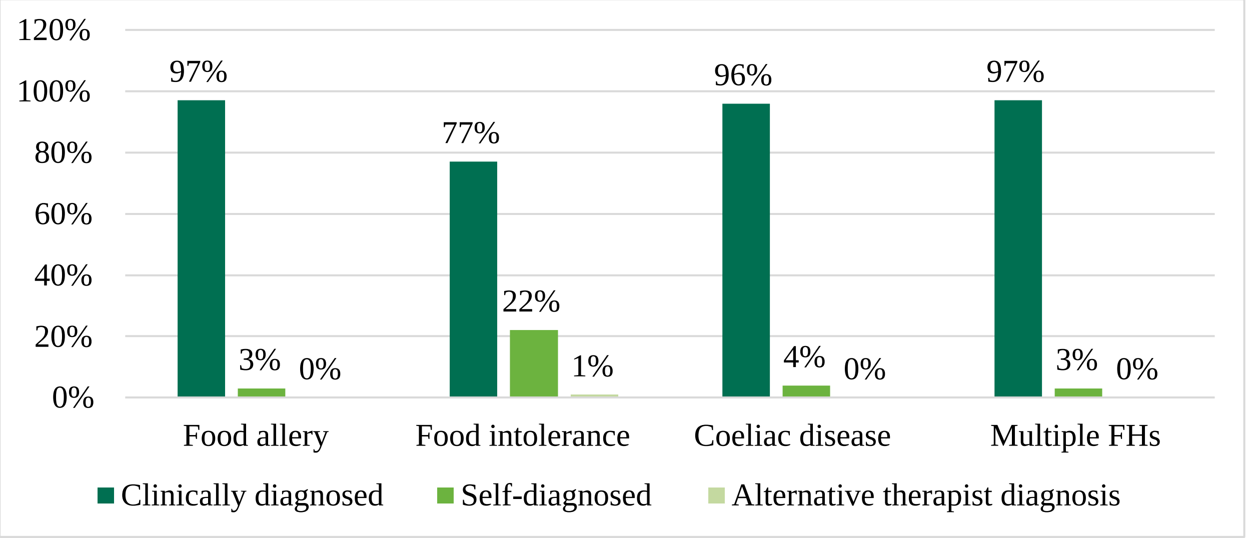
Diagnosis

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 = 1,334; 94% of all foods reported, Figure 40).

Most parents reported that their children were diagnosed by a hospital doctor (n = 530; 39%), GP (n = 249, 19%), or Nurse at the hospital (n = 142; 11%) or Nurse at the GP's (n = 144; 11%). Most parents reported that children were diagnosed by either a skin prick test (n = 463; 25%) or blood test for allergy (n = 425; 23%). See Annex B Table 39 for full breakdown.

The mean age for diagnosis of their child's reaction across all foods was 6.1 years old (combined SD = 4.2).

Figure 40: Diagnosis by hypersensitivity



Base: Diagnosis for all foods reported on in each hypersensitivity group (1382): Food allergy (574); Food intolerance (196); Coeliac disease (26); Multiple FHs (586).

About their reaction

Many parents reported that their children had not had a reaction to their stated food in the previous 12 months (n = 350; 24%) but for 74% (n = 1063) of all reactions, their child had had a reaction. For parents of children with allergy (17% of reactions) or multiple hypersensitivities (24% of reactions), a reaction was most likely to have occurred once in the last 12 months. For those reporting children with food intolerance, a reaction was most likely to have occurred between 3-6 times (28%) and for children with coeliac disease, a reaction was most likely to have occurred once or 3-6 times (23% each respectively) in the last 12 months (if they had experienced a reaction; Annex B Table 40).

Parents also reported where their child's most recent reaction occurred (for example, where their child first started experiencing symptoms of a reaction), however this does not give any information about where the food itself was prepared. The majority of reactions were reported by parents to have happened at home (52%, n = 715), with school as another common place for them to have happened (14%, n = 189). This was also reflected across the hypersensitivities, except for parents reporting on children with multiple hypersensitivities (n = 116, 20%) and coeliac disease (n = 4, 17%), who also reported that their child reacted at their place of work (for those children who were 16-17 years old) (Annex B Table 41).

Anaphylaxis

The total number of anaphylactic reactions that children had ever experienced, reported by parents was 657 (47% of all reactions that were reported on across the three foods), of which 60% of these reactions were experienced by children in the multiple hypersensitivities group, 34% (n = 223) were experienced by children in the food allergy group, 4% (n = 28) by those with food intolerance and less than 1% (n = 3) with coeliac disease. For anaphylactic reactions occurring within the last 12 months, parents reported 488 (35% of all reactions that were reported on across the three foods) reactions, the majority of these were reported by parents of those with multiple hypersensitivities (n = 338; 69%). However, 24% (n = 118) of all anaphylactic reactions were reported by parents in the food allergy group, indicating that children with multiple hypersensitivities were most likely to report an anaphylactic reaction (see Annex B, Tables 43 and 44). A small percentage from the food intolerance (4%) and coeliac disease (<1%) groups also reported anaphylactic reactions.

Further, for 63% (n = 913) of all reactions reported, parents reported that their child had been prescribed an adrenaline auto-injector, of which 54% (n = 490) of these responses were reported by parents of children in the multiple hypersensitivities group, 40% (n = 363) were those with food allergy, 4% (n = 36) were those in the food intolerance group and less than 1% (n = 5) were those with coeliac disease.

Treatment

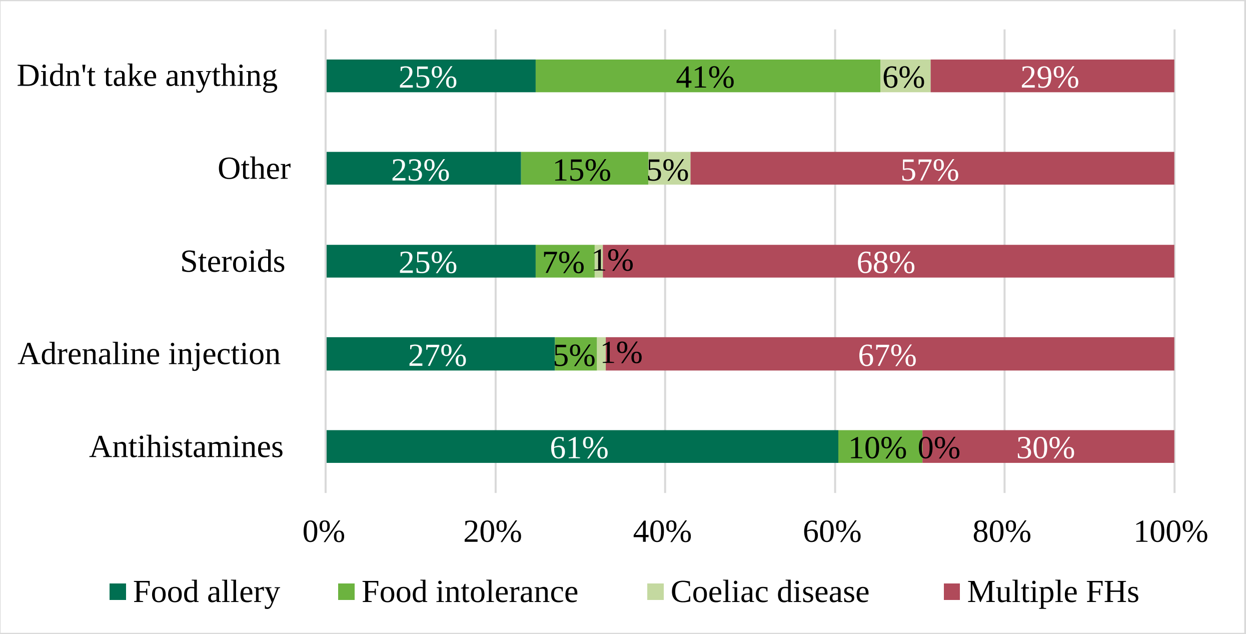
Parents were asked about the treatments their children had received for reactions to food reported. For 45% of reactions, parents reported treating these themselves. This was also true across hypersensitivities (see Annex B, Table 42), however for parents of children with multiple hypersensitivities, parents also reported that for 28% of reactions their child treated their reaction themselves and for 26% of reactions, the reaction was treated by someone medical.

