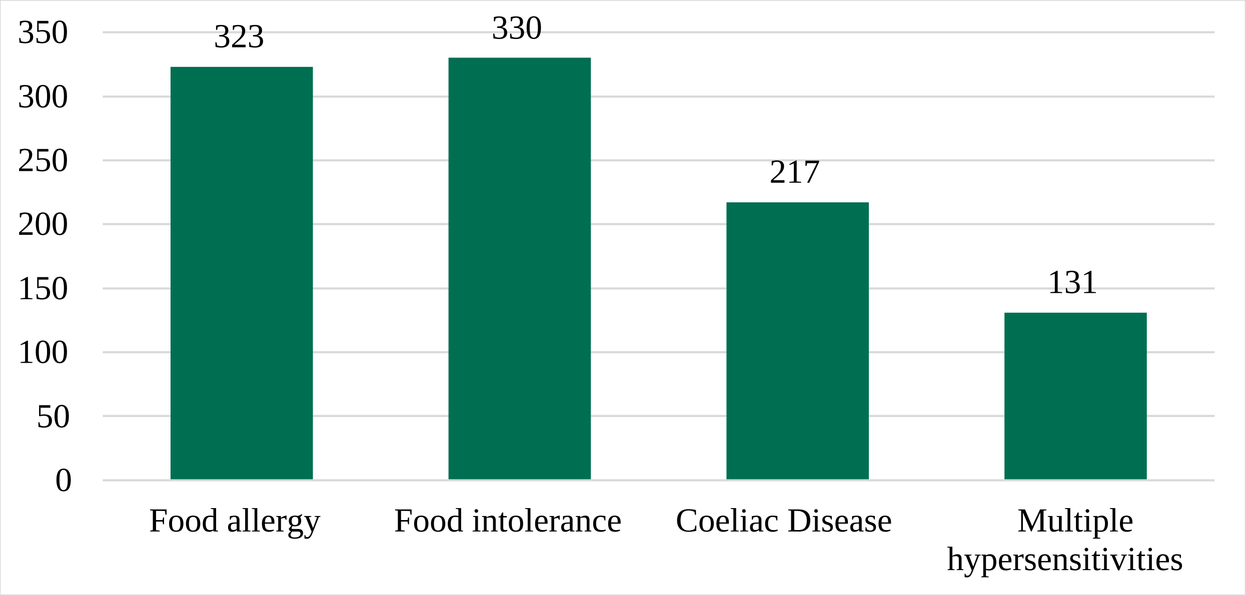
Part 1: Adults with Food hypersensitivities

A total of 1,065 adults with FH completed the wave 2 survey, which included 64 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 ‘all adults’ figures. Of these 1065 adults, 313 were adults who had previously completed a survey at wave 1 (for key comparisons of these samples see pages 53-57 and Table 25).

Prevalence of food hypersensitivities

Approximately a third of the adult sample was made up of those with food intolerance (31%) a third with food allergy (30%) and almost a fifth with coeliac disease (18%).

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



Base: All adults excluding 'other' and 'don't know' (1001)

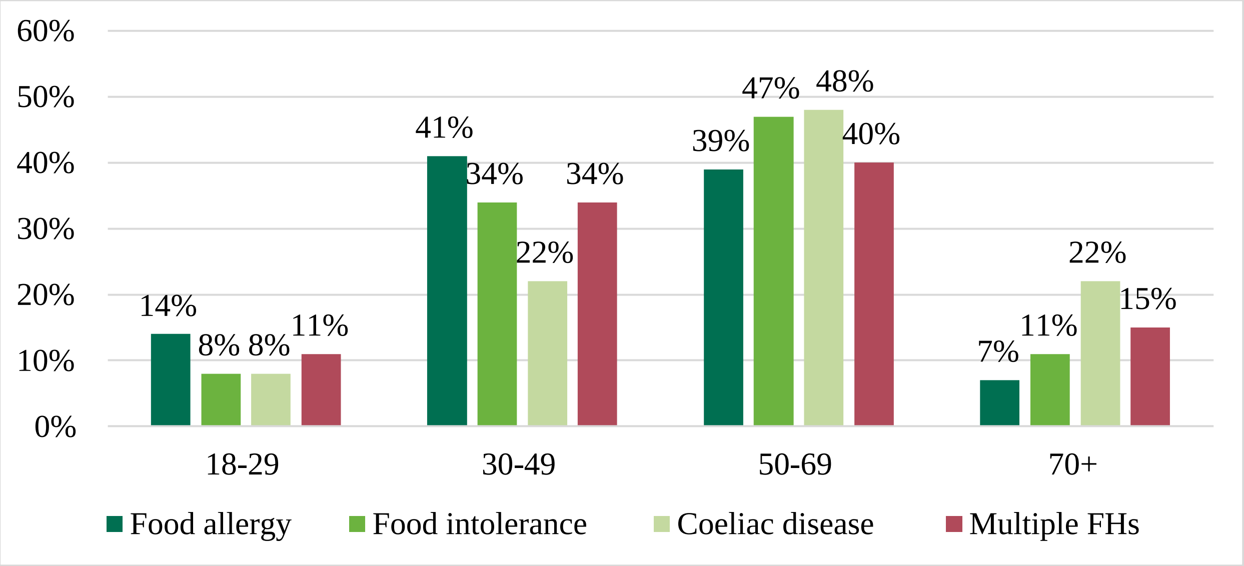
Profile of adult participants

Key demographics

From a total of 1,065 adults, 76% (n = 812) of those reporting a food hypersensitivity were women (23%; n = 245 were men). The mean age of all participants was 51 years old (SD = 15.2), with a range from 18 to 86 years old. The majority of adults were of White British ethnicity (n = 915; 86%). (See Annex A: Table 4).

Participants with a food allergy were typically younger (mean age: 46.9 years old; SD = 15.0) than those reporting a food intolerance (mean age: 52.2 years old; SD = 14.3), coeliac disease (mean age: 55.8; SD = 15.6) or multiple hypersensitivities (mean age: 51.6; SD = 15.5; Figure 2 for age distribution).

Figure 2: Age distribution by hypersensitivity



Base: all adults (excluding ‘other’ and ‘don’t know’) 959; Food allergy (308); Food intolerance (316); Coeliac disease (213); Multiple FHs (122).

More women also reported each of the four hypersensitivities than men, reflecting the large proportion of women who responded to the survey. Similar to the overall sample average, across hypersensitivities, the majority of adults were from a White British background, meaning the sample may not be representative of all those with food hypersensitivities (see Annex A Table 4 for a full breakdown).

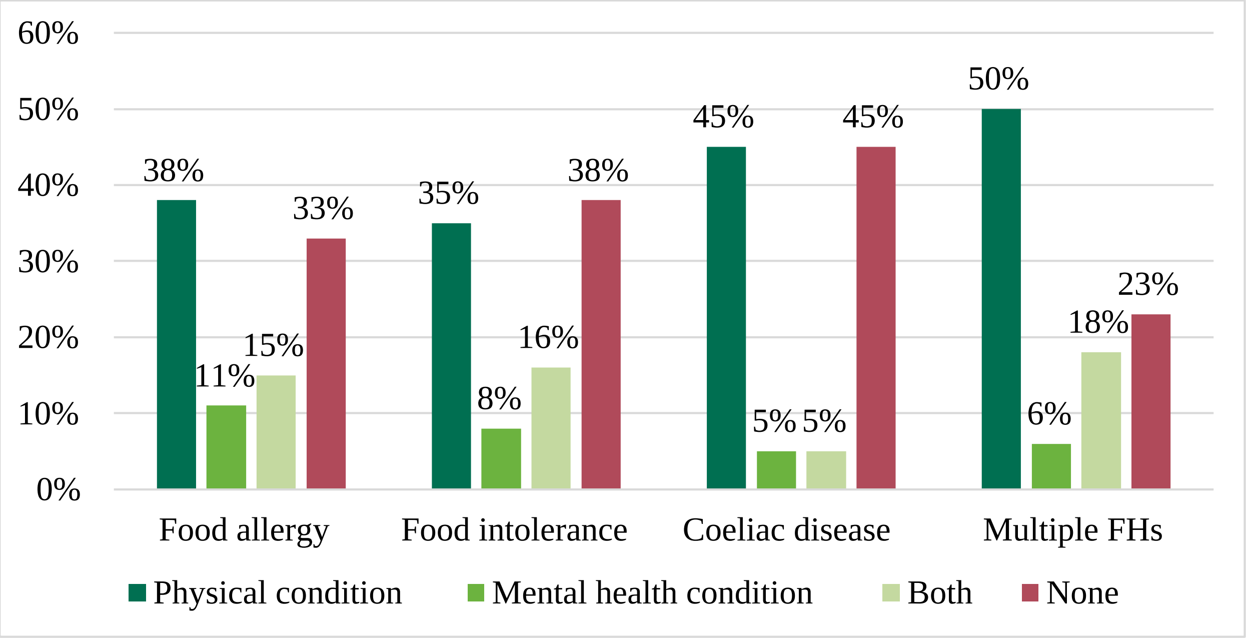
The most common region for adult respondents living with a food hypersensitivity was the South East of England (n = 202, 19%; see Annex A Table 5). Approximately a third (n = 313, 29%) had an undergraduate degree.

Thirty-three percent (n = 347) of the sample were in full-time employment, 25% (n = 267) were retired and 18% (n = 192) were working part-time. Only 3% (n = 36) were unemployed (see Annex A Table 6 for a full breakdown). Across the hypersensitivities, those with food allergy (n = 118, 38%), food intolerance (n = 104; 32%) and multiple hypersensitivities (n = 44, 34%) had the highest percentage in full-time employment, whilst those with coeliac disease (n = 91, 42%) were most likely to be retired.

Other long term conditions

Other long-term conditions included both mental and physical conditions. Forty percent of the whole sample reported a physical condition (n = 425), 8% (n = 89) reported having a mental health condition and 14% (n = 146) reported having both a physical and mental health condition. Participants with multiple hypersensitivities had the highest proportion of those reporting a physical health condition (50%), whereas those with food allergy reported the highest proportion of those with a mental health condition (11%).

Figure 3: Other long-term conditions

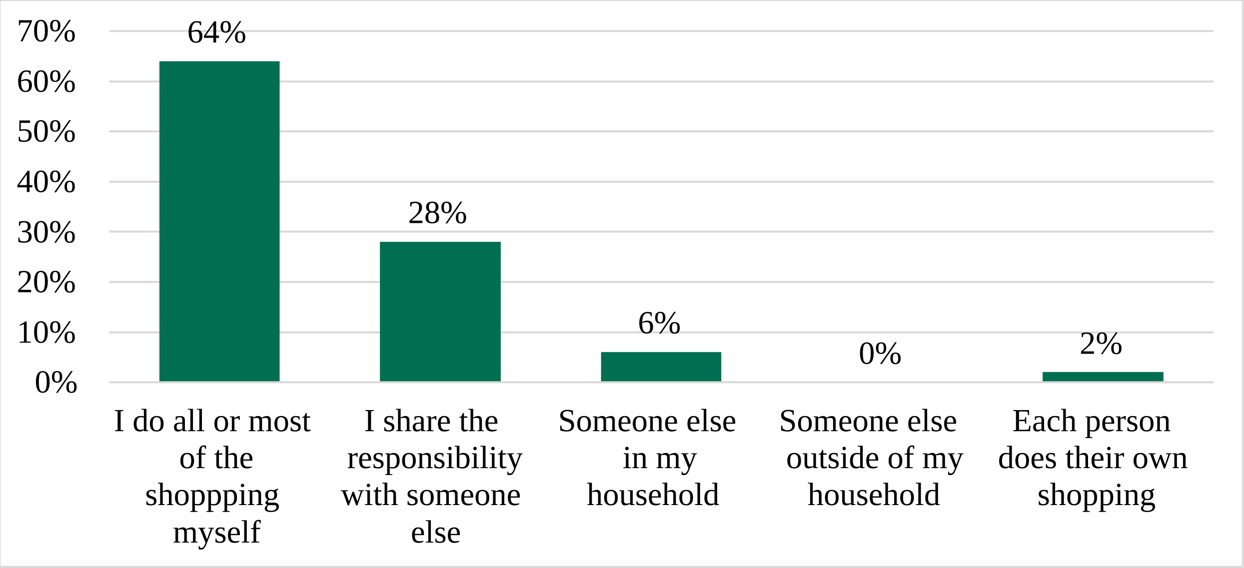


Base (all adults excluding ‘Other’ and ‘Don’t know’) 997; Food allergy (321); Food intolerance (329); Coeliac disease (217) and Multiple hypersensitivities (130).

Food preparation

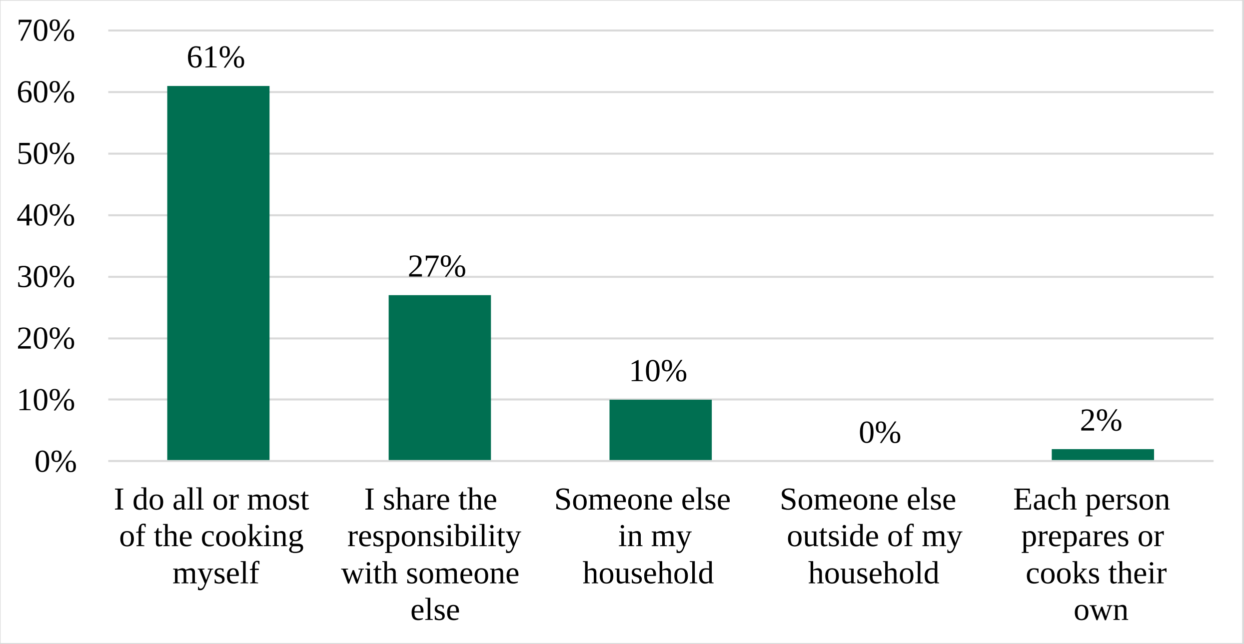
Data was collected on different aspects of food preparation, such as who did the shopping and cooking in each participants’ household (Figures 4 and 5). The majority of all participants did the shopping (64%) and cooking themselves (61%).

