

## Qualitative research: interview findings

Online interviews were completed with 22 people living with FHS (or their carers) to inform the development of the survey questions. Interviews allowed the study team to discuss consumption habits and adjustments made due to FHS in detail and resulted in the identification of common areas of the financial burden for people living with FHS. The interviews were then analysed, and the findings are grouped thematically in the subsections below (the topic guide is available in Appendix 3).

### 4.1 Main findings from the online interviews

#### 4.1.1 Preparing food

Ownership of personal utensils and other separate kitchen equipment were mentioned by interviewees as essential for preparing food and avoiding cross-contamination, and that these needed to be replaced regularly. One interviewee said they carry their own set of cutlery when eating outside the home. Another said they spend considerable time on cooking everything from scratch because processed food products contain more ingredients and are riskier. Another interviewee said they must cook separately from their family, buy substitutes, and spend time adjusting recipes to ensure meals are safe to eat.

#### 4.1.2 Reading food labels

People living with FHS (or their carers) were asked about their normal shopping habits and the time spent on grocery shopping. These questions prompted interviewees to describe their shopping routine and a few mentioned reading food labels as a particularly time-consuming activity that increases the time spent on food shopping. One person said they can spend up to two hours at a grocery shop just checking labels. Another said it takes up to three hours to do a grocery shop because half of that time is spent reading labels.

Two interviewees said they must visit multiple stores to buy their preferred allergen-free products. Another said they prefer to shop at one supermarket chain but visit another chain to purchase bread (this person avoids another large supermarket chain due to perceived poor labelling). One interviewee said they shop online because it takes less time, while another interviewee avoids online shopping because food labels can be inaccurate/ incomplete. Food purchased online is at higher risk of being wasted than food purchased in store as its safety can only be checked on delivery.

Three interviewees said they were concerned about labelling legislation and 'that it does not go far enough'. They highlighted the limitations of the 14 main allergens for mandatory labelling. Labels for allergens outside this list (eg chickpeas, pea) can be poor and dog food (transferred by touch) can cause allergic reactions as these products do not have to comply with mandatory allergen labelling. One interviewee expressed concern about the impact of the UK exiting the EU on allergen labelling and food safety.

A reoccurring theme was the constant change in product ingredients. People living with FHS cannot repeat buy 'safe' processed products without checking the labels first. One interviewee provided an example of a leading brand of sunflower spread that was previously safe but changed the formula to include their child's allergen.

### 4.1.3 Takeaway

Two interviewees said they do not order takeaways because they do not trust food business operator staff to manage allergen exposure. Another interviewee avoided takeaways after needing to attend A&E, following food contamination with an allergen.

### 4.1.4 Holidays

Most interviewees reported that holidays were a major source of concern and stress, especially those with children with FHS. This topic was raised unprompted by most interviewees. They emphasised the additional financial cost and lost time, as well as the anxiety involved.

Flying is a concern for individuals who are at risk of a severe reaction. One interviewee said they do not fly, because they cannot risk a fellow passenger opening a bag of nuts. Another interviewee said the risk of anaphylaxis co-factors when flying is too high and so they avoid it. One interviewee explained the difficulties in getting airlines to make allergen warning announcements on board. The burden falls on the person living with FHS to repeatedly ask for the announcement and negotiate with the cabin crew.

Three interviewees prefer self-catering holidays so they have more control of food preparation, but this can be more expensive than holiday packages with fully inclusive food options while another participant said they avoid hotel buffets. Some opt for large hotel chains because they perceived them to be safer and more accountable. One person said they take food from home and do not eat out on holiday.

A few interviewees said they spend a lot of time researching the destination to assess food safety before travel. Interviewees said they research allergen policies and hotel protocols, local hospital provision, and suitable catering options. Two interviewees said they have decided not to travel after completing research due to uncertainty and risks. Language barriers were also a concern for those travelling with FHS. One interviewee shared their experience of explaining their allergies to the hotel staff and being served food containing allergens anyway.

## 4.2 Implications for the study from the interviews

**Table 4.1: Implications from the qualitative findings (interviews) for people living with FHS**

Findings	Implications
Preparing food	Cooking and food preparation are the most common sources of higher costs. We found that interviewees often buy new, separate kitchen equipment to avoid cross-contamination (for example, through utensils or chopping boards). The purchasing of separate food preparation equipment is another direct cost that needs to be accounted for in the study. <b>Question added to the survey: Do you need to use any special or additional equipment for cooking and preparing food?</b>
Reading food labels	Interviews highlighted indirect costs associated with time lost reading food labels, due to the ambiguity of labelling practices, unclear ingredient labelling, and limited availability of products with sufficient allergen information provided. The time spent on reading labels in the supermarket is considerable. Poor labelling online can increase the financial burden if products need to be thrown away after they are delivered. The experiences described by the participants in the interviews provided a rationale for a decision to include labelling in the survey and monetise the indirect costs incurred. <b>Question added to the survey: On top of the time spent shopping, how much time do you estimate that you spend planning your food shop and checking/reading labels per week?</b>

Findings	Implications
Takeaway	While the direct costs of eating out were captured in the draft survey design, takeaways were not included. During the interviews, some participants mentioned takeaways when discussing eating out. Therefore, a decision was made to combine 'eating out' and 'takeaways' into one topic. <b>Question expanded in the survey: Takeaways added to the topic of eating out .</b>
Holidays	The interviews highlighted the challenges of booking a safe holiday, particularly foreign holidays, and parents of children with FHS. They face more limited choices when choosing a destination, accommodation, and catering options. Although holidays are not essential, the time spent on researching and preparing for a holiday and choosing not to travel if it is not safe, has a detrimental impact on people living with FHS and their families. Some interviewees said it is more expensive to choose safer options, such as self-catering and overland travel to avoid flying. Higher food costs can be incurred on holidays. These findings informed our decision to include a question around the topic of holidays in our survey to capture this experience. <b>Question added to the survey: How does the food hypersensitivity impact holidays and trips away?</b>

In addition to the inclusions set out in Table 4.1 above, other considerations emerged from the qualitative research which were captured by the survey:

- household size: the decision was made to ask about household size for household shopping costs in the survey to enable more accurate cost analysis
- highest level of education: a question was added on the highest level of education as a socioeconomic indicator to enable more accurate cost analysis.