Parents were also asked about treatments given by themselves or a non-medical person and by those that were administered by a medical professional. For reactions that were treated by a non-medical person, antihistamines were reported as the most common treatment 40% (n = 500). For treatments administered by a medical professional, adrenaline injections (25%, n = 125) were the most commonly reported treatment. Treatments were most commonly reported by parents of children with food allergy and multiple hypersensitivities (see Figures 41 and 42).

Hospital admission

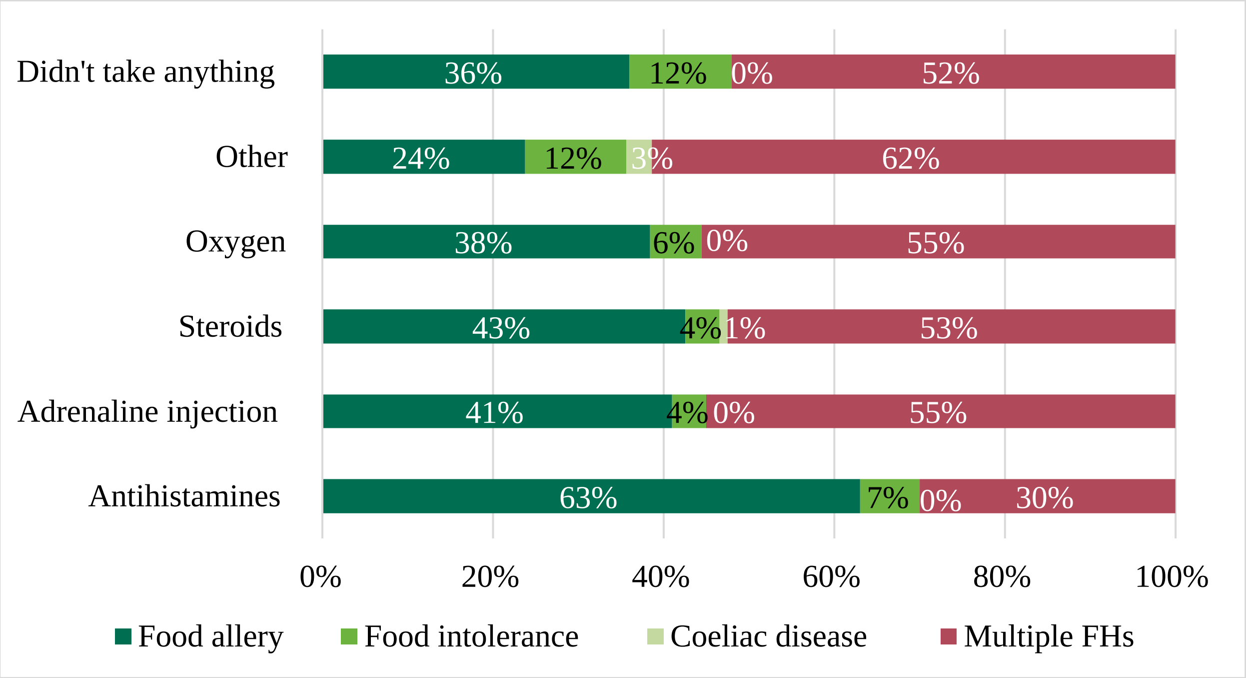
For 47% (n = 648 out of 1386) of reactions to foods, parents reported they had called an ambulance for their children, and for 51% of all reactions (n = 710 out of 1,396 who answered) parents reported that their children had been admitted to hospital. For those that had been admitted to hospital (n = 700 respondents to this question), 23% (n = 162) had not been admitted in the last 12 months, 26% (n = 185) had been admitted once, 25% (n = 177) were admitted twice and 15% (n = 108) were admitted between 3-6 times, 7% (n = 46) were admitted between 7-10 times, 2% (n = 16) were admitted more than 10 times and 1% (n = 6) did not know (Annex B, Table 45). Across all foods reported on, for 79% (n = 539) 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, 61% (n = 434) of those being admitted to hospital were children with multiple hypersensitivities and 77% (n = 336) of these 434 went the first time they reacted. A further 31% (n = 220) of those admitted to hospital were children with food allergy, and 75% (n = 164) of these were also admitted the first time they reacted (Annex B, Table 46).

Figure 41: Treatments given by a non-medical person for reaction to foods, across hypersensitivity



Base: All treatments for foods reported on in each hypersensitive group (1,231): Food allergy (484); Food intolerance (172); Coeliac disease (22); Multiple FHs (553).

Figure 42: Treatments given by a medical professional, across food hypersensitivity



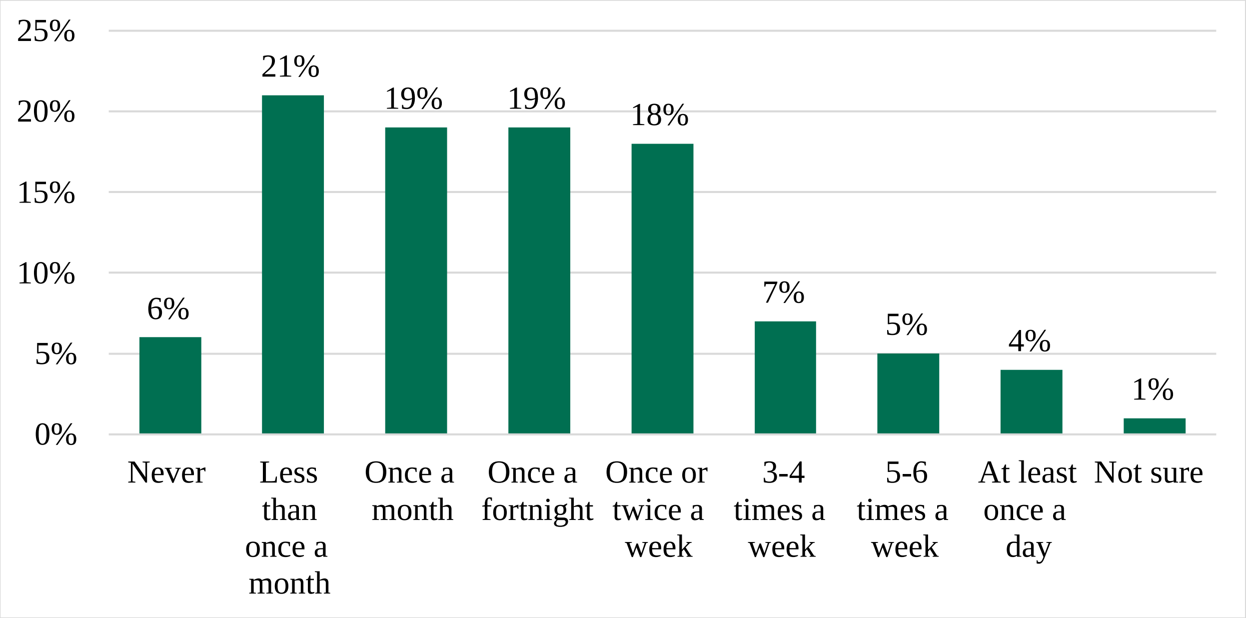
Base: All treatments for foods reported on in each hypersensitive group (493): Food allergy (221); Food intolerance (30); Coeliac disease (2); Multiple FHs (240).

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 = 139; 21%), however 72% (n = 470) eat out more frequently than this (Figure 43). There were significant differences by type of food hypersensitivity in terms of how often parents reported eating out, F(3) = 20.1, p <.001, ?p² = .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 and food intolerance, who on average ate out around once a month (all ps<.008; see Annex B Table 47).