Figure 4: Responsibility for food shopping



Base: All adults (1,060)

Figure 5: Responsibility for food preparation and cooking



Base: All adults (1,045)

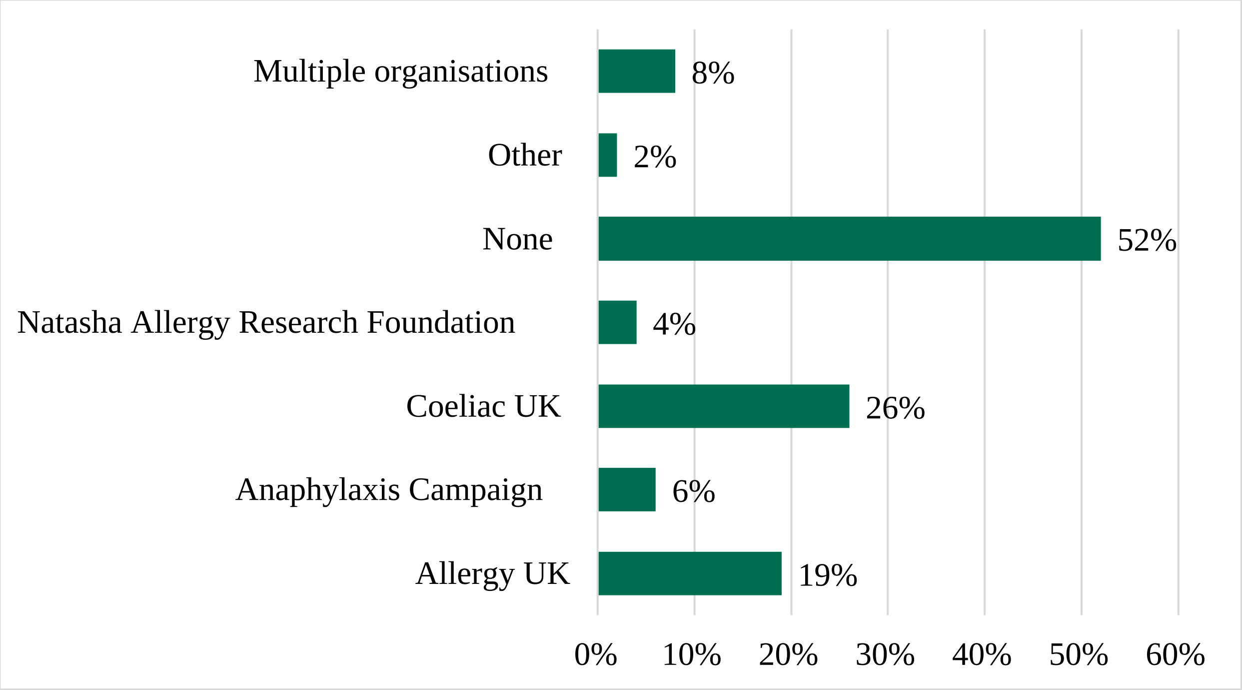
These proportions were also similar for each of the food hypersensitivities, with the majority of participants shopping and cooking for their own food or sharing the responsibility with someone else.

Patient organisation membership

Participants were asked to report on whether they were a member of any patient organisations. As one of the primary recruitment methods to the study was through patient organisations, 48% adults were members of established organisations supporting those with food hypersensitivities, especially Coeliac UK (26%) (see Figure 6) (footnote 1). It is possible that these respondents are likely to be highly informed about their condition and have been more motivated to take part in the survey.

Membership differed according to hypersensitivity; the majority of adults with food allergy (60%) and food intolerance (77%) were not members of a patient organisation, whereas the majority of those with coeliac disease (88%) and multiple hypersensitivities (69%) were members.

Figure 6: Membership of patient organisation groups (%)



Base: All adults (1,065)

Reactions to food

Initially, participants were provided with a list of foods and asked to select all foods they experienced a bad or unpleasant physical reaction to, and there was no limit on the number of foods that could be reported here. Cereals, milk, fruit and vegetables were the most frequently reported foods, as well as ‘Other’ foods, which included meats and meat replacements, fish, herbs and spices (for example, chilli), cheese, pulses, chocolate, condiments (for example, honey, mayonnaise), dairy products, alcohol, coconut, colourings, artificial sweeteners/flavourings, and tea/coffee. Please see Table 7 (Annex A) for a full breakdown of frequencies of foods reported by hypersensitivity.

Participants were then asked to report the foods they experienced reactions to that had a big impact on their lives. Participants could report up to three individual foods, and the reactions they experience in relation to these, in more detail. Most respondents only reported experiencing an adverse reaction to one food (n = 720, 68%), however, 206 (19%) participants reported a second food and 139 (13%) reported three foods.

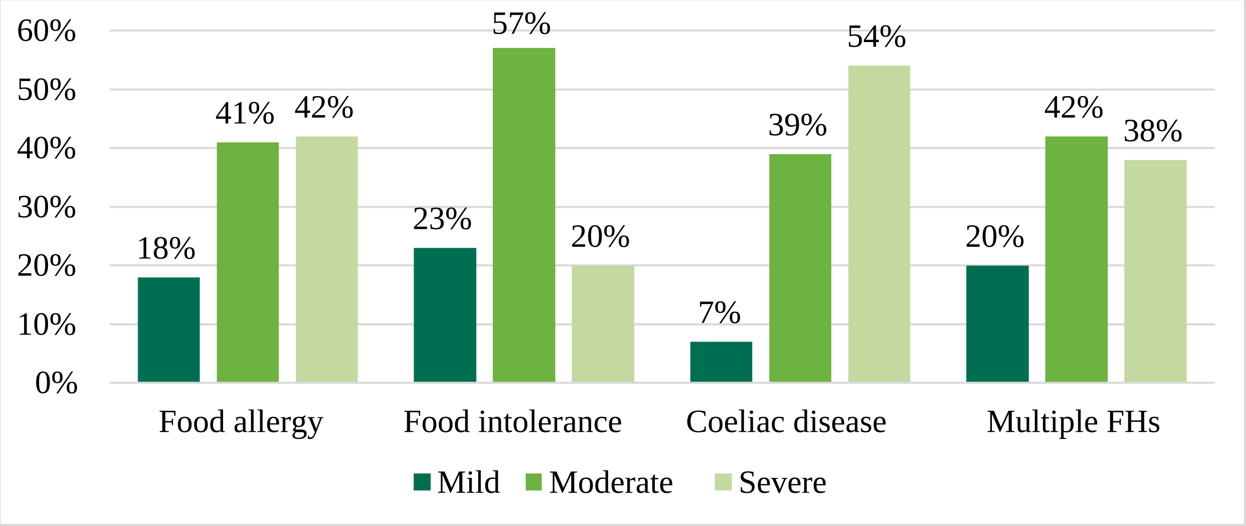
Food with adverse reactions

A total of 1,549 foods were reported individually (please note this is not separate types of food but the number of foods reported in total by adults). The most common food reported was cereals containing gluten (n = 403; 26%), and 92% of those with coeliac disease reported this as their only allergen. However, there were some other foods (8%) that those self-identifying as having coeliac disease also reported, which may not strictly result in a coeliac reaction (for example, molluscs).

Milk (n = 178; 11%) and ‘other’ (n = 222; 14%) foods were also common sources of adverse reactions. A reaction to milk (47%; n = 83) and ‘other’ foods (37%; n = 82) was most commonly reported by those with food intolerance. For a full breakdown of foods by hypersensitivity please see Annex A, Table 8.

Respondents were asked to report whether they thought their reaction to the stated food was mild, moderate, or severe, as part of the self-report questionnaire. No objective measures or definitions were given of what was classed as mild, moderate, and severeand this was left to the interpretation of respondents. Most reactions to food were self-reported as severe or moderate (36%, n= 558 and 46%, n = 714 respectively). Only 18% (n = 272) of reactions were categorised by respondents as mild (Figure 8). For food intolerance and multiple hypersensitivities, more participants reported their reactions as moderate compared to mild and severe. For those with coeliac disease, the majority reported this as severe and for those with food allergy, this was split between moderate and severe (Figure 7).

Figure 7: Severity of reaction to all foods reported, by hypersensitivity



Base: All foods reported by adults with hypersensitivities (excluding ‘other’ and ‘don’t know’; 1439); Food allergy (465); Food intolerance (429); Coeliac disease (230); Multiple FHs (315).

Symptoms

Participants reported 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). Participants could choose all symptoms relevant to their reactions, so numbers reflect how many times each symptom type was chosen by respondents.

Across the three foods respondents could report on, the majority of symptoms typically experienced were gastrointestinal (44%; n = 4183). Similarly, across all three foods reported on, for those with food intolerance (64%; n = 1180), coeliac disease (82%; 1052) and multiple hypersensitivities (47%; 936) the most common symptoms were also gastrointestinal symptoms. However, for those with food allergy, the most common symptoms reported were breathing symptoms (28%; n = 1053) (see Annex A Tables 9-11 for a full breakdown).

When asked to report the most severe symptoms they had experienced to the foods they reported, for adults with food intolerance (62%; n = 762), coeliac disease (80%; n = 585) and multiple hypersensitivities (46%; n = 612) gastrointestinal symptoms were reported as the most common severe symptoms. For adults with allergy, the most common severe symptom type was breathing symptoms (25%; n = 611; Annex A Table 12).

Participants reported that their symptoms most frequently started between 5 to 30 minutes (n = 451; 30%) after ingesting the stated food. However, for those with food intolerance (n = 211;

51%), coeliac disease (n = 157; 69%) and multiple hypersensitivities (n = 131, 41%) symptoms more frequently occurred after 30 minutes. For those with food allergy, symptoms most commonly started within 5 minutes (n = 216, 47%; Annex A Table 13).

Diagnosis

Across all three foods reported, the majority of respondents with food allergy (75%) or coeliac disease (97%) reported their reactions as clinically diagnosed (both diagnosis methods and the healthcare professional who diagnosed them were clinically based). Whereas, the majority of those with food intolerance reported that their reactions were self-diagnosed (diagnosed by themselves only; n = 226, 56%; Figure 8). A small number of adults across the hypersensitivities reported that they had been diagnosed by an alternative therapist (n = 27; 2%).

The majority of reactions reported by adults were diagnosed by a hospital doctor, GP, or nurse (n = 775 combined, 58%). The most common method of diagnosis was a blood test for antibodies (n = 315, 17%) and a healthcare professional's diagnosis without any tests (n = 312, 17%; see Annex A, Table 14). 'Other' tests were also reported by 15% (n = 276) of adults which included unexpected anaphylaxis or other reaction, diagnosis when they were a child, or as a co-morbidity of another condition. Other diagnostic tests, such as endoscopy, biopsy and elimination diets were also reported for 'Other'. Twenty-eight percent (n = 507) of the sample reported that they had noticed symptoms themselves as one of their diagnosis methods. However, participants could choose multiple options for diagnosis method, which may have included a clinical method such as blood tests in addition to reporting that they had noticed the symptoms themselves. Only those who reported just noticing the symptoms themselves, or diagnosing themselves were classed as self-diagnosed.

Figure 8: Diagnosis by hypersensitivity

Base: All foods reported by adults with hypersensitivities (1386); Food allergy (442); Food intolerance (404); Coeliac disease (230); Multiple FHs (310).

When focussing on diagnosis methods only, by hypersensitivity those with food allergy most often reported being diagnosed by a healthcare professional (n = 122; 22%), or noticing symptoms themselves (n = 120; 21%) as one of their diagnosis methods. For those with coeliac disease, it was 'Other' (n = 127; 44%) methods of diagnosis. For participants with food intolerance (n = 230; 51%) and multiple hypersensitivities (n = 101; 28%), noticing the symptoms themselves was the most common diagnosis method reported. (Note: these numbers are different to the groupings as shown in Figure 8, which reflect the combined categorisation based on both diagnosis method as well as the healthcare professional adult participants were diagnosed by. Here, it is just the diagnosis method which is reported on.)

Mean age for diagnosis was 33.5 years old (SD = 17.9) when looking at the first food that adults had the most significant reaction to (footnote 2). Respondents with food allergy were, on average (mean = 25.7, SD = 16.8), diagnosed significantly younger than respondents with other hypersensitivities (food intolerance mean = 34.9, SD = 16.3; coeliac disease mean = 40.3, SD = 17.0; multiple hypersensitivities mean = 34.6; SD = 18.3) F(3) = 31.5, p <.001, ?p^2 = .08 (all comparisons, p <.001).

About their reaction

Participants were asked how many times they had reacted to the food in the previous 12 months. Across all foods reported, for 36% (n = 542) of reactions, the sample reported that they had not reacted to their stated food in the previous 12 months, however 58% (n = 882) of reactions had occurred in the last 12 months, with 17% (n = 257) occurring between 3 and 6 times, and 13% (n = 193) occurring once. On a scale from 1 (not reacted to this food in the last 12 months) to 6 (more than 10 times), participants with food intolerance reported they had reacted to food significantly (footnote 3) more often in the last 12 months (mean = 3.3, SD = 1.8) on average reporting they had experienced two reactions in the previous 12 months, compared to those with food allergy (mean = 2.4, SD = 1.6), coeliac disease (mean = 2.6, SD = 1.6) and multiple food hypersensitivities (mean = 2.7; SD = 1.7), who reported reacting once in the last 12 months (all ps<.008; Annex A Table 15).

Additionally, participants were asked where they were when their most recent reaction to the food reported occurred (for example, where they first started experiencing symptoms of an adverse reaction). Across all foods, 62% (n = 901) of reactions occurred at home, however 14% (n = 204) also occurred whilst eating out. Participants were only asked where their reaction occurred however (for example, where they first started to experience symptoms of an adverse reaction), and not where the food they reacted to was prepared. Seven percent of reactions were also reported to have occurred at work (n = 106, 7%) or a family or friend's house (n = 100, 7%), 5% (n = 80) occurred at other locations, for 3% (n = 49) participants couldn't remember the location and 1% of reactions occurred on public transport (n = 21). This was also reflected across the hypersensitivities (see Annex A, Table 16).

Anaphylaxis

The total number of reactions where participants reported experience of anaphylaxis (footnote 4) was 351 (24%), of which 57% (n = 201) were those with food allergy and 26% (n = 91) were those with multiple food hypersensitivities. A further 12% (n = 42) reporting this had food intolerance and 1% (n = 4) were those with coeliac disease. For 14% (n = 213) of all reactions, participants had also experienced anaphylaxis in the last 12 months, of which 45% (n = 96) were those with food allergy and 30% (n = 64) were those with multiple hypersensitivities, indicating those with food allergy in this sample were most at risk of anaphylaxis (see Annex A, Tables 18 and 19). Fifteen percent (n = 33) of those experiencing anaphylaxis in the last 12 months were those with food intolerance and 2% were those with coeliac disease. However, given that anaphylaxis is not a typical reaction for coeliac disease or food intolerance, some respondents may have incorrectly reported this reaction, or possibly misdiagnosed their hypersensitivity or misunderstood the question, despite being given a definition.

Furthermore, for 27% (n = 403) of all foods reported, participants had been prescribed an adrenaline auto-injector (AAI). This was mostly reported by participants with food allergy (62% of those prescribed an AAI, n = 248), though it was also reported by respondents with multiple food hypersensitivities (22%, n= 90).

