Food Sensitive Study: Conclusions

This survey was completed by over 2,000 people with FH from all regions of the UK. Similar to wave 1, a wide variety of foods were reported as causing an unpleasant reaction which included the 14 allergens which are required by law to be listed as ingredients, with foods containing gluten, milk, tree nuts and peanuts reported most often. Similarly, participants reported a range of symptoms, from gastrointestinal, skin reactions, breathing difficulties, swelling and anaphylaxis. Participants with clinically diagnosed as well as self-diagnosed FHs answered a range of questions about their reactions to food, including their behaviour when eating out and their quality of life.

Eating out

Participants were asked to report how often they ate out and how comfortable they were with various aspects of this activity, such as asking staff for information because of a concern about experiencing an adverse or unpleasant physical reaction. The findings from wave 2 are very similar to wave 1. Across adults, parents and children, the majority reported that they check or review information at each stage of eating out (such as before choosing where to eat, and before ordering) to enable them to identify foods that may cause an unpleasant reaction, with some differences across types of food hypersensitivity. Similar proportions (over 50%) of adults, children with FH and parents of children with FH reported they felt comfortable asking a member of staff for information because of a concern about experiencing an unpleasant physical reaction and were confident in written information provided about allergens. This is encouraging data for children who need to learn to manage their FH as they grow older and become more independent of their parents.

Despite feeling comfortable asking staff about FH concerns, adults and parents reported being more confident in written information provided by staff when eating out, compared to information provided verbally. However for those adults who completed both waves, confidence in written information was less in wave 2 compared to wave 1. It is unclear why this difference might be. Legislation for pre-packed food for direct sale came into law in October 2021 when the second survey was launched, meaning that full ingredient labelling was needed, but this may not have had much impact on consumers in the short time the surveys were live. The worldwide Covid pandemic and the UK leaving the EU disrupted supply chains and substitutions to foods may have increased the use of precautionary allergen labelling, which may have contributed to this. Around a fifth of parent and child respondents and a third of adult respondents reported previously being refused service or having been asked to sign a disclaimer. It may therefore be important to investigate the ability and confidence in waiting staff in restaurants to provide suitable information for people with FH.

There were no other differences in eating out between wave 1 and wave 2 apart from an increase in the frequency with which parents reported eating out. This is unsurprising given the lifting of many Covid-19 restrictions between the times wave 1 and wave 2 data were collected.

Quality of life

Participants were asked to complete a health-related quality of life scale appropriate to the type of self-reported FH they reported for their first food and a generic health related quality of life scale. All participants reported that their FH or their child's FH impacted their lives by 'quite a bit' or 'very much'. A number of clinical factors were related to quality of life. In particular, markers of FH severity were related to poorer quality of life across many of the groups, such as having another atopic condition (for example, asthma or eczema), being prescribed an adrenaline auto-injector, having experienced anaphylaxis, being admitted to hospital, the number of foods they react to and self-reported severity.

Self-reported or parental reported severity of FH for teens was related to the level of quality of life as measured by the FH specific validated QoL scales. In the regression models severity also significantly predicted QoL for adults with food allergy or intolerance and for teens with food allergy. The relationship between self-reported severity and QoL ratings is similar to that found in wave 1 and has been reported in previous studies in parents of children with peanut allergy (Acaster et al., 2020a, 2020b). Asking about severity may be a good indicator of the impact of FH , particularly for food allergy, which can be completed very quickly by individuals and families. FH specific QoL was also related to eating out activities in meaningful ways. Being able to eat out more frequently was related to better FH specific QoL. Being more comfortable asking staff for information about food, and higher confidence in the verbal or written information provided about food when eating out, were also related to better FH specific quality of life. However, a greater frequency with which participants had to check information at various stages of eating out was related to poorer FH specific QoL. As noted in the report for wave 1, checking behaviour may create a greater burden on the individual or parent, which has an impact on QoL.

In regression models for adults, more frequent checking of information when eating out and frequency of asking staff for information significantly predicted poorer QoL. Similarly for 8-12 year olds more frequent checking of information when eating out significantly predicted poorer QoL (see Table 75 in the Annex for a summary of the significant predictors found for the regression models). For many of the parent and child models, a good proportion of variance in quality of life was explained, but few or no individual predictors were significant. As noted for the results from wave 1, this may be due to multicollinearity in the data, with predictor variables correlating with each other. Further analysis should take this into account and control for the variance explained by clinical variables before entering variables related to eating out and reading of labels.

Adults, parents of children and children themselves with food allergy reported better generic quality of life than those with food intolerance or coeliac disease and those with multiple FHs often scored poorest. This was also reported in wave 1 and requires further investigation to see whether the people with different FHs require different types or level of support to help improve their QoL. For adults, generic quality of life was reportedly worse than UK norms and for all groups generic quality of life related to pain, anxiety and depression was reportedly worse than other sub-domains such as usual activities, mobility or self-care. This is similar to the wave 1 findings and also needs further investigation. Those who completed the surveys at both time points, reported generic QoL was significantly worse at wave 2 compared to wave 1, however, adults with food intolerance or coeliac disease reported significantly poorer FH specific QoL in wave 1 compared to wave 2. Further analysis of the data comparing the whole of cohort 1 and cohort 2 could provide reasons for this, such as differences in clinical factors or severity for these participants. For all groups who completed the surveys at both time points, reported generic QoL was significantly worse at wave 2 compared to wave 1. As this is generic QoL, this reduction could be due to factors beyond FH, such as the continued impact of Covid and the restrictions this has brought to day-to-day living.

Limitations

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

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

Some groups reported symptoms that would not be expected. For example, a small number with self-reported coeliac disease or food intolerance reported anaphylaxis (as was found in wave 1). A definition of anaphylaxis was given to participants and so confusion as to what the term meant may not be the cause of this. It is possible that some participants had undiagnosed food allergy which caused an anaphylactic reaction, but it is unlikely that such a severe reaction would have gone undiagnosed. It may also be the case that these participants misinterpreted their condition and had a food allergy. Misunderstanding of the different FHs and erroneous self-diagnosis is common (Knibb, 2019).

Covid-19 restrictions were different in wave 1 compared to wave 2, with stricter restrictions during wave 1. This might have had an impact on experiences such as eating out. The change in restrictions across the year should also been considered when examining the results.