Figure 43: How often parents' households eat out or get food to take away

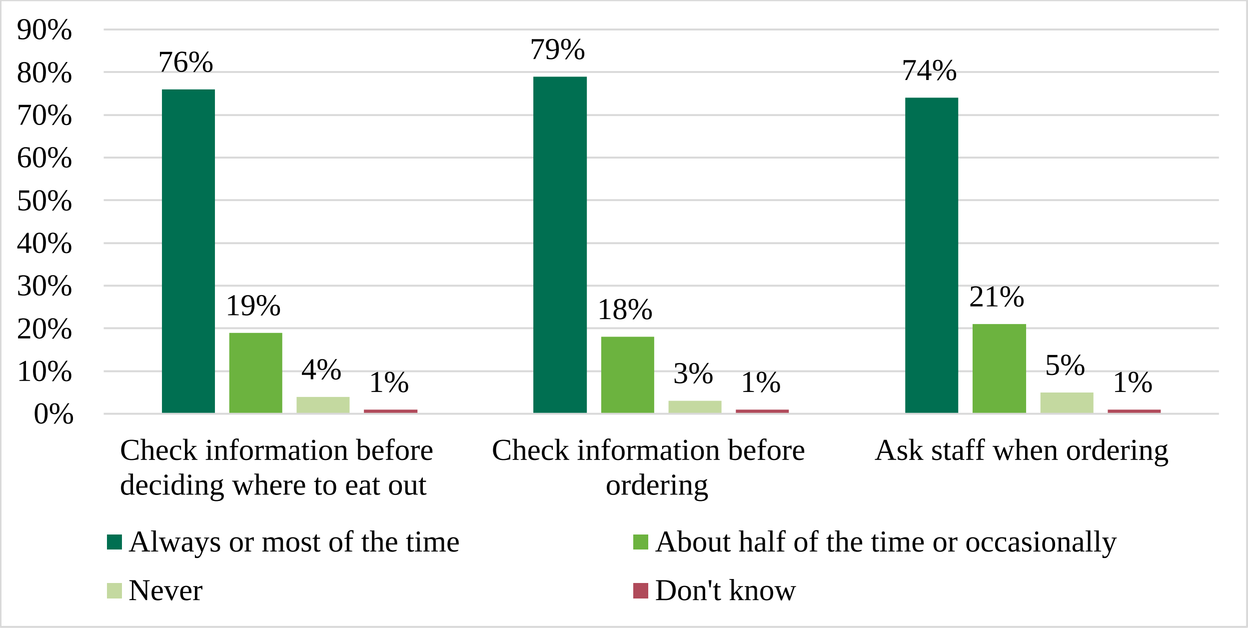


Base: All parents (653)

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, with less than 5% at each stage reporting that they never check available information (see Figure 44).

Figure 44: How often participants review information when eating out

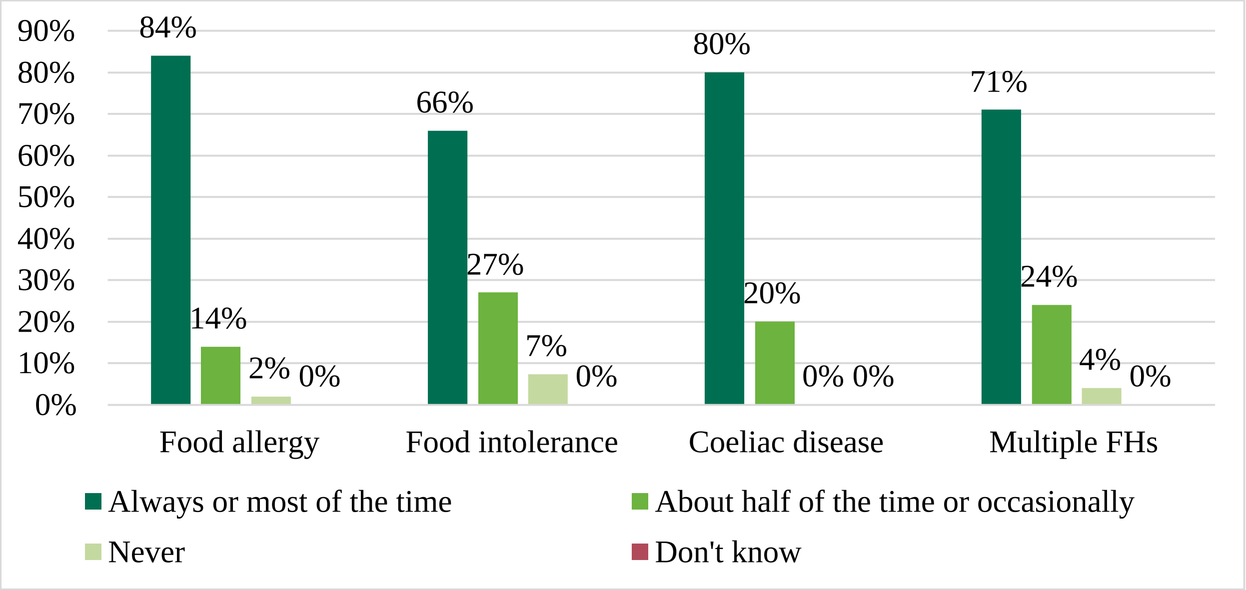


Base: All parents: Check information before choosing where to eat out (613); Check information when ordering (604); Ask staff when ordering (605).

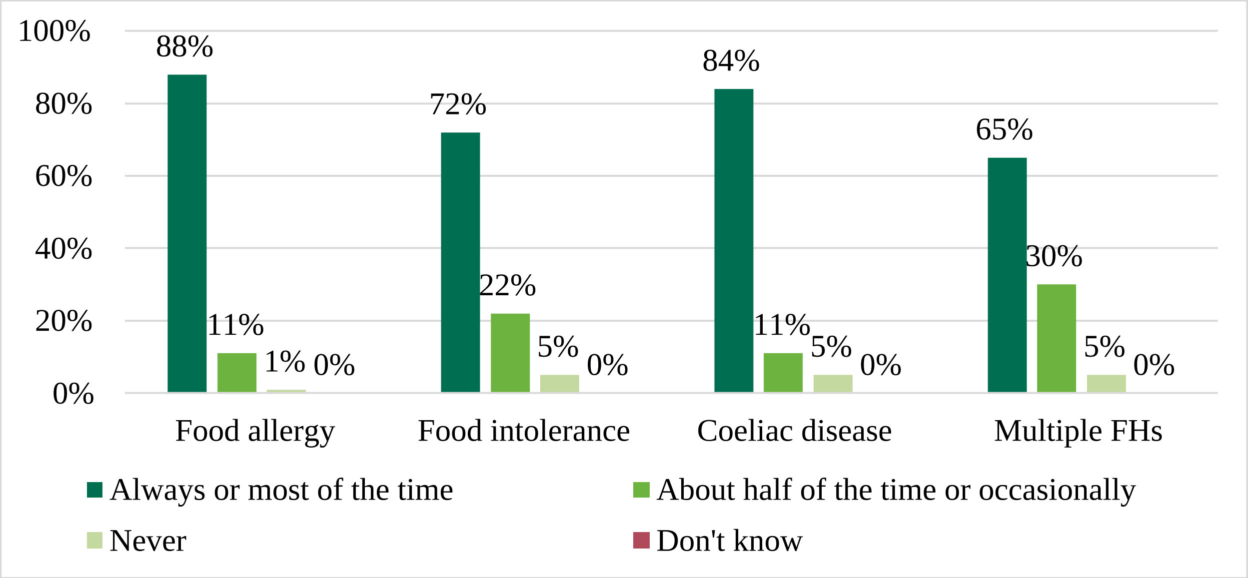
There were significant differences between hypersensitivity groups for how often parents reported checking and reviewing information. Participants with children with food allergy (mean = 4.4, SD = 1.0) reported they check that there is information available before deciding where to eat out significantly more often than those with children with food intolerance (mean = 3.8, SD = 1.3) or multiple hypersensitivities (mean = 3.9, SD = 1.2; all ps<.008), on average reporting that they always check this, or most of the time (Figure 45).