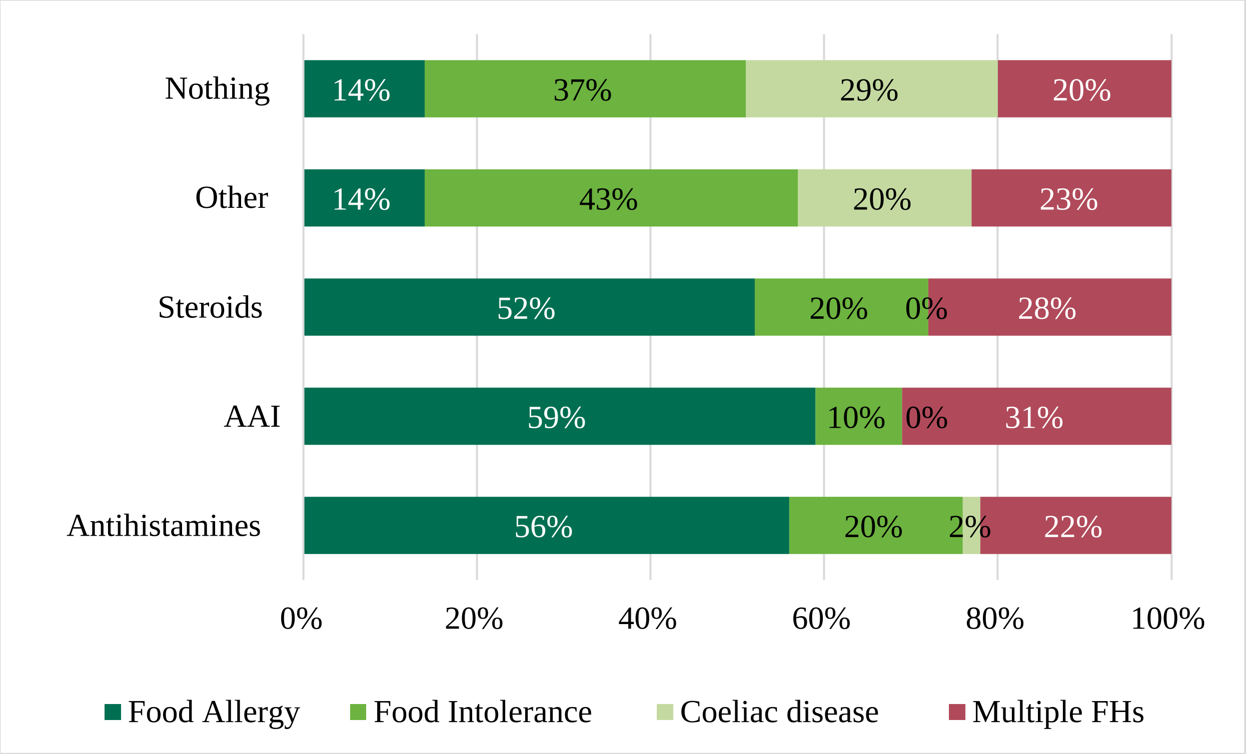
Treatment

Participants were asked about different aspects of treatments to their most recent reactions, including who treated them. Across all reactions reported on, 74% of adults reported that they treated the reactions themselves, with 15% also reporting that they received medical help. Across hypersensitivities, those with food allergy (n = 114, 24%) and multiple hypersensitivities (n = 47, 15%) reported higher frequencies of seeking medical help for treatment of their reaction, than those with food intolerance (n = 39, 9%) and coeliac disease (n = 9, 4%; see Annex A, Table 17).

Participants could select all applicable treatments administered themselves or by a non-medical person for their stated food hypersensitivities. Just over a third (36%, n= 462) reported not taking anything. The most common treatment reported across all foods was antihistamines (n = 426; 33%). Treatments were most commonly reported by those in the food allergy group (see Figure 9).

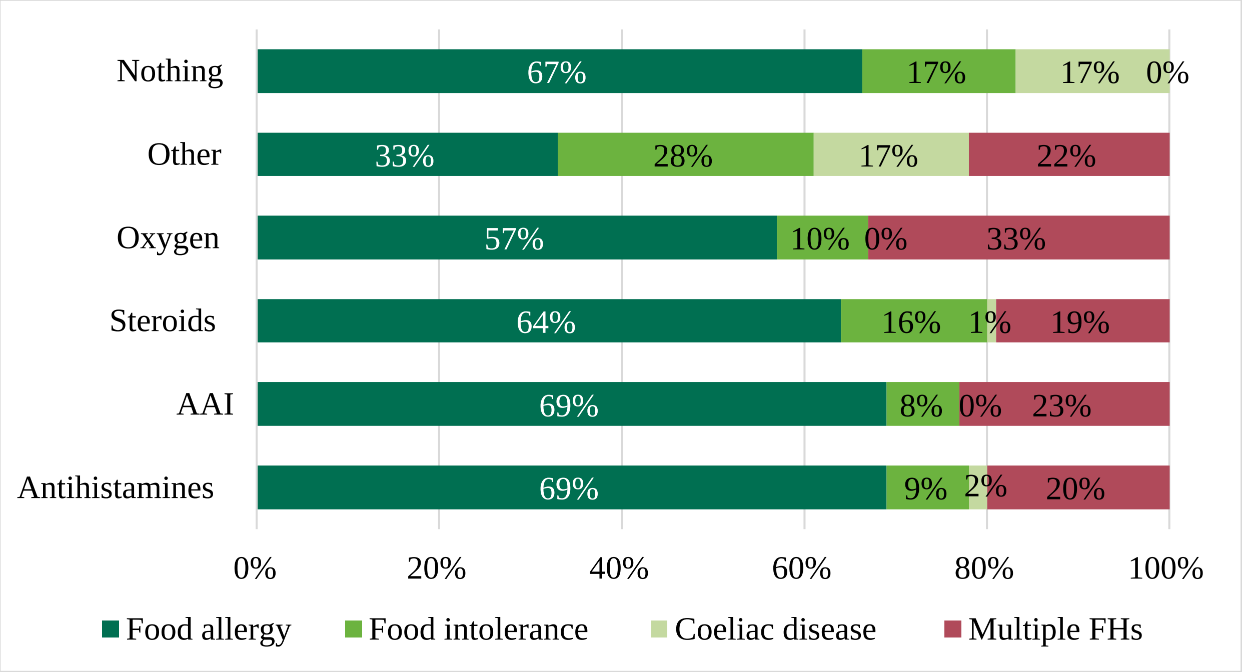
Participants also reported on treatments administered by a medical professional. Of these, antihistamines (n = 116, 29%) were the most commonly administered treatments across all reactions reported on. Across hypersensitivities, those with food allergy received more treatments than other hypersensitivities (see Figure 10).

Figure 9: Treatments by non-medical persons for reaction to all foods reported, by hypersensitivity



Base: All adults (excluding other and ‘don’t know’; 1201): Food allergy (380); Food intolerance (368); Coeliac disease (183); Multiple hypersensitivities (270).

Figure 10: Treatments by medical professionals for all foods reported, by food hypersensitivity



Base: All adults (excluding other and ‘don’t know’; 370): Food allergy (232); Food intolerance (47); Coeliac disease (10); Multiple hypersensitivities (81)

Hospital admission

For the majority of foods reported (84%, n = 1,225) participants had never had to call an ambulance, and three quarters (78%, n = 1142) had never been admitted to hospital as an emergency for their reactions to their stated food. For those reactions where participants had been admitted to hospital (n = 316, 22%), three quarters (75%, n = 221 of those responding n = 296) were admitted the first time that they reacted to their stated food and 24% (n = 75) were admitted just once. Adults with food allergy were the most likely to be admitted to hospital for their reactions to their stated food (n = 159; 37% of those with food allergy and 50% of all those admitted), followed by those with multiple hypersensitivities (n = 78; 25% of respondents with multiple FH and 25% of all those admitted) and those with food intolerance (n = 42; 10% of respondents with food intolerance and 13% of all those admitted). Those with coeliac disease were least likely to be admitted (n = 21; 7%).

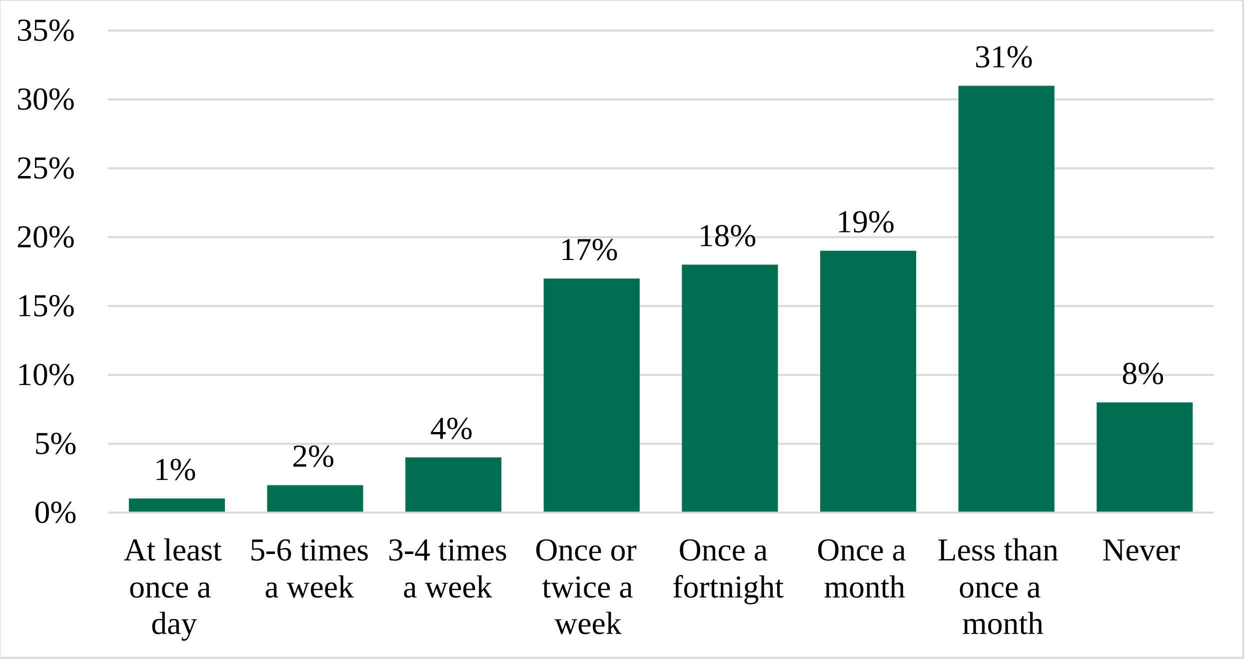
For all groups, the majority of participants who had been admitted to hospital (n = 144), had been admitted between once and 3 to 6 times (n = 123, 85%). Across hypersensitivities it was most common for participants to report reacting once, with those with allergy reporting this more compared to other groups (n = 42; 56% of those being admitted once; see Annex A Table 20 for full breakdown). Those from the food allergy group were most likely to be admitted the first time they reacted to their stated food (n = 114, 52% of those admitted first time), compared to those with food intolerance (n = 26, 12%), coeliac disease (n = 5, 2%) or multiple hypersensitivities (n = 64, 29%; Annex A Table 21).

Eating out

Participants were asked how often they eat out, and how comfortable they feel with various aspects of eating out, such as asking for information from a member of staff. Respondents were asked about their current eating out behaviour.

A third of participants reported that they eat out or get food to take away from a restaurant or other food outlet less than once a month (n = 313, 31%), but over half of the overall sample reported they eat out more frequently than this (n = 601; 60%; Figure 11).

Figure 11: How often participants eat out or get food to take away

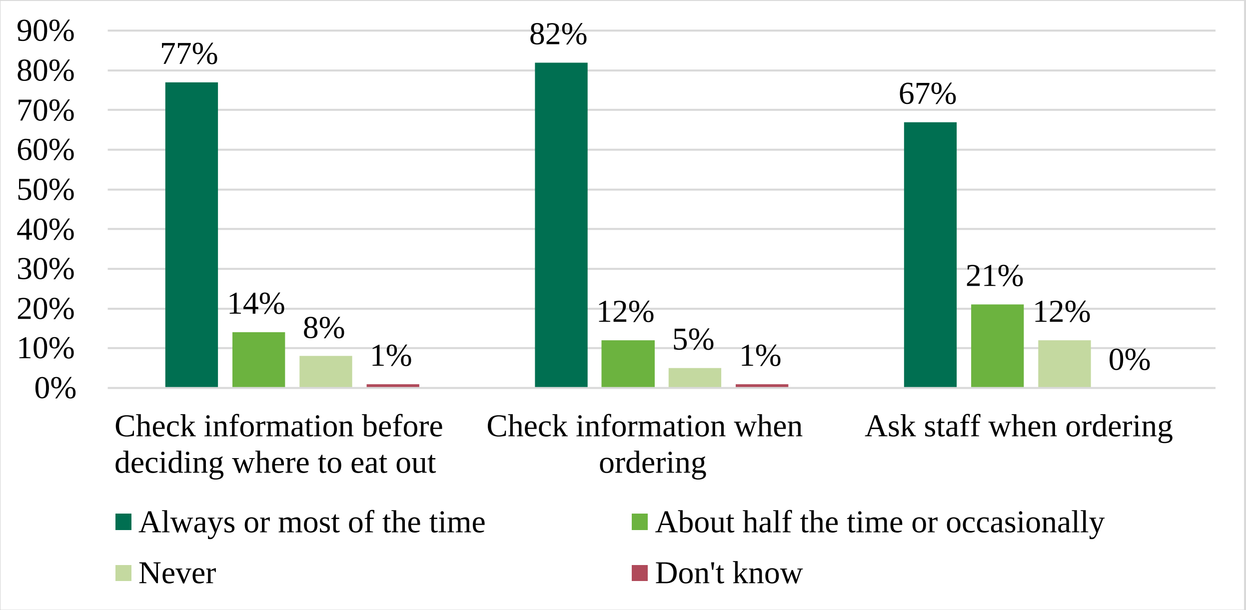


Base: All adults (996).

However, there were significant differences in how often adults with different hypersensitivities eat out, F(3) = 4.95, p =.002, ?p² = .02. On a scale of 1 (Never) to 8 (at least once a day), those with food allergy (mean = 3.6, SD = 1.6) and those with multiple hypersensitivities (mean = 3.5, SD = 1.9) reported eating out once a month or fortnight, and for those with food allergy this was significantly more often than those with food intolerance (mean = 3.2, SD =1.5) and those with coeliac disease (mean = 3.1, SD = 1.3; all ps <.008), who on average ate out around once a month (see Annex A Table 22).

Participants reported almost always reviewing information at each stage of eating out, with a small minority never checking available information at any stage of eating out (see Figure 12).

Figure 12: How often participants review information when eating out (all adults, %)



Base: All adults answering each question; Check information before choosing where to eat out (920); Check information before ordering (913); Ask staff for information when ordering (918).

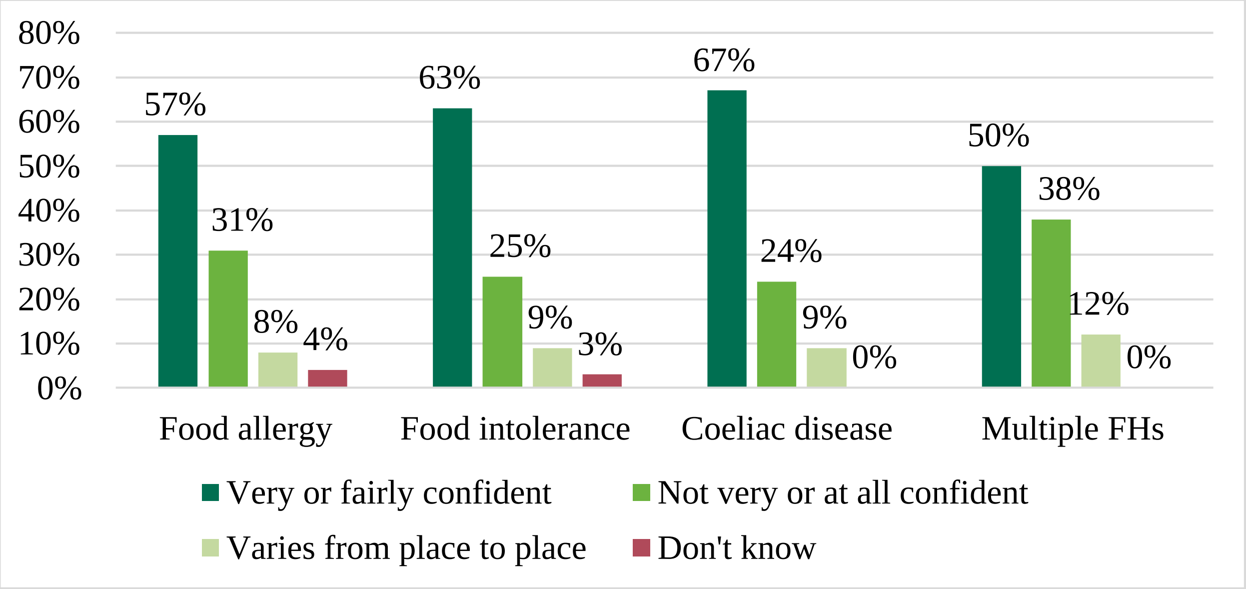
Within each hypersensitivity group, most adults reported they always or most of the time check and review any available information that allows them to identify foods that will cause a bad or unpleasant physical reaction before deciding where to eat out. However, on a scale of 1 (Never) to 5 (Always) there were significant differences between hypersensitivity groups. Adults with multiple hypersensitivities (mean = 4.5, SD = 0.9) and coeliac disease (mean = 4.7, SD = 0.7) checked information when deciding where to eat out significantly more often than those with food allergy (mean = 3.9, SD = 1.4) or food intolerance (mean = 3.7, SD = 1.4; all ps<.008), on average reporting that they always check this.