When asked how often parents review the available information before ordering food, parents of children with food allergy (mean = 4.5, SD = 0.9) reviewed this information always or most of the time, and significantly more often than parents of children with food intolerance (mean = 3.9, SD = 1.3) and multiple hypersensitivities (mean = 3.8, SD = 1.3; all ps <.001), who only checked either about half or most of the time (Figure 46).

Figure 45: How often parents check information before choosing where to eat out, by hypersensitivity



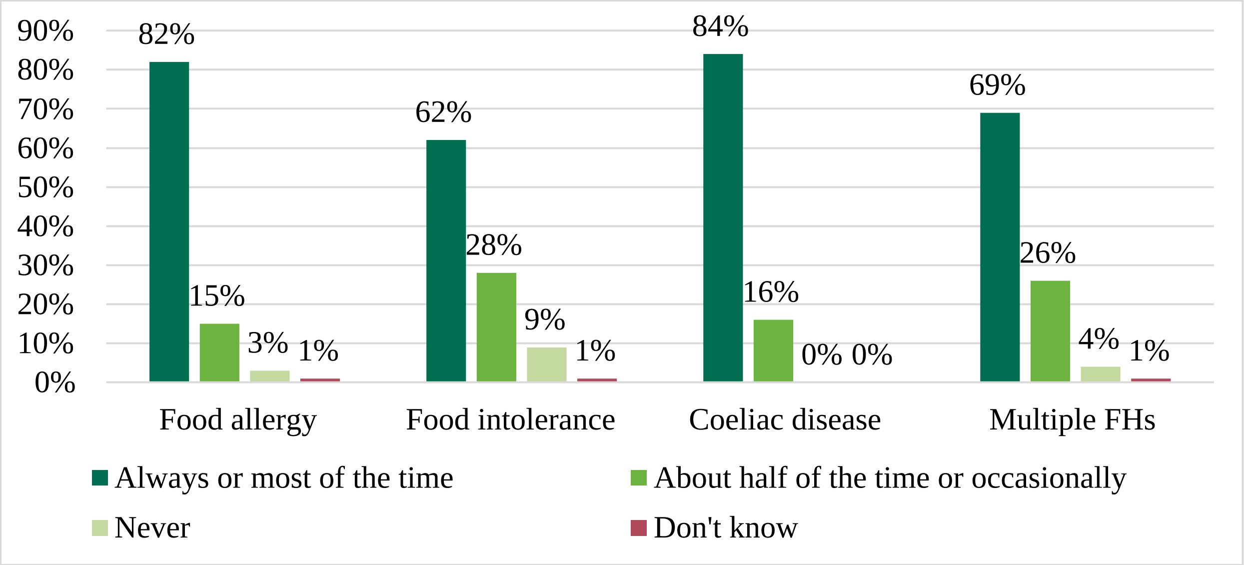
Base: All parents of children with a hypersensitivity (593): Food allergy (313); Food intolerance (148); Coeliac disease (20); Multiple FHs (112).



Base: All parents of children with a hypersensitivity (588): Food allergy (313); Food intolerance (149); Coeliac disease (19); Multiple FHs (107).

Finally, parents of children with food allergy (mean = 4.4, SD = 1.1) 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 intolerance (mean = 3.6, SD = 1.4) or multiple hypersensitivities (mean = 3.9, SD = 1.1; all ps <.008; Figure 47).

Figure 47: How often parents asked staff for information before ordering, by hypersensitivity



Base: All parents of children with a hypersensitivity (591): Food allergy (314); Food intolerance (150); Coeliac disease (19); Multiple FHs (108).

Confidence in information provided when eating out

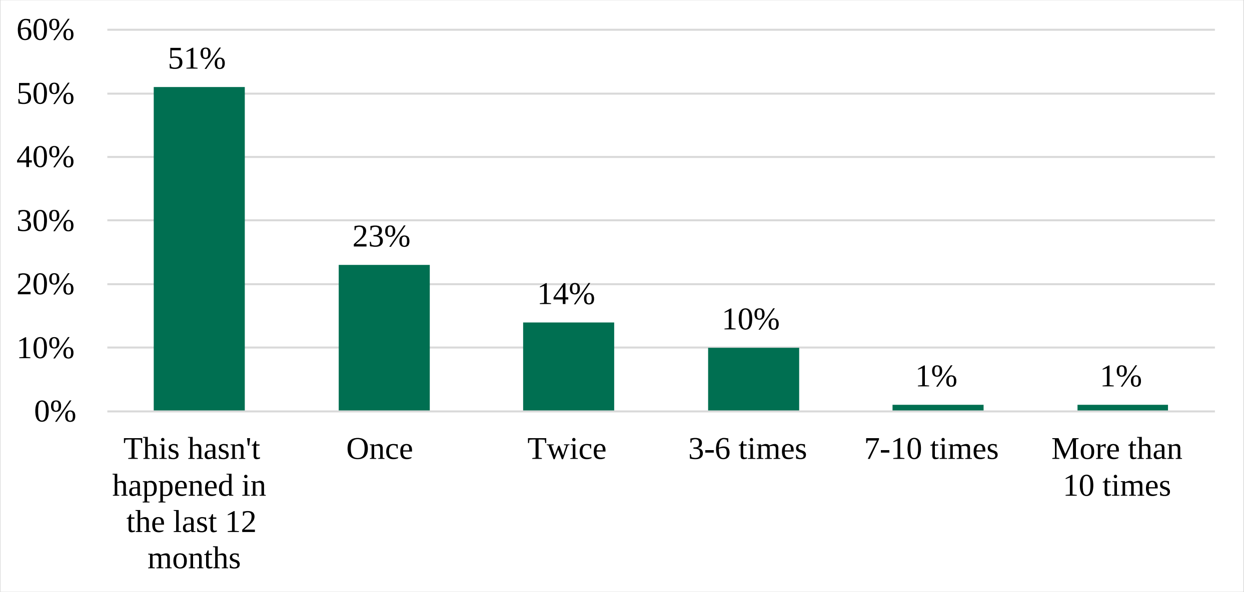
Parents were asked how comfortable they felt when asking a member of staff for information about the food they are selling because of a concern about their children experiencing a bad or unpleasant physical reaction. Parents were also asked how confident they were that the information provided to them 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 = 433; 72% were very or fairly comfortable). This was reflected across the four hypersensitivity groups (Annex B Table 48). Additionally, those with food allergy (mean = 3.2, SD 0.9) and food intolerance (mean = 3.2, SD = 0.8) were significantly more comfortable with asking staff for allergen information than those with multiple hypersensitivities (mean = 2.9, SD = 1.0, both ps <.008).

Most parent participants were very or fairly confident (n = 390; 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 = 335; 55%). 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 food allergy (mean = 2.6, SD = 1.0) were significantly less confident in verbal information provided by staff than parents of children with food intolerance (mean = 2.9, SD = 0.8; p = .004; see Annex B Tables 49 and 50).

Experiences when eating out

When asked how many times their children had been given a food that would cause a bad or unpleasant reaction in the last 12 months, despite them checking the available information, just over half of parents reported that this had not happened (n = 309, 51%), 37% reported that this had happened once or twice. This was also reflected across the hypersensitivities (see Figure 48 and Annex B Table 51).