When asked how often participants review any available information before ordering food, adults with food intolerance (mean = 3.9, SD = 1.4) review this information significantly less often (about half or most of the time) than adults with food allergy (mean = 4.2, SD = 1.2), coeliac disease (mean = 4.8, SD = 0.6) and multiple hypersensitivities (mean = 4.6, SD = 1.0; all ps <.001), who review this either always or most of the time. Finally, adults with coeliac disease (mean = 4.6, SD = 0.8) and multiple hypersensitivities (mean = 4.4, SD = 1.1) on average reported asking a member of staff for information that enables them to identify foods that cause a bad or unpleasant reaction significantly more often than those with food allergy (mean = 3.8, SD = 1.4) or food intolerance (mean = 3.0, SD = 1.6; all ps <.001).

As well as asking how often participants check available information when they eat out, they were also asked how comfortable they felt doing so, and how confident they were that the information provided would allow them to identify foods that cause bad or unpleasant physical reactions. Over half of all participants were comfortable in asking staff for information when eating out because of a concern about experiencing a reaction (n = 576; 63% were very or fairly comfortable). This was the case across all hypersensitivities (64% of the food allergy, 59% of the food intolerance and 67% of the coeliac disease groups, and 64% of the multiple hypersensitivities group reported being very or fairly comfortable asking for information; see Annex A Table 23). There were no significant differences in how comfortable participants with different hypersensitivities were in asking for information, F(3) = 1.19, p = .31, ?p² = .005.

Adults were mostly confident that the written information provided when eating out allows them to identify foods that cause a reaction (n = 549; 60% were very or fairly confident). There were no significant differences in how confident adults with different hypersensitivities were in written information F(3) = 0.59, p = .63, ?p² = .002. See Annex A Table 24 and Figure 13.

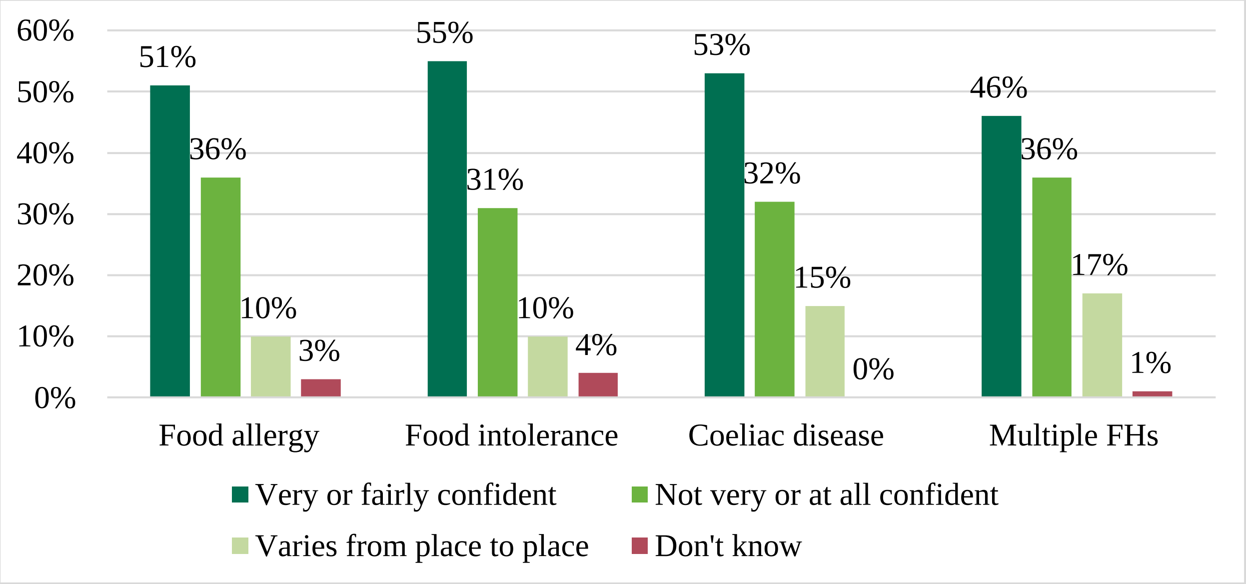
Figure 13: Confidence in written information by hypersensitivity



Base: All adults with hypersensitivities (870); Food allergy (279); Food intolerance (273); Coeliac disease (205); Multiple FHs (113).

Participants were more divided in opinion on how confident they were that the information provided verbally by staff when eating out allows them to identify foods that cause a reaction, with 52% (n = 475) very or fairly confident in information provided, but 34% (n = 312) not very or not at all confident. There were no significant differences across the different hypersensitivities for confidence in verbal information, F(3) = 0.17, p = .92, ?p² = .001 (see Annex A Table 25 and Figure 14).

Figure 14: Confidence in verbal information by hypersensitivity

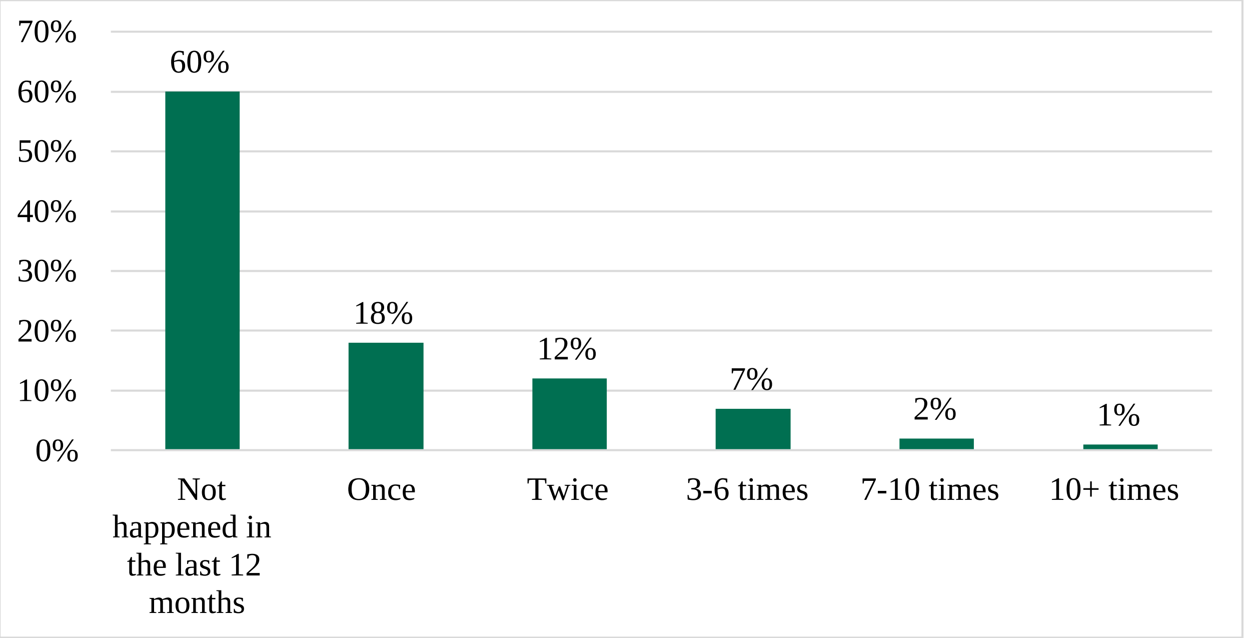


Base: All adults with hypersensitivities (870); Food allergy (279); Food intolerance (273); Coeliac disease (204); Multiple FHs (114).

Participants were also asked in the last 12 months how often they had been served a product or dish containing a food they react to, even though they had checked the available allergen information. For the majority of participants, this had not happened in the last 12 months (60%; n = 515). However, for 30% of adults (n = 260) this had happened once or twice in the last 12 months. Across hypersensitivity, those with multiple hypersensitivities (31%, n = 34) most often reported that this had happened once and those with coeliac disease (16%, n = 32) most often reported that this had happened twice (see Table 26 and Figure 15).

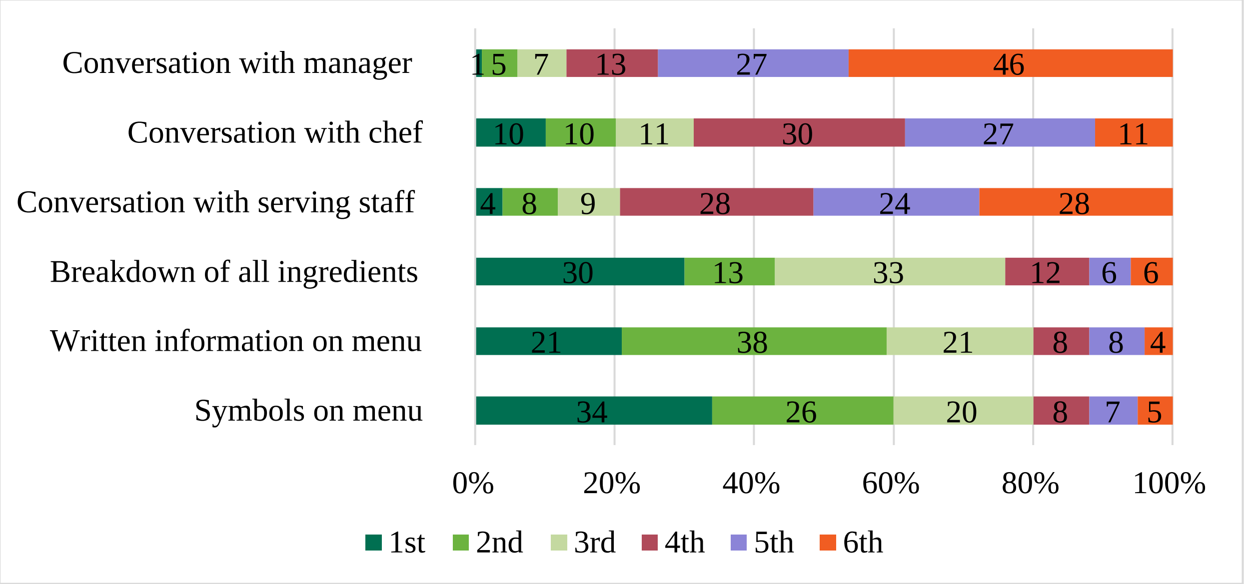
Additionally, participants were asked to rank their most useful sources of allergen information when eating out. Overall, 34% (n = 307) reported that menus with symbols showing which allergens are present in each dish are the most helpful, and a further 38% (n = 341) reported that menus with written information showing which allergens are present in each dish were the second most helpful source of information. The third most helpful source of information was a breakdown of all ingredients in each dish (33%, n = 301; see Figure 16). The same pattern was also reflected across the hypersensitivity groups.

Figure 15: Frequency of being served allergen in the last 12 months



Base: All adults (860)

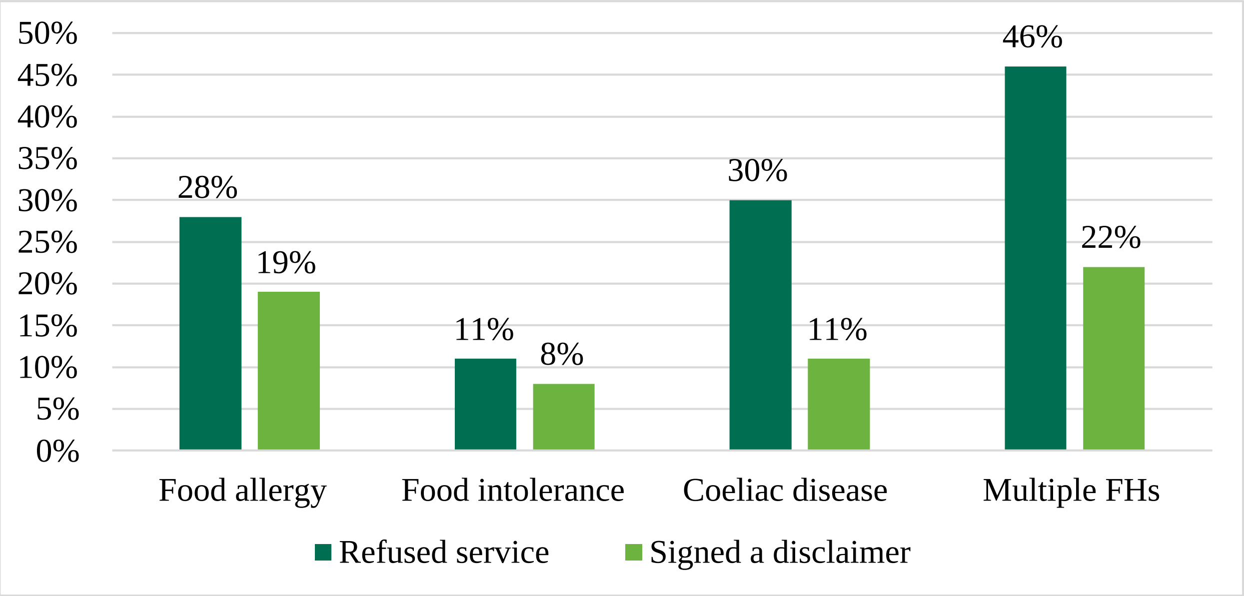
Figure 16: Rank of most useful sources of information for adults, when eating out



Base: All adults (907)

One in four (25%, n = 246) participants reported they had previously been refused service because of their hypersensitivity, and one in ten (14%, n = 116) reported that they had been previously asked to sign a disclaimer when eating out. Those with multiple hypersensitivities reported the highest percentages of being refused service (46%, n = 57) and being asked to sign a disclaimer (22%, n = 27), whilst those with intolerance reported the lowest percentages of being refused service (10%, n = 32) and asked to sign a disclaimer (8%, n = 23) as a result of their conditions. See Figure 17 for percentages reported by hypersensitivity.

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



Base: Adults with hypersensitivities (Refused service (RS): 925; Signed disclaimer (SD): 929); Food allergy (RS: 295; SD: 297); Food intolerance (RS: 297; SD: 298); Coeliac disease (RS: 208; SD: 210); Multiple FHs (RS: 125; SD: 124).

Quality of life

Food hypersensitivity specific quality of life

Participants were asked to complete a health-related quality of life scale appropriate to the type of self-reported food hypersensitivity they reported for their first food. Those with food allergy completed the Food Allergy Quality of Life Questionnaire (FAQLQ) (footnote 5), those reporting food intolerance completed the Food Intolerance Quality of Life Questionnaire (FIQLQ), for Coeliac Disease participants completed the Coeliac Disease Quality of Life scale (CDQoL). Respondents reporting multiple different hypersensitivities completed the scale relevant to the first food they reported (those reporting food allergy = 49; those reporting food intolerance = 28, those reporting coeliac disease = 47). For example, if someone reported food allergy to their first food, food intolerance to their second and third, they only completed the FAQLQ as it was considered too difficult for respondents to identify the different impacts on quality of life that their different hypersensitivities may have.

Quality of life in all adults

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

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

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

Measure	FAQLQ (Food allergy) N=345 (including 49 with multiple food hypersensitivities)	FIQLQ (Food Intolerance) N=325 (including 28 with multiple food hypersensitivities)	CDQoL (Coeliac disease) N=242 (including 47 multiple food hypersensitivities)
Mean total (SD)	4.8 (1.6)	4.2 (1.7)	50.6 (18.3)
Out of a possible total of:	7	7	100

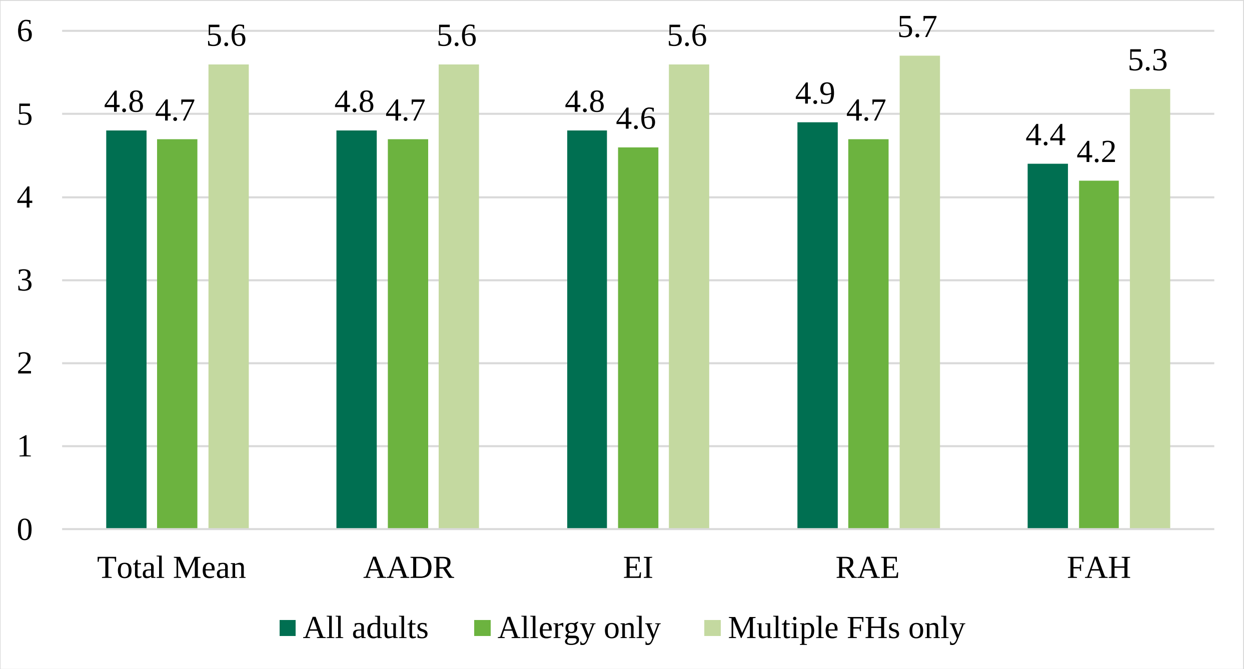
Quality of life in adults reporting allergy

Each scale consists of food hypersensitivity specific subscales. For those completing the FAQLQ, these are: Allergen Avoidance and Dietary Restrictions (AADR), which considers the impact that a restrictive diet has on quality of life and the impact this also has on social activities; Emotional Impact (EI) relating to the worries and concerns about having an allergic reaction or consuming allergens; Risk of Accidental Exposure (RAE), relating to vigilance and awareness needed to avoid ingesting allergens; and Food Allergy related Health (FAH), relating to specific health anxiety about having an allergy or reaction. A total of 345 adults completed the FAQLQ (of which 296 were from the allergy only group; the remaining 49 from the multiple hypersensitivities – see below section on this group).

On the scale from 1 (least impairment) to 7 (most impairment on quality of life) used by the FAQLQ, participants scored similarly high for total impact on quality of life and for all subscales. Scores for the total mean (4.8 out of 7, SD = 1.6; response option ‘quite’ troubled or worried) and all subscales of the FAQLQ were above the mean level of 4 (out of 7). The lowest mean score was for the Food Allergy related Health subscale (mean = 4.4 out of 7, SD = 1.7; response option ‘moderately’), indicating less impairment on quality of life from health related anxiety about having allergies, compared to other aspects such as avoiding allergens, concerns about having a reaction and other social and dietary limitations that come with having a food allergy.

While it appears that those with multiple hypersensitivities who completed the FAQLQ had the most impaired quality of life, this group was a lot smaller than those with just food allergy and so means may be inflated for this group. Means for both groups are shown in Figure 18.

Figure 18: Mean FAQLQ scores for all adults, allergy only adults and adults with multiple hypersensitivities



Base: Adults responding to FAQLQ (345); Allergy only group (296); Those with allergy as part of multiple hypersensitivities (49).

Clinical factors were examined to see whether they were significantly associated with impairment to quality of life in adults with food allergy. Quality of life was significantly more impaired in those who reported having a long-term physical condition (for example, diabetes, heart disease, mean= 5.1, SD= 1.4) compared to those who did not (mean= 4.3 SD= 1.6; t(204.7)= 3.85). Additionally, those with both a mental and physical condition had significantly more impairment to quality of life (mean = 5.1, SD = 1.6), than those with no condition (mean = 4.3, SD = 1.6; t(148) = -2.73, p =.007), however group sizes were unequal so caution should be taken in interpreting these results. This was also the case for those with asthma (mean= 5.3 SD= 1.4) compared to those without (mean= 4.4 SD= 1.6; t(302.6)= 4.80) and for those with eczema (mean= 5.2 SD= 1.4) compared to those without (mean= 4.5 SD=1.6; t(286.8)= 4.30; all ps <.05).

The number of foods reported which result in an adverse reaction was significantly correlated with impairment to quality of life in adults reporting food allergy (r = .42), as was the reported severity of participants' reaction to their first food (r = .45; both ps <.001). Those prescribed an auto-injector had significantly greater impairment to quality of life (mean= 5.6 SD=1.1) than those without (mean= 4.1 SD= 1.6; t(267.1) = 9.21). Those who had experienced anaphylactic shock to their first stated food reported greater impairment (mean= 5.5 SD= 1.1) than those who had not (mean= 4.1 SD= 1.6; t(223.6) = 8.53). Those who had been admitted to hospital in an emergency for the reaction to food one also reported greater impairment to their QoL (mean= 5.4 SD= 1.2) than those who had not (mean= 4.5, SD= 1.7; t(294.3)= 5.62), (all ps <.001).

Factors related to eating out were also significantly correlated with quality of life in adults with allergy. Whilst greater frequency of eating out was significantly correlated with better quality of life (r = -.11, p= .048), how often they checked information before choosing where to eat (r = .55), frequency of reviewing this information before ordering (r =.50), and asking staff for available information (r = .55) were all significantly correlated to impairment of quality of life (all ps<.001). Being served a dish containing an allergen that participants may have a reaction to in the last 12 months was also significantly correlated with impairment of quality of life (r = .29, p <.001). Finally, however, how comfortable participants were in asking for information (r = -.22), and how confident they were in both written (r = -19) and verbal information (r = -.19) were significantly associated with less impairment to quality of life (all ps <.01).

A regression model was run to see which of the variables described above might predict level of food allergy specific quality of life. All the variables which were significantly correlated with quality of life were included in the model (n=17 predictors). The overall model was significant (p<0.001) and 54% of the variance in quality of life was explained, indicating that 46% of the variance was due to other unknown factors. Number of foods reacted to was the strongest predictor of impairment to quality of life, with those reporting a higher number of foods reporting more impairment to their quality of life (standardised Beta = 0.33). Greater self-reported severity also significantly predicted greater impairment to quality of life (standardised beta 0.29). How often participants checked information before choosing where to eat out (standardised beta = 0.19) and how often they asked a member of staff for information (standardised beta = 0.20) also predicted poorer QoL. In addition, the frequency that adult respondents had reacted to an allergen when eating out in the last 12 months, despite checking available information also significantly predicted impairment to quality of life. None of the other predictors were significant (standardised betas ranged from -0.05 to 0.10 and confidence intervals for each predictor crossed zero).

Quality of life in adults reporting food intolerance

The FIQLQ was also scored on a scale of 1 (least impairment on quality of life) to 7 (maximum impairment on quality of life). Subscales comprise: Emotional Impact (EI), related to the stresses and concerns of having to be aware of foods that could cause a reaction; Social and Dietary restrictions (SDR), related to the impact that having an intolerance has on diet and social activities (for example, eating out); and Reactions and Avoidance (RAv), related to negative feelings about having a reaction (for example, embarrassment and discouragement). A total of 325 adults with food intolerance completed the FIQLQ.

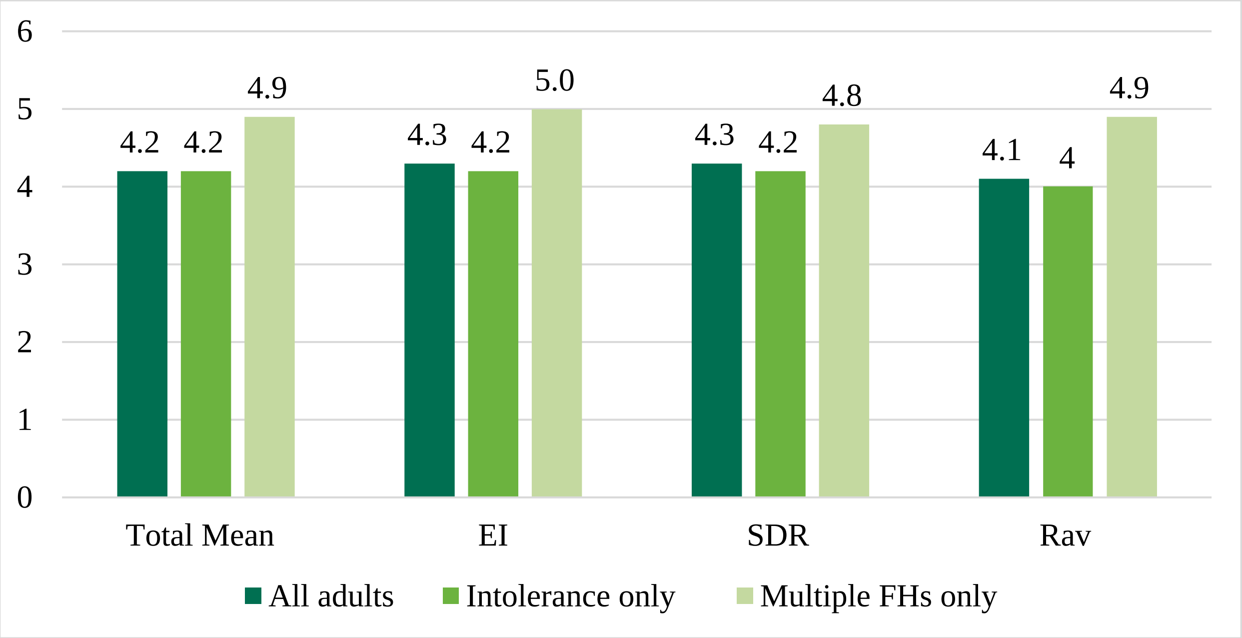
Adults with food intolerance reported a mean score of 4.2 (out of 7, response option ‘moderately’ or ‘quite a bit’; SD =1.7) for impairment on quality of life across all subscales (see Figure 19), with the mean score for Reactions and Avoidance showing least impairment in quality of life than the other FIQLQ subscales. This could indicate that those with food intolerance may be least concerned about negative feelings as a result of a reaction, and their quality of life is instead more impacted by the everyday concerns about managing their intolerance and the dietary and social limitations it has (see Figure 19).

For those with multiple hypersensitivities, 28 completed the FIQLQ. These individuals reported a greater impact on quality of life compared to those who only reported food intolerance (see Figure 19), however again this may be inflated due to the comparatively small numbers.

Quality of life was significantly more impaired in those who reported having a long-term physical condition (mean= 4.8, SD= 1.5) compared to those who did not (mean= 3.6, SD= 1.6; t(225)= 5.62, p<.001), as well as for those with both a mental health and physical condition (mean = 4.4, SD = 1.8, t(165) = 2.67, p = .008), although again groups were unequal and so should be interpreted with caution.

The number of foods reported which result in an adverse reaction (r = .22, p <.001) was significantly correlated with impairment to quality of life, as was the reported severity of participant’s reaction (r = .40; p <.001).

Figure 19: Mean FIQLQ scores for all adults, adults with food intolerance only and adults with multiple hypersensitivities



Base: Adults responding to FIQLQ (325); Intolerance only group (297); Those with food intolerance as part of multiple hypersensitivities (28).

Factors related to eating out that were significantly positively correlated with impairment to quality of life in adults with intolerance included: how often they checked information before choosing where to eat out (r = .62), reviewing available information before ordering (r =.61), and asking staff for available information (r = .59) (all ps<.001), as well as being served a dish containing an allergen that participants may have a reaction to in the last 12 months (r = .18, p =.004). However, how comfortable participants were in asking for information about food when eating out (r = -.20, p= .002) and how confident they were in the verbal information (r = -.18, p = .005) provided when eating out, were significantly correlated with better quality of life.

A regression model was run to see which of the variables described above might predict levels of quality of life. All the variables above which had a significant association with quality of life were included in the model (n= 10 predictors). The overall model was significant (p<0.001) and 51% of the variance in quality of life was explained. The strongest predictor was how often participants asked staff for available allergen information when eating out, with those asking more frequently reporting more impairment to quality of life (standardised beta = 0.29). Other variables related to eating out including frequency of checking information when choosing where to eat out (standardised beta = 0.20) and checking information before ordering (standardised beta = 0.18) significantly predicted impairment to quality of life, with those reporting greater frequency of checking information also reporting more impairment to quality of life.   A higher severity rating also significantly predicted more impairment to quality of life (standardised beta 0.18). However, adult participants who were more comfortable in asking for information reported significantly less impairment to quality of life (standardised beta = -0.19). None of the other predictors were significant (standardised betas ranged from .02 to -0.08 and confidence intervals for each predictor crossed zero).