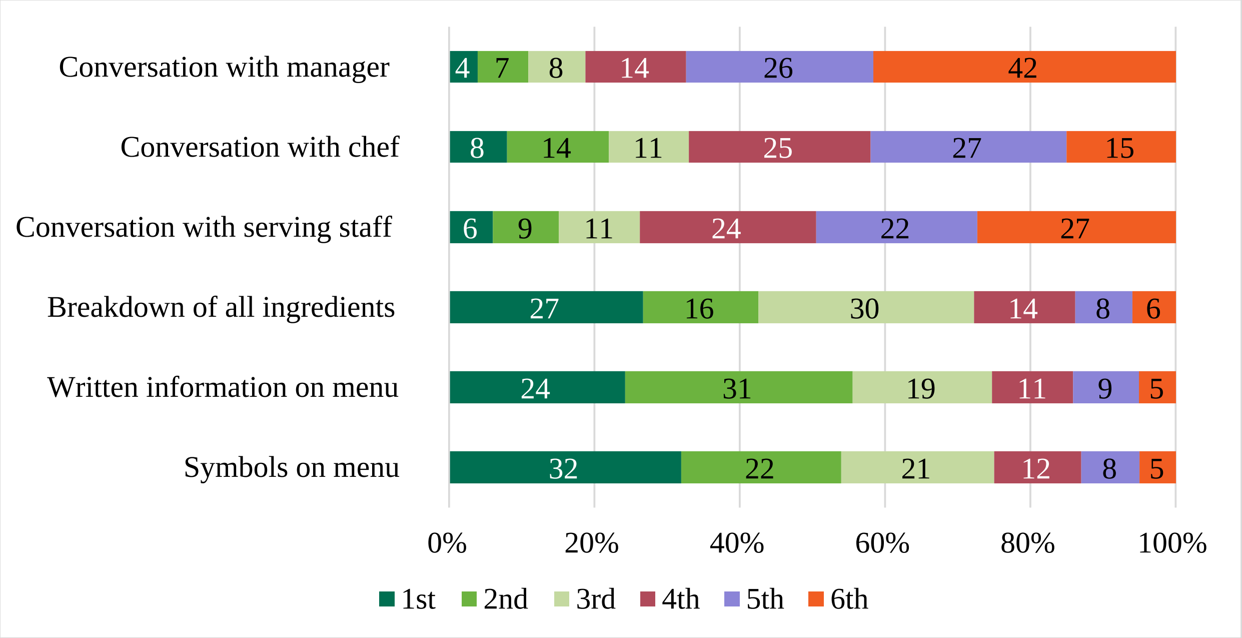
Figure 48: How often parents reported their children being offered an allergen in the last 12 months when eating out



Base all parents (604)

Parents were also asked what sources of allergen information they found most useful when eating out, to avoid their child having a bad or unpleasant reaction. Menus with symbols indicating allergens were rated as most helpful (n = 183; 32%), menus with written allergen information were the second most helpful sources of information (n = 180; 31%) and a breakdown of all the ingredients included in a dish was rated the third most helpful source of information (n = 169; 30%; Figure 49).

Figure 49: Rank of most useful sources of information for parents, when eating out

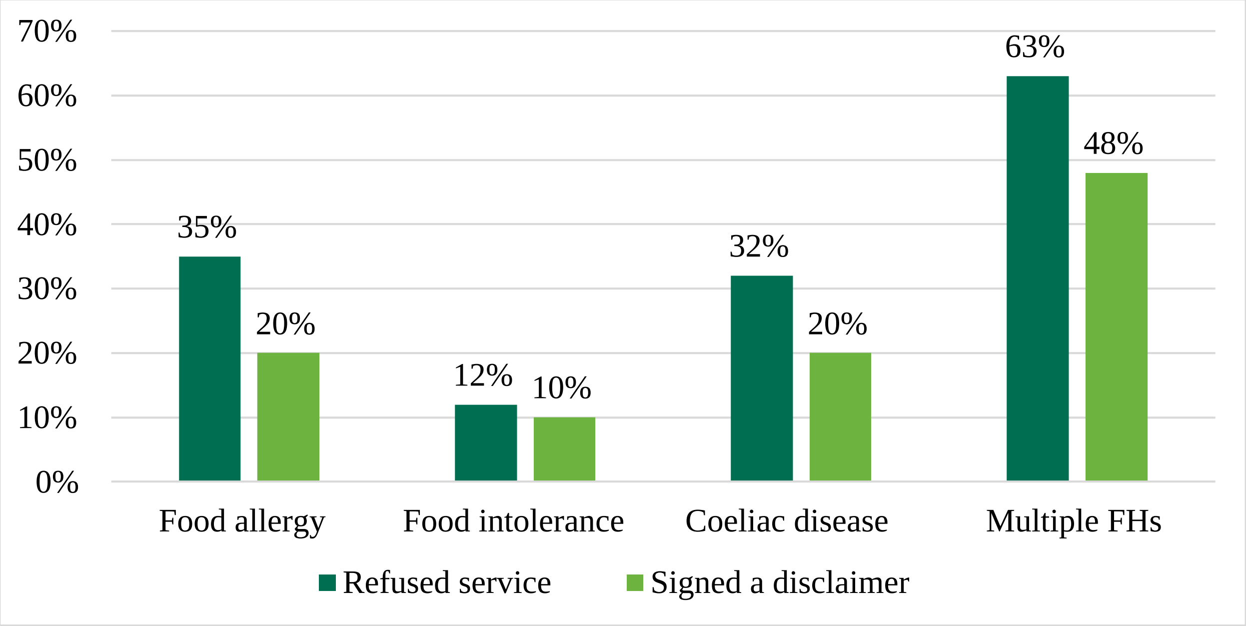


Base: All parents (572)

By hypersensitivity, for those with food intolerance the pattern was the same as for all parents, with the top three most useful sources of information when eating out being menus with symbols indicating allergens (n = 58, 48%), written information on menus (n = 50, 34%) and a breakdown of all ingredients on the menu (n = 54, 37%). However, for parents in the food allergy group both menus with symbols indicating allergens (n = 89, 29%) as well as a breakdown of all ingredients in dishes on the menu (n = 91, 30%) were rated as the most useful source of information. Additionally, for those with multiple hypersensitivities, menus with symbols (n = 28, 27% each) and written information on menus (n = 31, 30%) were ranked equally as first most useful sources of information. A breakdown of all ingredients was ranked as the third (n = 32, 31%) most helpful source of information when eating out for parents in the multiple hypersensitivities group.

Around a third (34%; n = 209) of parent participants reported having been previously refused service when eating out because of their child or children's hypersensitivity (n = 400; 66% had not). Twenty three percent (n = 141) reported they had been asked to sign a waiver or disclaimer when eating out (n = 476; 77% had not). Additionally, of all parents while 63% of those in the multiple hypersensitivities group had been refused service, of those parents who had been refused service, parents of children with food allergy (55%) were significantly more likely to report being refused service, ?²(3) = 73.7, p <.001, demonstrating the larger sample of parents in the food allergy group (Figure 50).

Figure 50: 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 (609). Asked to sign a disclaimer (617): Food allergy (RS: 326; SD: 326); Food intolerance (RS: 152; SD: 155); Coeliac disease (RS: 19; SD: 20); Multiple FHs (RS: 112; SD: 116).

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 (for example, 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 (for example, 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) (footnote 1).