Quality of life in adults reporting coeliac disease

For the CDQoL scale, subscales comprise of:

- limitations, relating to social and dietary limitations of having coeliac disease
- dysphoria, related to negative feelings of having coeliac disease

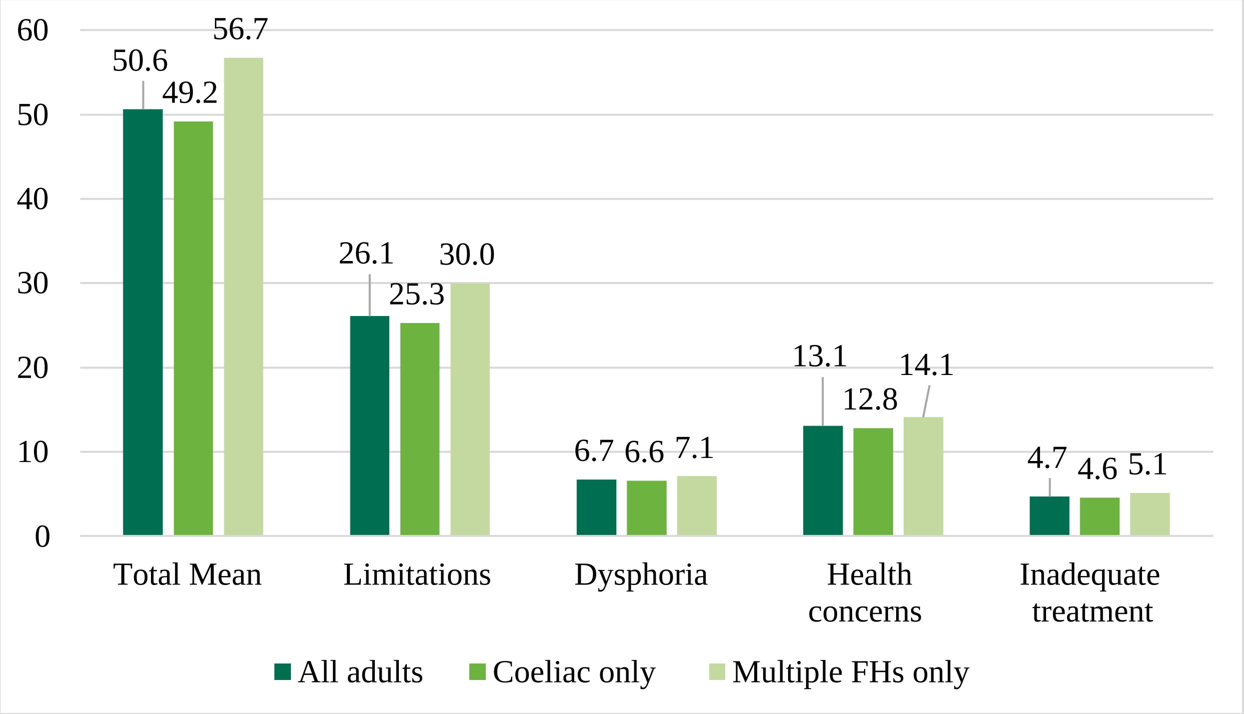
- health Concerns, concerns about the wider impact having coeliac disease will have on health
- inadequate treatment, feelings that there are not enough treatment options for the disease

A total of 209 adults reporting coeliac disease completed the CDQoL, with total scores from 20 (least impact) to 100 (maximal impact).
For adults completing the CDQoL, total scores reflected ‘moderate’ impairment on quality of life (mean = 49.2 out of 100, SD = 18.0). Scores on the subscales were a lot more varied as these subscales had a different range by which they were scored, (for example, Limitations subscale was scored 9 – 45; Dysphoria was scored 4 – 20). However, adults scored around the mean for each of these scales (means = 25.3 for Limitations subscale, scored from 9 (least impairment) – 45 (most impairment); 6.6 for Dysphoria scale scored from 4 (least) -20 (most), 12.8 for Health concerns scored 5 (least) – 25 (most) and 4.6 for Inadequate treatment scale scored from 2 (least impairment) -10 (most impairment)), meaning impairment was ‘moderate’ for those with coeliac disease for all aspects of quality of life.

For those reporting multiple hypersensitivities, 47 completed the CDQoL. Again, these individuals scored within the mean range (40-60), however scores were slightly higher compared to those with just coeliac disease, indicating a slightly higher impact on quality of life for adults with coeliac disease as part of multiple hypersensitivities. See Figure 20 for means.

Significant factors related to impairment to quality of life in adults reporting coeliac disease included the reported severity of participant’s reaction which was significantly associated with impairment to quality of life (r = .20; p =.002), as well as the number of foods reported (r = .22, p =.001). Additionally, how often participants had reacted to their first stated food in the last 12 months was significantly positively correlated with impairment to quality of life (r = .23, p<.001).

Figure 20: Mean CDQoL scores for all adults, adults with coeliac disease only and adults with multiple hypersensitivities



Base: Adults responding to CDQoL (256); Coeliac disease only group (207); Those with food intolerance as part of multiple hypersensitivities (47).

Other factors related to eating out were also significantly correlated with quality of life in adults with coeliac disease. How often participants checked information before choosing where to eat out (r = .18, p = .007), as well as being served a dish containing an allergen that participants may have a reaction to in the last 12 months (r = .36, p <.001) were both significantly correlated with impairment of quality of life. However, how comfortable participants were in asking for information (r = -.36), how confident they were in the written information (r = -.39, p = .02) and verbal information (r = -.39, all ps <.001) provided were all significantly correlated with better quality of life.

A regression model was run to see which of the variables described above might predict level of quality of life. All the variables above (n=8 predictors) which had a significant association with quality of life were included in the model. The overall model was significant (p<0.001) and 42% of the variance in quality of life was explained. How comfortable adult respondents were in asking for available information when eating out was the strongest predictor of impairment to quality of life, with those who felt more comfortable reporting less impairment (standardised beta = -.25). Greater confidence in written information also significantly predicted less impairment to quality of life (standardised beta = -0.18). However, higher frequency of checking available information before choosing where to eat out (standardised beta = 0.17), as well as higher frequency of being offered a dish containing an allergen in the last 12 months (standardised beta = 0.21) both significantly predicted greater impairment to quality of life. Reporting a greater number of foods which could cause an adverse reaction also significantly predicted poorer QoL for coeliac respondents (standardised beta 0.19). None of the other predictors were significant (standardised betas ranged from -.08 to 0.11 and confidence intervals for each predictor crossed zero).

Differences in Quality of Life by hypersensitivity

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

Food allergy only

Of the food allergy only group, 296 adults completed the FAQLQ. Subsample sizes were not equal for comparisons to be made by gender (males 63, females 201).

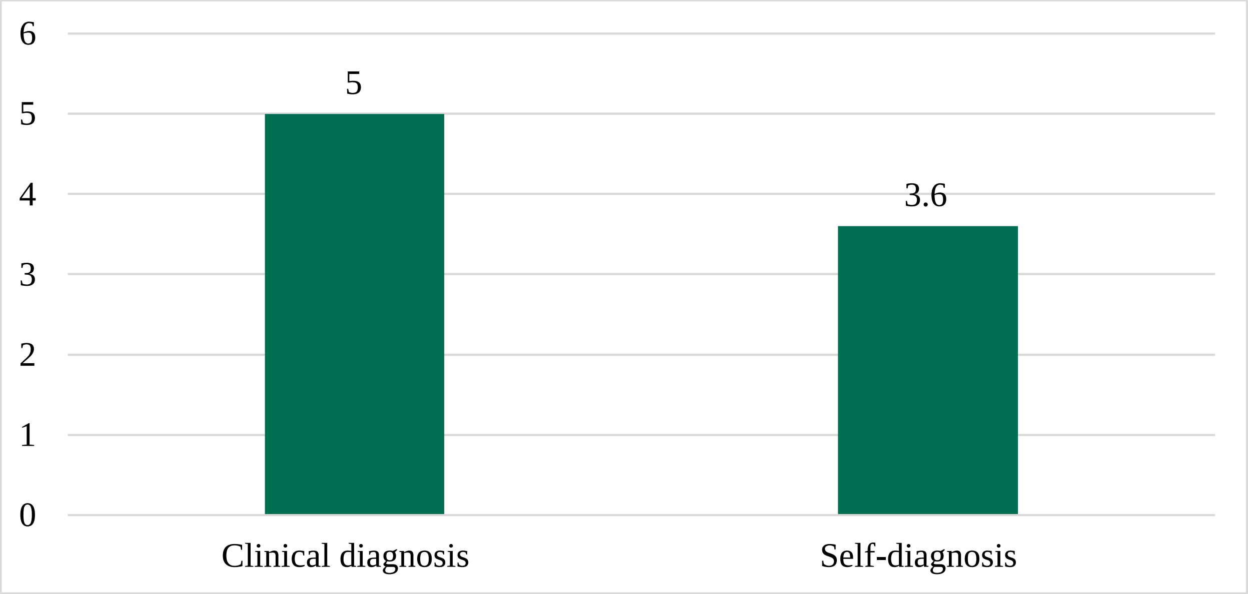
Clinical diagnosis

There was a significant difference in impairment to quality of life in those reporting a clinical diagnosis (n = 187) and those reporting a self-diagnosis (n = 65), t(97.4) = 6.04, p <.001. Those with a clinical diagnosis (mean = 5.0, SD = 1.4) reported more impairment to quality of life than those with a self-diagnosis (mean = 3.6, SD = 1.7; Figure 21).

Number of foods

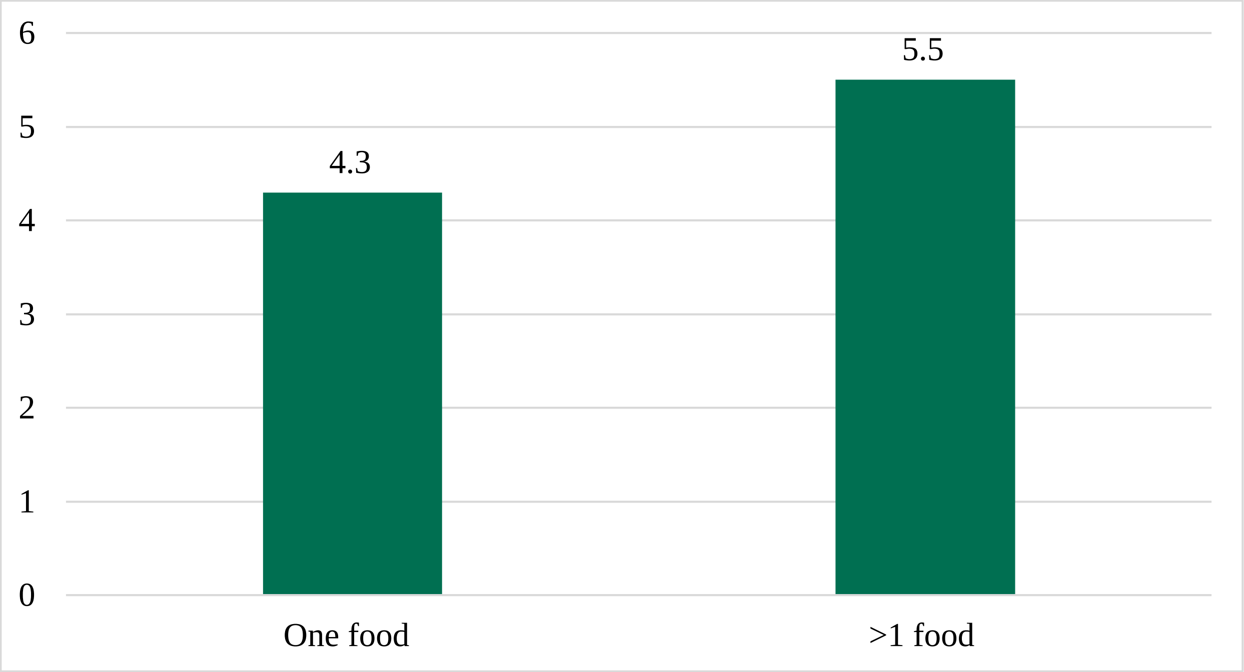
To be able to assess meaningful differences by number of foods reported by participants, respondents were recoded into those who reported just one food (n = 178) and those reporting two or three foods (n = 88). There was a significant difference between those reporting adverse reactions to only one food, and those reporting reactions to more than one food, F(1) = 43.1, p <.001, ?p^2 = .14. The means indicated that those reporting more than one food (mean = 5.5, SD 1.1) had higher impairment to their quality of life, than those reporting just one food (mean = 4.3, SD = 1.6; Figure 22).

Figure 21: Mean quality of life scores across diagnosis type



Base: All adults with food allergy reporting diagnosis type (252): Clinical diagnosis (187); Self-diagnosis (65).

Figure 22: Mean quality of life scores across numbers of foods for allergy group

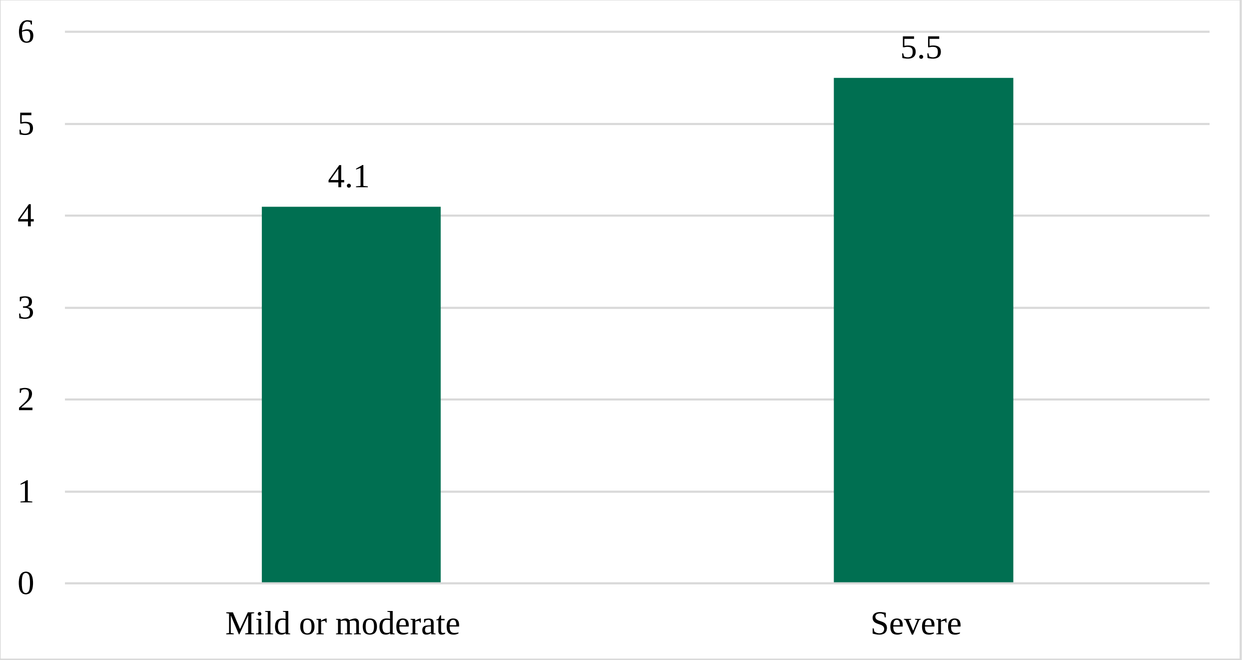


Base: Adults with allergy reporting number of foods (266): One food (178); Two or three foods (88); line with *** indicates significance; *** p <.001.

Severity

As the numbers of those experiencing a mild reaction was too small, categories were also recoded for severity, to make meaningful comparison between those with a mild or moderate reaction (n = 153) and those with a severe reaction (n = 113). There were significant differences in impairment to quality of life by the severity of reaction for those with food allergy, F(1) = 55.3, p <.001, ?p² = .17. Those reporting a mild or moderate reaction to their first food (mean = 4.1, SD = 1.6) reported significantly less impairment to quality of life than those reporting a severe reaction, (mean = 5.5, SD = 1.2; Figure 23).

Figure 23: Mean quality of life scores by severity of reaction for allergy group



Base: Adults with allergy reporting severity of reaction (266): Mild or moderate (153); Severe (113); *** p <.001.

Food intolerance only

Of the food intolerance only group, 297 adults completed the FIQLQ.