Parents of children with food allergy reported high mean scores (4.5 and 4.9 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 3.4 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=274	FAQLQ Teen (food allergy) N=88	FIQLQ (food intolerance) N=160	CDDUX (Coeliac disease) N = 36
Mean Total (SD)	4.5 (1.3)	4.9 (1.1)	4.5 (1.3)	3.4 (1.0)
Out of a possible total of:	7	7	7	5

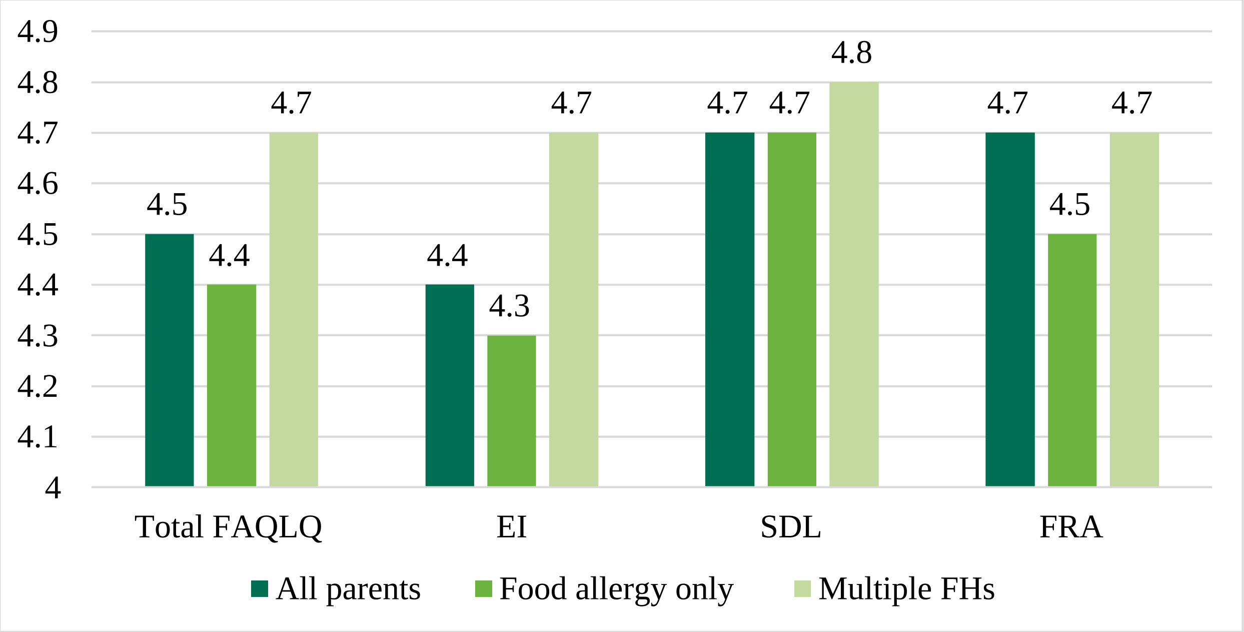
Quality of Life in younger children with food allergy, reported by parents

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 247 parents of 0-12-year-olds with food allergy completed the FAQLQ (of which 197 were from the food allergy only group; the remaining 50 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 = 4.5, SD = 1.3). For the food allergy only group, the mean total score for the FAQLQ was also higher than average (mean = 4.4, SD = 1.3). This was also true for the subscales, particularly for the social and dietary limitations subscale (mean = 4.7, SD = 1.4), which indicated that parents perceived that social and dietary limitations due to food allergy had the most impact on 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 = 4.7, SD = 1.1) and means for subscales also indicated that according to parents, social and dietary limitations had the most impact on their child's quality of life. Means for each of subscale are shown in Figure 51.

Figure 51: 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 (247): Children with only food allergy (197); children with allergy as multiple hypersensitivities (50) Scores out of 7

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. Children with non-food allergies in addition to a food hypersensitivity (for example, cat/dog, bee/wasp, medication) had significantly more impairment of quality of life (mean= 4.9 SD= 1.2) than those who didn't (mean= 4.2, SD=1.2, t(156)= 3.25, p = .001).

Parents reported that those children who had been prescribed an auto-injector had significantly more impairment of quality of life (mean= 4.8 SD= 1.28) than those who had not (mean= 4.0, SD= 1.3, t(165) = 3.62, p= .001). Children who had experience of anaphylactic shock to the first stated food also had significantly more impairment of quality of life (mean= 4.8 SD= 1.2) than those who had not (mean= 4.3 SD= 1.3, t(145)= 2.64, p = .009). This was also the case for children whose parents had called an ambulance for their reaction (mean = 4.8, SD = 1.2) compared to those whose had not (mean = 4.3, SD = 1.2, t(157)= 2.61, p = .01), as well as those children who had been admitted to hospital in an emergency for their reaction to food one (mean= 4.8 SD= 1.2) compared to those who had not (mean= 4.3 SD= 1.3, t(158)=2.82, p =.005).

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 = .27), reviewed this information before ordering (r=.19) and asked staff for available information (r = .24) were all significantly correlated to impairment of their child's quality of life (all 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 = 8 predictors). The overall model was significant (p<0.01), however only 8% of the variance in quality of life was explained, indicating that 92% of the variance was due to other unknown factors. None of the predictors were significant (standardised betas ranged from -0.07 to 0.23 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 (for example, checking labelling) and the need for awareness around food their teenager has, due to having a food allergy. A total of 88 parents of teens completed the FAQLQ. This comprised of 73 parents from the food allergy only group, and 15 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 almost identical, and indicated higher than average impact on quality of life (mean = 4.9, SD = 1.1). Scores on the psychological impact (mean = 5.1, SD = 1.4) and food allergy awareness (mean = 5.3 and 5.2 respectively, SD = 1.4) 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, however there were no significant differences for teens without or without these on impact of quality of life (all ps >.05).

Parents' reported severity of their teen's reaction was significantly positively correlated with perceived impairment to quality of life (r = .41; p <.001). Those who had been prescribed an auto-injector had significantly more impairment of quality of life (mean=5.1 SD= 0.9) than those who had not (mean=4.4, SD= 1.2, t(35.9)= 2.87, p = .002). Teens who had experience of anaphylactic shock to the first stated food also had significantly more impairment of quality of life (mean = 5.1, SD= 0.9) than those who had not (mean= 4.5 SD=1.2, t(68)= 2.41, p = .02).

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 = .26), as well as how often they asked staff for available information (r = .24), were both significantly and positively correlated to impairment of their adolescent's quality of life (all 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= 5 predictors). The overall model was significant (p<0.01) and 16% of the variance in quality of life was explained, indicating that 84% of the variance was due to other unknown factors. However, only severity of reaction reported by parents significantly predicted impairment to quality of life (standardised beta = .32), indicating that the greater parents reported their teenager's reaction to be, the more impaired they reported their teenager's quality of life to be. None of the other predictors were significant, as confidence intervals for each predictor crossed zero.

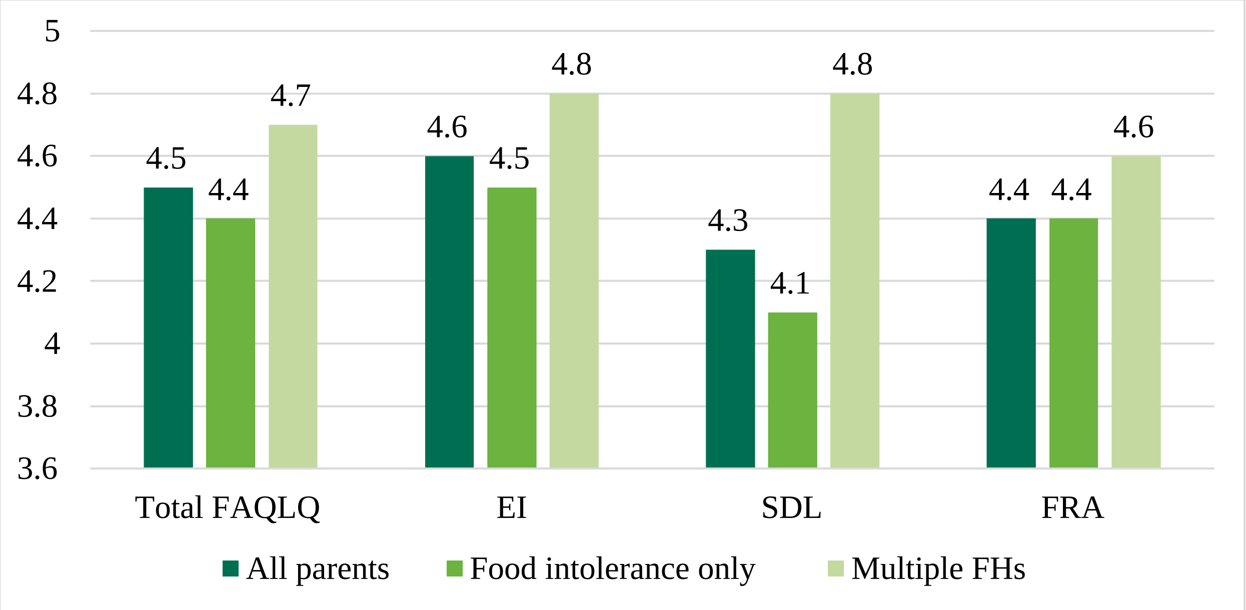
Quality of Life in children with food intolerance, reported by parents

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 160 parents of children with food intolerance completed the FIQLQ, of which 120 were those with children with food intolerance only and 40 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 = 4.5, SD = 1.3). On average, parents of children who only had food intolerance reported slightly less impact on quality of life (mean = 4.4, SD = 1.3) than parents of children with food intolerance as part of multiple hypersensitivities (mean = 4.7, SD = 1.1).

Parents reported the emotional impact of having food intolerance as having the most impact on their child's quality of life (mean = 4.6, SD = 1.3; see Figure 52). 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 = 4.1, SD = 1.6) in relation to their child's social and dietary restrictions than those with multiple hypersensitivities (mean = 4.8, SD = 1.2; see Figure 50).

Figure 52: 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 (160): Children with only food intolerance (120); children with intolerance as multiple hypersensitivities (40)

Clinical factors were examined to see if they were significantly associated with parents perceived impairment to quality of life in children with food intolerance. The severity of the reaction to the first food parents reported their child had a reaction to was significantly positively correlated with impairment to their child's quality of life (r = .25; p =.004). Those who had been prescribed an auto-injector had significantly more impairment of quality of life (mean= 4.9 SD= 1.2) than those who had not (mean= 4.3 SD= 1.3, t(126)= 2.63, p =.009). Children who had experience of anaphylactic shock to the first stated food also had significantly more impairment of quality of life (mean= 5.0, SD= 1.1) than those who had not (mean= 4.2 SD= 1.3, t(121)= 3.19, p =.002). This was also the case for children whose parents had called an ambulance for their reaction (mean = 5.0, SD = 1.0), compared to those whose parents had not (mean = 4.2, SD = 1.4, t(124)= 2.94, p =.004), as well as children who had been admitted to hospital in an emergency for their reaction to food one (mean= 5.0, SD=1.1) compared to those who had not (mean= 4.2 SD= 1.3, t(123)= 3.45, p =.001).

Factors related to eating out were also significantly correlated with parent's perceived quality of life of their children with food intolerance. Frequency of checking available information when choosing where to eat out (r = .42), as well as checking available information before ordering (r =.37) and how often parents asked staff for available information when eating out (r = .42) were all significantly correlated with parents' perceived impairment to their child's quality of life (all ps <.001).
A regression model was run to see which of the variables described above might predict level of quality of life. Variables above which had a significant association with quality of life were included in the model (n= 8 predictors). The overall model was significant (p<0.001) and 22% of the variance in quality of life was explained, indicating that 78% of the variance was due to other unknown factors. No single predictor was significant (confidence intervals crossed zero).

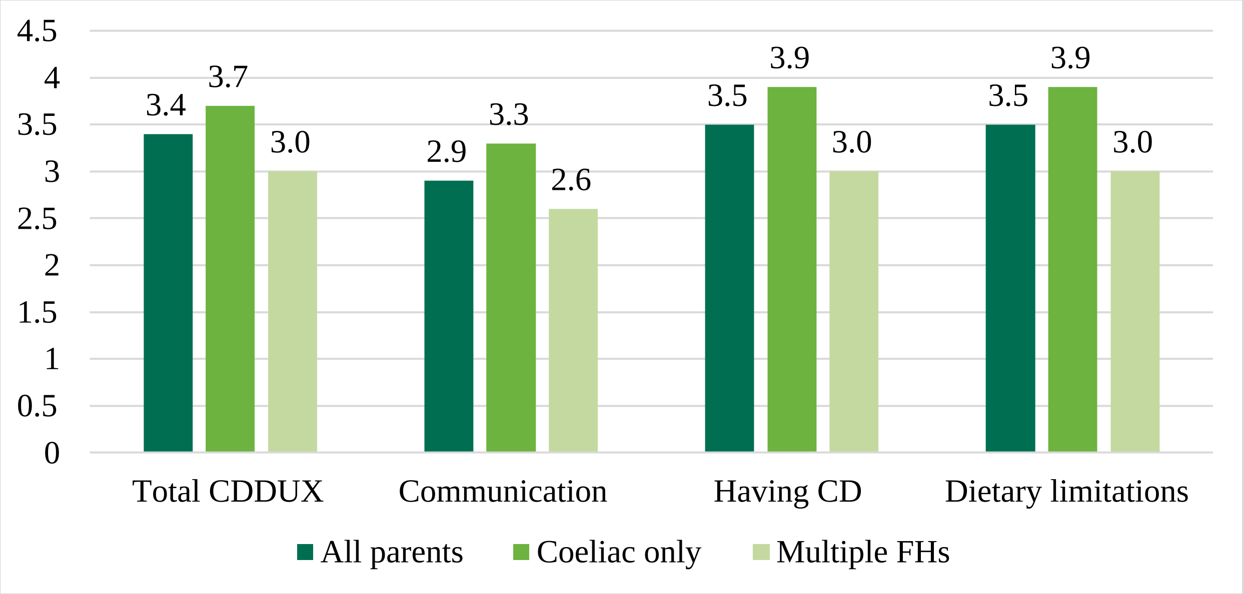
Quality of Life in children with coeliac disease, reported by parents

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 36 parents of children with coeliac disease completed the CDDUX, of which 20 parents were those of children with only coeliac disease, and 16 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 = 3.4, SD = 1.0). This was highest on the 'Having Coeliac disease' and 'Dietary Limitations' scales, 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 well as having to eliminate gluten-containing foods from their diet as having the most impact on their child's quality of life (see Figure 53 for means).

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.

Figure 53: 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 (36): Children with coeliac disease only (20); children with coeliac disease as one of multiple hypersensitivities (16).

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, 197 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(129) = .008, p = .93, 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 77 male children and 52 female children. There was no significant difference in impact upon quality of life for male and female children with food allergy, t(127) = 0.14, p = .89. Means were similar for quality of life between males (mean = 4.4, SD = 1.3) and females (mean = 4.5, 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 = 74) and severe (n = 54). However, there were no significant differences in parent's reported impact upon quality of life for the severity of their child's allergic reaction, t(126) = -1.16, p = .25. Parents reporting a mild or moderate reaction for their child's first food (mean = 4.3, SD = 1.2) and those reporting a severe reaction (mean = 4.6, SD = 1.4) reported around the same impact on their child's quality of life.

Number of foods

For their first child, 89 parents reported one food and 40 parents reported two or three foods. There were no significant differences in reported impairment to quality of life for those parents who reported one food (mean = 4.4, SD = 1.3) and more than one food (mean = 4.5, SD = 1.4; t(127) = -0.22, p = .83).

Food allergy only – (teen FAQLQ)

Of the food allergy only group, 73 parents completed the FAQLQ about their teen with allergy. Numbers in subgroups were too small to compare differences across number of foods reported by parents.

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(67) = .03, p =.79, indicating that the age of teens was not associated with their reported impact upon quality of life.