Gender

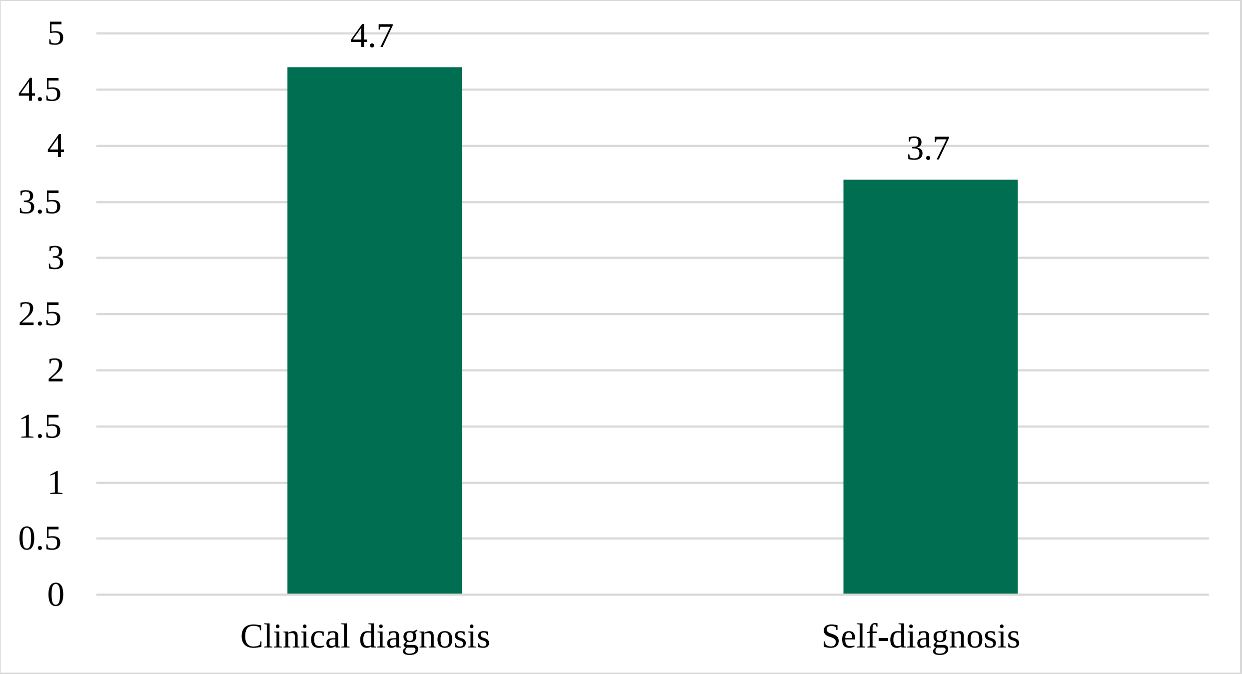
Of those with food intolerance and who completed the FIQLQ, 70 were men, 213 were women. As these groups were not equal sizes, results should be taken with caution.

There were no significant differences between men (mean = 4.1, SD = 1.5) and women (mean = 4.2, SD = 1.7) in impairment to their quality of life from food intolerance, F(1) = 0.11, p = 7.4, ?p² = .00.

Clinical diagnosis

Of the adults reporting food intolerance, the quality of life of those with a clinical diagnosis (mean = 4.7, SD = 1.5) was significantly more impaired than those who reported self-diagnosis (mean = 3.7, SD = 1.7), t(246.3) = 4.96, p <.001 (Figure 24).

Figure 24: Mean quality of life scores by diagnosis for food intolerance group



Base: Adults with intolerance reporting diagnosis type (265): Clinically diagnosed (108); Self-diagnosed (157); *** p <.001

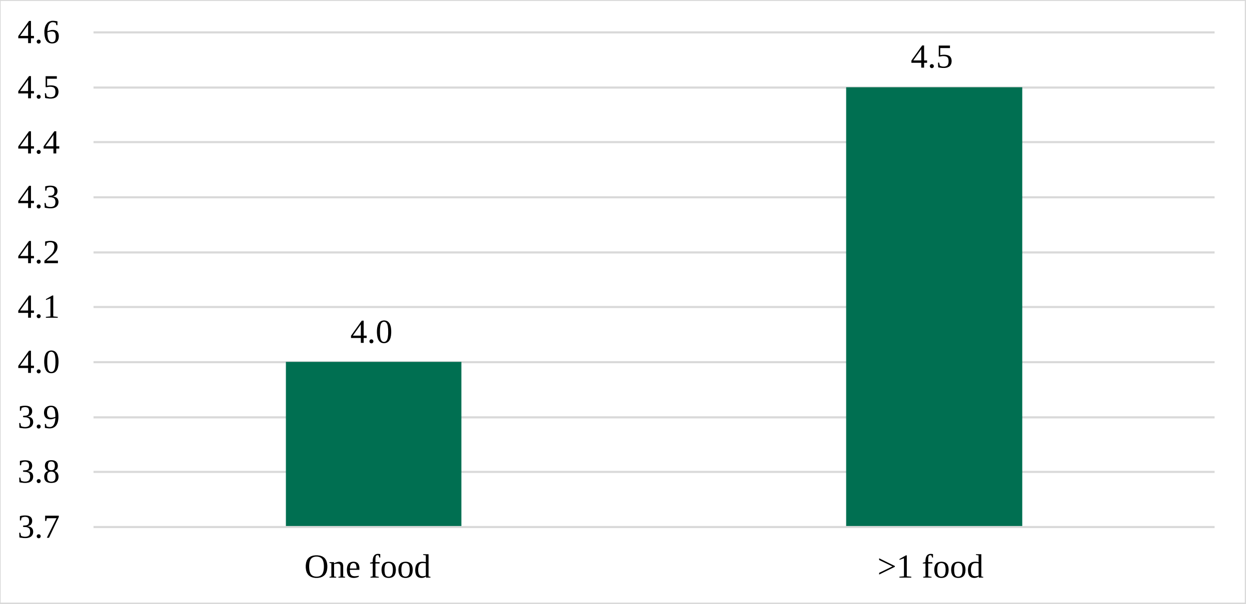
Number of foods

Those reporting one food (n = 213, mean = 4.0, SD = 1.7) had significantly less impairment to quality of life compared to those reporting more than one food (n = 69, mean = 4.5, SD = 1.4), F(1) = 4.50, p = .04, ?p^2 = .02. However, groups were very unequal and so caution should be taken when interpreting these results (Figure 25).

Severity

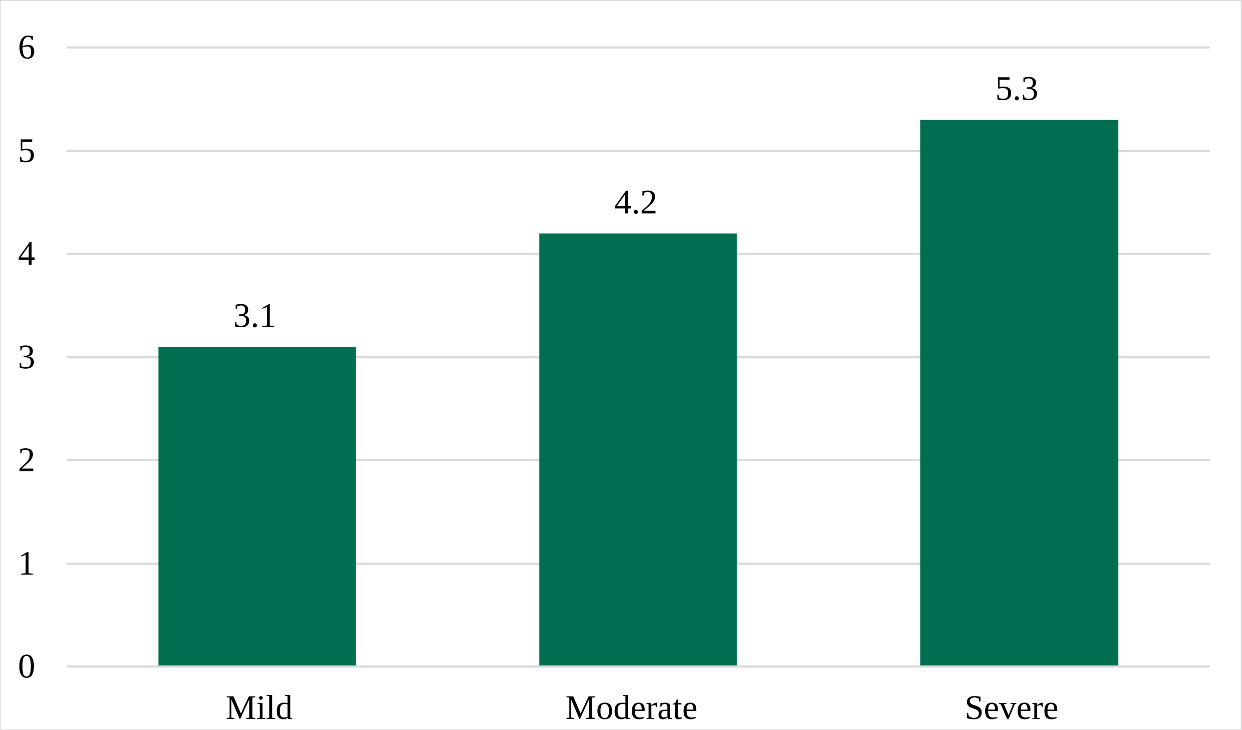
There were significant differences in quality of life according to severity of reaction to the first food amongst food intolerant participants, F(2) = 28.9, p <.001, ?p^2 = .17. Those with self-reported mild reactions had significantly better QoL (n = 65; mean = 3.1, SD = 1.5) than those with moderate reactions (n = 165; mean = 4.2, SD= 1.6), t(228) = -4.63, p <.001. Those with mild reactions also had significantly better QoL than those with severe reactions (n = 53; mean = 5.3, SD = 1.3), t(116) = -8.00, p <.001 and those with moderate reactions had significantly better QoL than those with severe reactions, t(104.1) = -4.91, p <.001 (Figure 26). However, comparisons including moderate severity should be taken with caution as this group was much larger than the other groups and so differences could be inflated.

Figure 25: Mean quality of life scores across number or foods for adults with intolerance



Base: All adults with food intolerance reporting number of foods (283): One food (213); One or more foods (69); * p <.05.

Figure 26: Mean quality of life scores by severity of reaction, in food intolerant adults



Base: Adults with food intolerance reporting severity of reaction (283): Mild (65); Moderate (165); Severe (53); *** p <.001.

Coeliac disease only

For those in the coeliac group, 207 completed the CDQoL. It was not possible to make comparisons for diagnosis or by number of foods reported as the subsample sizes were too small.

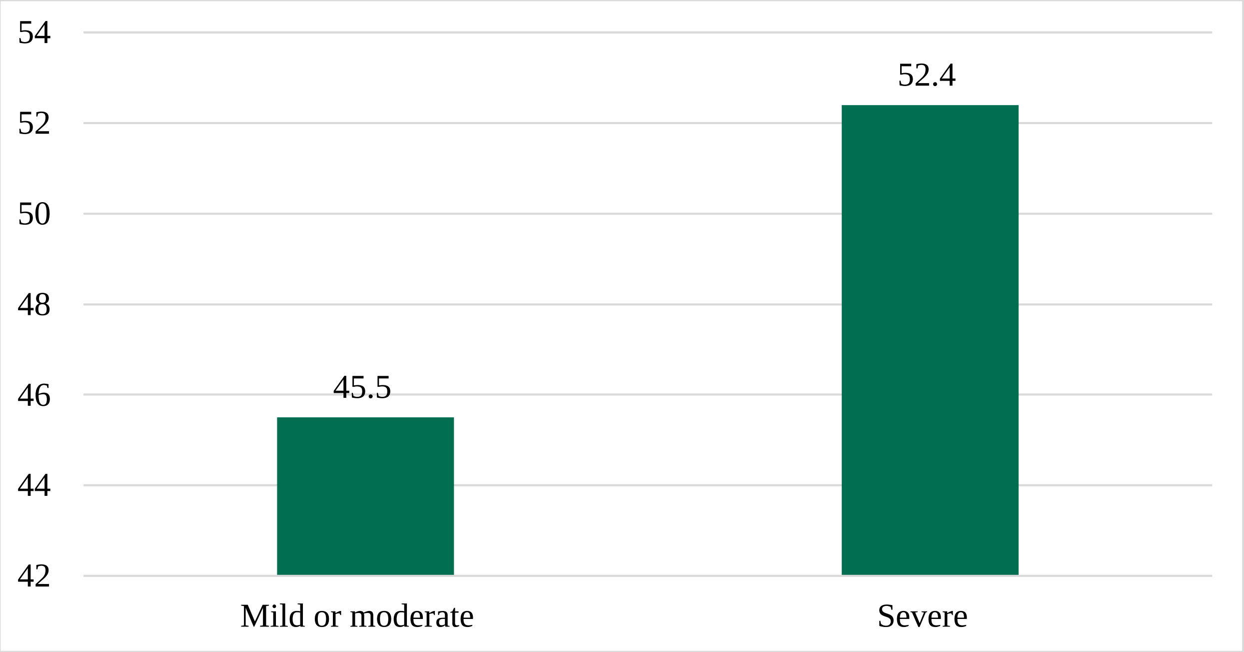
Gender

For gender, the number of men was 38 and the number of women was 159, 1 person classed themselves as ‘Other’, however as no significant differences would be detected this person was excluded from this analysis (gender only). There was no significant difference in QoL between genders, t(195) = -1.85, p = .07, with women (mean = 50.2, SD = 18.0) reporting similar impairment to quality of life as men (mean = 44.3, SD = 17.1).

Severity

Numbers were recoded to account for the small numbers of those experiencing a mild reaction and so comparisons were made for those experiencing a mild or moderate reaction (n = 91) and those experiencing a severe reaction (n = 105). There were significant differences in impairment on quality of life according to severity, t(192.9) = -2.76, p = .006. Those reporting severe reactions (mean = 52.4, SD = 19.4) had significantly more impaired quality of life than those with a mild or moderate reaction (mean = 45.5, SD = 15.5; Figure 27).

Figure 27: Mean quality of life scores by severity of reactions for adults with coeliac disease



Base: Adults with coeliac disease reporting severity of reaction (196): Mild or moderate (91); Severe (105); ** p <.01.

Multiple hypersensitivities

For those with multiple hypersensitivities, 49 completed the FAQLQ, 28 completed the FIQLQ and 47 completed the CDQoL. Comparisons for those with multiple hypersensitivities could not be made as sample sizes were too small to allow for accurate comparisons.

Generic quality of life

All adults completed the EQ-5D-5L which measures generic quality of life. On the visual analogue scale (0-100 with 0= death and 100= full health) those with coeliac disease reported a higher mean score (n= 209, mean = 77.4, SD = 17.7) than those with food allergy (n= 301, mean = 70.5, SD = 21.8), food intolerance (n= 296, mean = 69.0, SD = 19.8), or multiple hypersensitivities (n = 123, mean = 68.6, SD = 21.8) who all reported scores which were noticeably lower. This pattern across FHs was similar for the EQ-5D overall mean score (mean coeliac = 0.82; allergy = 0.80;

intolerance = 0.74).