Gender

Parents reported 30 male children and 37 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, t(65) = 1.50, p = .14. Means however indicated that parents reported that male teenager's quality of life was more impacted (mean = 5.1, SD = 1.0) than female teenager's quality of life (mean = 4.7, SD = 1.1), 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 = 33). 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, t(64) = -3.96, p <.001. Parents reporting a mild or moderate reaction for their teen’s first food (mean = 4.4, SD = 1.1) reported significantly less impact on quality of life than those reporting a severe reaction (mean = 5.3, SD = 0.8). Again, however, groups were still small and so these results may change with larger numbers.

Food intolerance only

Of the food intolerance only group, 120 parents completed the FIQLQ. Again, numbers in subgroups were too small to compare differences across number of foods, reported by parents.

Age

There was no significant difference in parents’ scores between younger (0-12s) (mean = 4.2, SD = 1.4) and older children (13-18s; mean = 4.8, SD = 1.0), t(91) = -2.14, p = .03. Groups were, however, unequal (62 and 31) and so results should be taken with some caution.

Gender

Of those with food intolerance and who completed the FIQLQ, 43 were male, 50 were female. There were no significant differences in impact upon quality of life reported by parents for male children (mean = 4.5, SD = 1.3) or female children (mean = 4.3, SD = 1.3) with food intolerance, t(91) = 0.60, p = .55.

Severity

As the numbers of parents reporting mild (30), moderate (58) and severe (6) reactions were not equal, comparisons were only carried out for those with mild and moderate reactions to their first food. Those parents who reported that their child’s reaction was mild (mean = 3.7, SD = 1.4) reported significantly less impairment to their child’s quality of life because of having food intolerance than those who had a moderate reaction (mean = 4.6, SD = 1.2; t(86) = -3.21, p = .002).

Coeliac disease only

For those parents in the coeliac group, only 20 completed the CDDUX and so comparisons for this group will not be reported on.

Multiple hypersensitivities

For those with multiple hypersensitivities, 50 completed the child FAQLQ, 15 completed the teen FAQLQ, 40 completed the FIQLQ and 16 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 allergy (n = 340, mean = 80.98, SD = 16.79), followed by food intolerance (n = 156, mean = 78.11, SD = 20.52), coeliac disease (n = 19, mean = 77.84, SD = 15.97). Children with multiple FHs scored lowest of all (n = 124, mean = 70.10, SD = 19.17). Across all children with FH on the EQ-5D-3L sub-domains, Pain and Anxiety dimensions were markedly worse than the other dimensions.

Comparisons between Wave 1 and Wave 2

A total of 77 parents completed both wave 1 and wave 2 (see Table 52 for a further breakdown). Across both waves, the majority of parents reported having children with food allergy (n = 52 at Wave 1 and n = 51 at wave 2), followed by multiple hypersensitivities, coeliac disease and food intolerance (see Figure 54). At wave 1, 3% (n = 2) and at wave 2, 3% (n = 2) also reported 'Other' reactions but these are not reported in the subsequent sub-analysis. It is important to note that at wave 1 a large proportion of parents reported on children with food allergy (n = 396, 58%) which may explain why the proportion of those in the food allergy group taking part at both time points is skewed (higher).

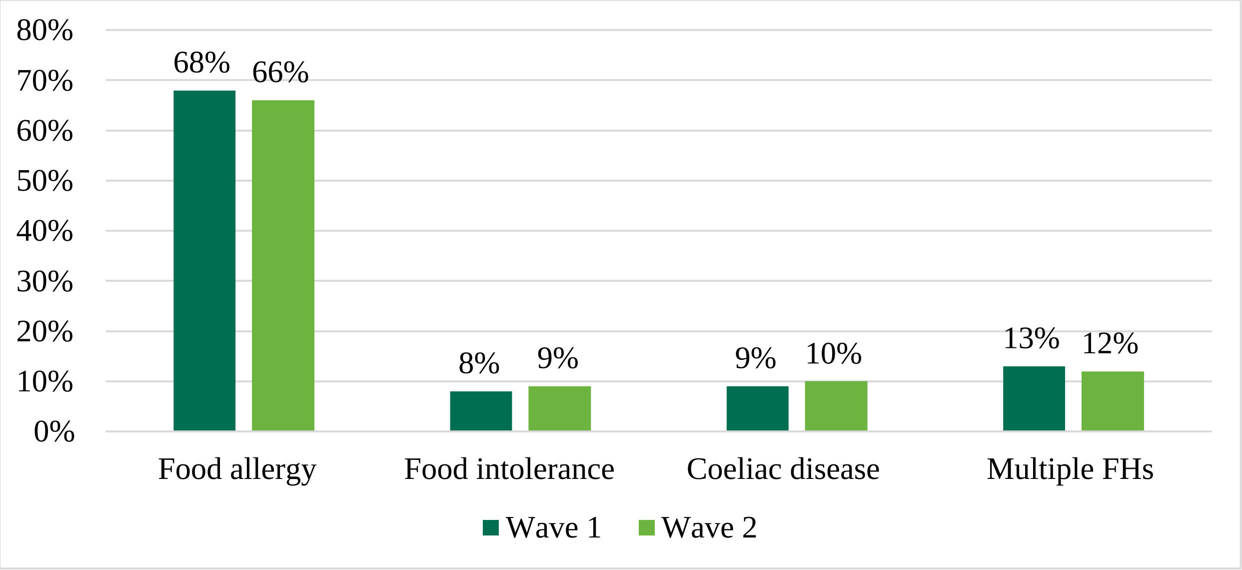
Eating out

Data was compared to see if there was any differences in how frequently participants ate out and checked available information when eating out.

There was a significant difference in how frequently parents at wave 1 (mean = 2.8, SD = 1.2) eat out, compared to at wave 2 (mean = 3.1, SD = 1.1) with participants reporting that on average they eat out less than once a month at wave 1 and around once a month at wave 2, t(68) = -2.48, p = .02. However, it is important to note that wave 1 data was collected at the time of the COVID-19 pandemic, so usual eating out behaviour may have been altered as a result of the restrictions associated with this.

However, there was no significant differences for how frequently parents checked available information when choosing where to eat out between wave 1 (mean = 4.6, SD = 0.9) and wave 2 (mean = 4.6, SD = 0.8) and before ordering between wave 1 (mean = 4.7, SD = 0.8) and wave 2 (mean = 4.8, SD = 0.6; both ps >.05), on average checking both of these most of the time or always. For frequency of asking staff for available information when eating out, there was no significant differences between wave 1 (mean = 4.7, SD = 0.9) and wave 2 (mean = 4.6, SD = 1.1, p = .77) with parents reporting that they check this most of the time or always.

Figure 54: Percentage of parents completing both wave 1 and wave 2 in each hypersensitivity group



Base: All parents completing both Waves with hypersensitivities: Food allergy (Wave 1: 52; Wave 2: 51); Food intolerance (Wave 1: 6; Wave 2: 7); Coeliac disease (Wave 1: 7; Wave 2: 8); Multiple hypersensitivities (Wave 1: 10; Wave 2: 9).

There were also no significant differences how comfortable parents of children with food hypersensitivities were in asking for information when eating out at wave 1 (mean = 3.3, SD = 0.9) and wave 2 (mean = 3.1, SD = 0.9). There were also no significant differences in how confident parents were in written information provided when eating out, reporting they were not very or fairly confident at wave 1 (mean = 2.7, SD = 0.7) and wave 2 (mean = 2.7, SD = 0.7). Finally, parents at wave 1 reported no significant differences in confidence in verbal information (mean = 2.4, SD = 0.8) than at wave 2 (mean = 2.5, SD = 0.8; all ps >.05), on average reporting that they are not very confident in verbal information provided by staff when eating out.

Quality of life

Comparisons for each of the food hypersensitivity specific quality of life measures (FAQLQ, FIQLQ and CDQoL) are not reported on as the numbers of parents completing the appropriate quality of life measure were too small to compare. For the generic QoL measure, scores in each sub-domain were lower at wave 2 compared to wave 1.

1. For further information please see the techincal report.