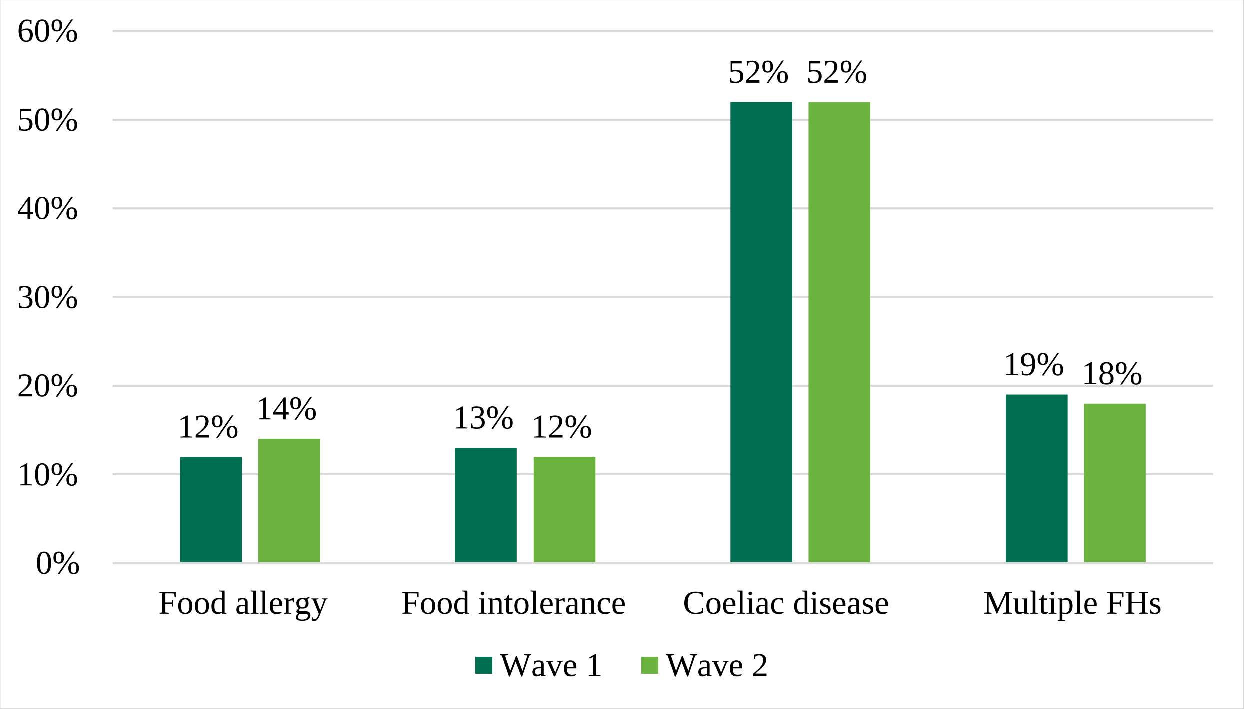
Distributions of scores on the EQ-5D-5L sub-domains were examined against known values for the UK population. Pearson's chi-squared tests indicate that the distributions of scores were different at the 1% level for Mobility (?_4^2= 16.64, Pr = 0.002), Selfcare (?_4^2 = 40.39 , Pr = 0.000), Usual Activities (?_4^2 = 48.41, Pr = 0.000), Pain (?_4^2= 71.40, Pr = 0.000) and Anxiety (?_4^2 = 219.02, Pr = 0.000). Inspection of the data suggest that the adults with FH report significantly lower proportions of those reporting the ‘best’ quality of life and a significantly higher proportion of those reporting moderate impact to quality of life on every dimension, compared to the UK population.

Comparisons between Wave 1 and Wave 2

Where appropriate analyses was also carried out to compare those participants who took part in wave 1 (in 2020) and this wave 2 survey, to see if their eating out behaviours and quality of life had changed over the course of a year. A total of 313 adults completed both time points (see Table 27 for details of each sample).

Across both waves, the majority of adults reported having coeliac disease (52%) and then multiple hypersensitivities, food allergy and food intolerance (see Figure 28). At Wave 1, 3% (n = 10) and at Wave 2, 4% (n = 13) 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 adults reported coeliac disease reactions (n = 409, 44%) which may explain why the proportion of those with coeliac taking part at both time points is skewed (higher).

Figure 28: Percentage of adults completing Wave 1 and Wave 2 in each hypersensitivity group



Base: All adults completing both Waves with hypersensitivities: Food allergy (Wave 1: 38; Wave 2: 44); Food intolerance (Wave 1: 40; Wave 2: 38); Coeliac disease (Wave 1: 164; Wave 2:162); Multiple hypersensitivities (Wave 1: 61; Wave 2: 56)

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 no significant differences in how frequently participants at wave 1 (mean = 3.0, SD = 1.3) ate out, compared to at wave 2 (mean = 3.0, SD = 1.3) with participants reporting that on average they eat out around once a month at each time point, t(294) = 1.23, p = .22.

Additionally, there was no significant differences for how frequently adults checked available information when choosing where to eat out between wave 1 (mean = 4.5, SD = 1.1) and wave 2 (mean = 4.5, SD = 1.0) and before ordering between wave 1 (mean = 4.7, SD = 0.8) and wave 2 (mean = 4.7, SD = 0.8; both ps >.05), on average checking this 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 = 4.4, SD = 1.1) and wave 2 (mean = 4.4, SD = 1.1, p = .77) with participants reporting that they check this most of the time or always.

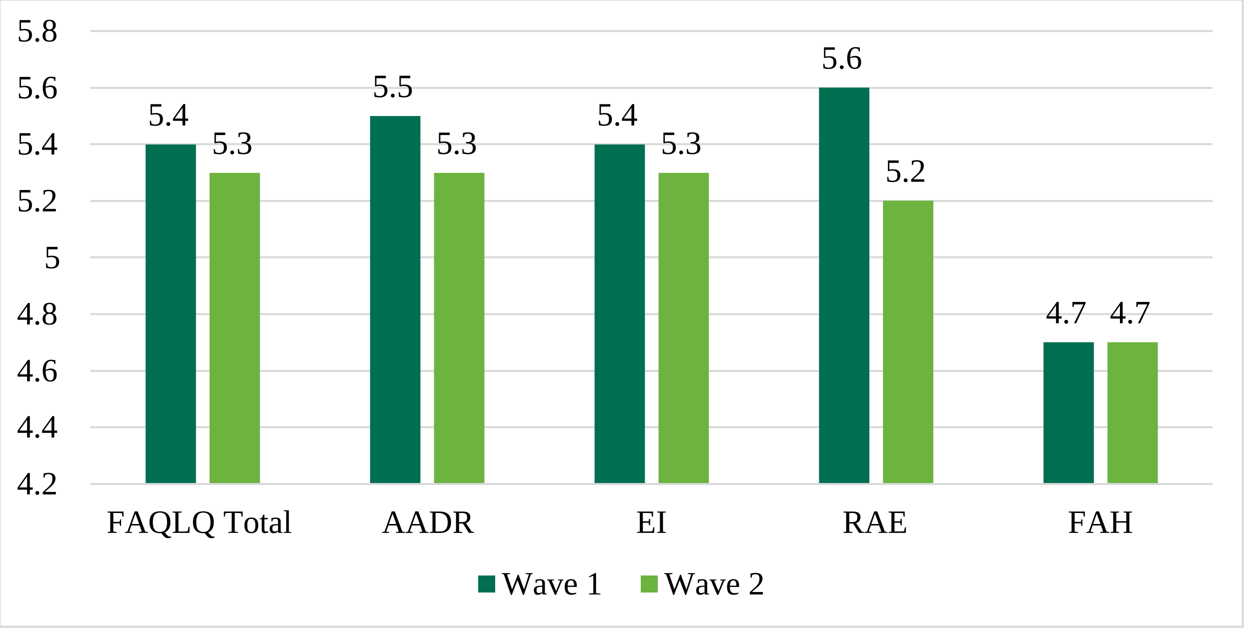
There were also no significant differences how comfortable adults were in asking for information when eating out at wave 1 (mean = 3.1, SD = 0.9) and wave 2 (mean = 3.1, SD = 0.9). There were also no significant differences in how confident adults were in verbal written, reporting they were not very or fairly confident at wave 1 (mean = 2.6, SD = 0.8) and wave 2 (mean = 2.6, SD = 0.8). However, adults at wave 1 reported being significantly more confident in written information (mean = 2.9, SD = 0.7) than at wave 2 (mean = 2.7, SD = 0.7), t(202) = 2.83, p =.01.

Quality of life

Comparisons for each of the food hypersensitive specific quality of life measures (FAQLQ, FIQLQ and CDQoL) were made, to compare participants quality of life in wave 1 with reported quality of life in wave 2. Participants who completed measures at each wave for their first food reported were included in the analysis.

Adults completing the FAQLQ (n = 35) at wave 1 (mean = 5.4, SD = 1.3) did not report significantly different impairment to quality of life than at wave 2 (mean = 5.3, SD = 1.4). There were also no significant differences reported across the subscales (see Figure 28 for means; all ps >.05). Adults with allergy reported higher than the mean impairment to quality of life (4 out of 7 indicating moderate impairment), often reporting instead that impairment to quality of life was ‘quite a bit’ (over 5 out of 7; Figure 29).

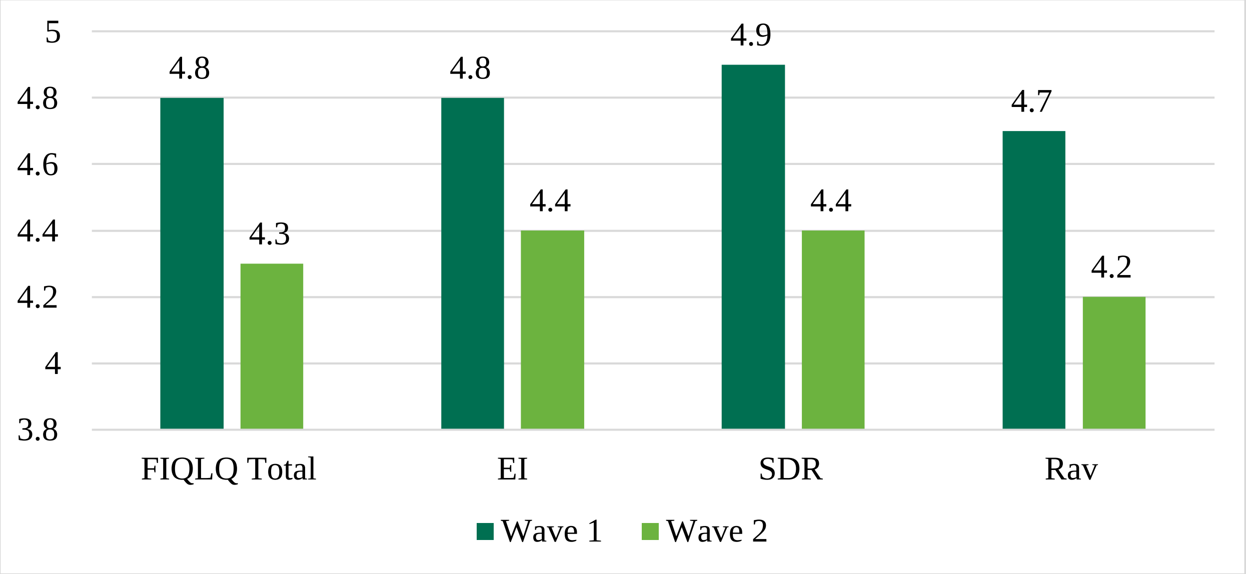
Figure 29: Mean quality of life scores for adults with allergy completing wave 1 and wave 2



Base: Adults completing the FAQLQ at wave 1 and wave 2 (35).

There were however significant differences for adults completing the FIQLQ (n = 31). Adults at wave 1 (mean = 4.8, SD = 1.2) reported significantly more impact on their total quality of life than those at wave 2 (mean = 4.3, SD = 1.9), t(29)= 3.87, p =.001, indicating moderate to 'quite a bit' of impairment. There were also significant differences across subscales (see Figure 30 for means; all ps <.01), with participants reporting significantly more impairment to quality of life at wave 1 because of the worries and concerns of having food intolerance, the dietary and social limitations and having to check foods to avoid a reaction, indicating 'quite a bit' of impairment.

Figure 30: Mean quality of life scores for adults with intolerance completing wave 1 and wave 2

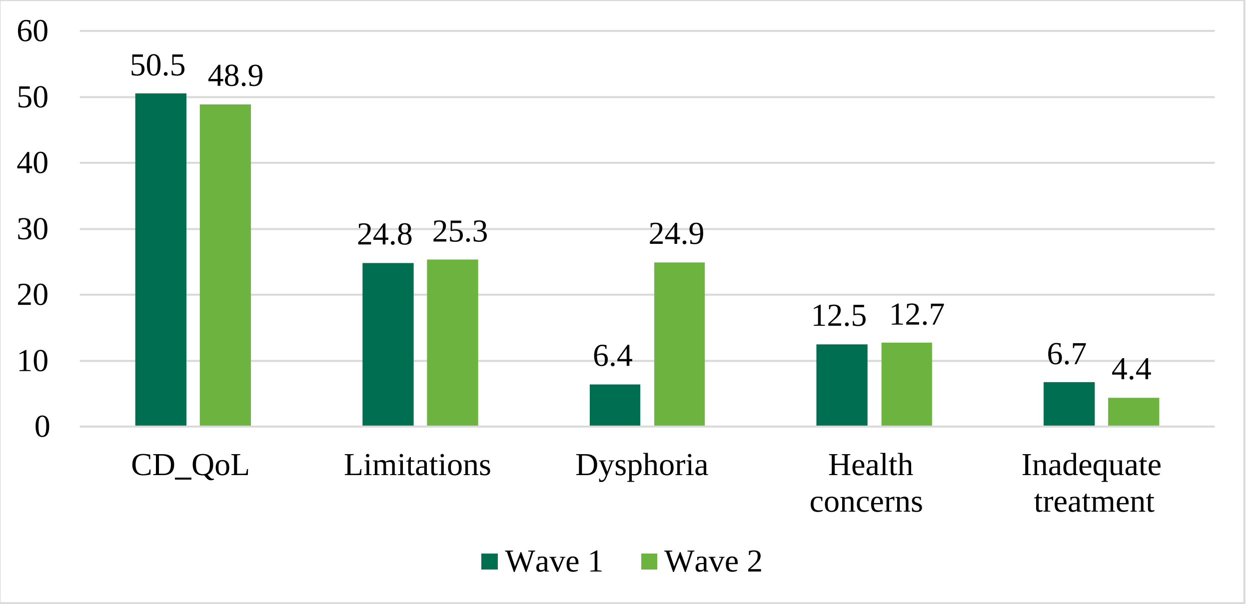


Base: Adults completing the FIQLQ and wave 1 and wave 2 (31).

For those with coeliac disease (n = 182), there were also significant differences across waves for those completing the CDQoL. Those at wave 1 (mean = 50.5, SD = 16.7) reported significantly more impairment to quality of life than at wave 2 (mean = 48.9, SD = 17.7), indicating moderate impairment (mean impairment = 50), t(159) = 2.24, p = .03. There were also significant differences on the dysphoria, t(173) = -30.5, p < .001 and inadequate treatment t(181) = 11.5, p <.001 subscales between the waves (see Figure 31 for means).

While there was an improvement to hypersensitivity specific quality of life at wave 2 for those with food intolerance and coeliac disease across the two waves, for comparisons between wave 1 and wave 2 for general quality of life (EQ5D), there was an overall decline in VAS scores, between wave 1 (mean = 73.8, SD = 19.1) and wave 2 (mean = 71.0, SD = 20.8). Further, across the different sub-domains, participants from the wave 2 sample reported poorer overall quality of life, with higher proportions reporting moderate impact to quality of life (for example, I have 'slight' or 'moderate' problems…), compared to those in the wave 1 sample. The largest differences were observed for the mobility (for example, 11% at wave 2 vs 6% at wave 1 reporting that they have moderate problems walking around), self-care (6% at wave vs 3% at wave 1 with moderate problems looking after themselves) and usual activities subdomains (12% at wave 2 vs 8% at wave 1 with moderate problems doing their usual activities).

Figure 31: Mean quality of life scores for adults with coeliac disease completing wave 1 and wave 2



Base: Adults completing the CDQoL at wave 1 and wave 2 (182).

1. 'Other' support groups included groups on social media (such as Facebook support groups; Mast Cell Action groups; Mastocytosis UK; IBS Network, Asthma UK; Crohn's and Colitis UK and other doctor-patient support groups).

2. Significance testing was completed only for first foods reported as sample sizes were too small to enable comparisons for second and third foods.

3. Significance testing was completed only for first foods reported as sample sizes were too small to enable comparisons for second and third foods.

4. Anaphylaxis was defined to respondents as 'You might have had an anaphylactic reaction if you had breathing difficulties and/or a drop in blood pressure quite suddenly after eating food. You may also have had a rash or stomach symptoms such as vomiting at the same time'

5. More information on the scales can be found in the methods