Other FHS household survey findings

8.1 Overview

In this chapter we present findings from the FHS household survey on direct and indirect costs, including the impacts on:

- food shopping habits
- eating out and takeaway habits
- overnight stays and holidays
- one-off costs around the time of diagnosis
- other findings including public attitudes towards FHS, mental health impact, impact on other people, and GF food on prescription withdrawal.

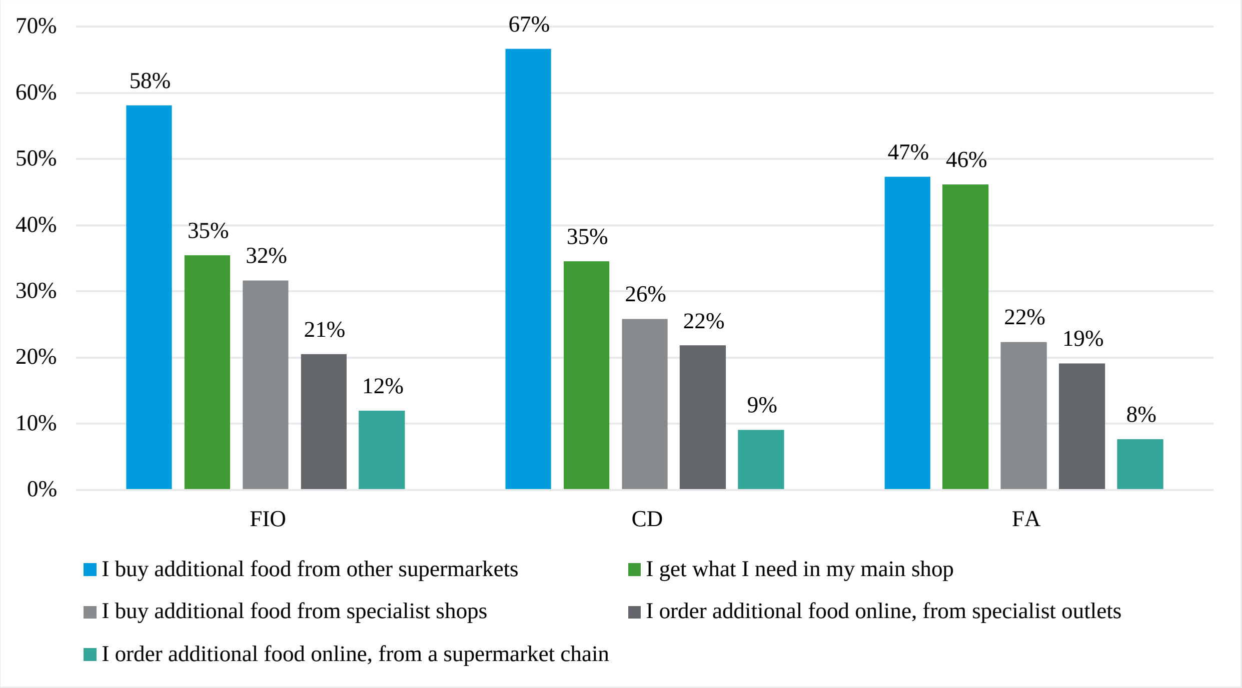
Note that for certain graphs, the percentage figures may add up to 101% or 99% rather than 100% due to rounding up / down of the percentage figures.

8.2 Impact on food shopping habits

FHS households were asked where they normally shop for food and 1,223 people provided their response. The majority (90%, n=1,105) said they visit a large supermarket chain. These responses were consistent across the three FHS cohorts. Out of 1,223 responses, only 8% of respondents said (n=91) that they regularly purchase their main food shop online, while just 2% (n=27) expressed a preference for other outlets (such as a specialist or independent stores).

FHS households were also asked whether they need to purchase additional products for people living with FHS from other shops and respondents could select more than one option. Most commonly, respondents said they purchase allergen free food items from a different supermarket (see Figure 8.1 below). These findings suggest that FHS customers are not able to purchase all their supplies in one single supermarket.

Figure 8.1: Additional shops to buy food (based on 100% of the sample used in the analysis, n=1,225) in England, Northern Ireland, and Wales according to an FHS household survey conducted online between November 2020 and January 2021.



We asked people living with FHS whether their food shopping habits had changed due to the Covid-19 pandemic. Out of 1,021 responses, 82% of FHS households (n=842) said their habits have changed and 33% (n=334) said they had started purchasing food online. Some respondents felt safer ordering food online, to limit the time spent reading labels in store and reduce the handling of products.

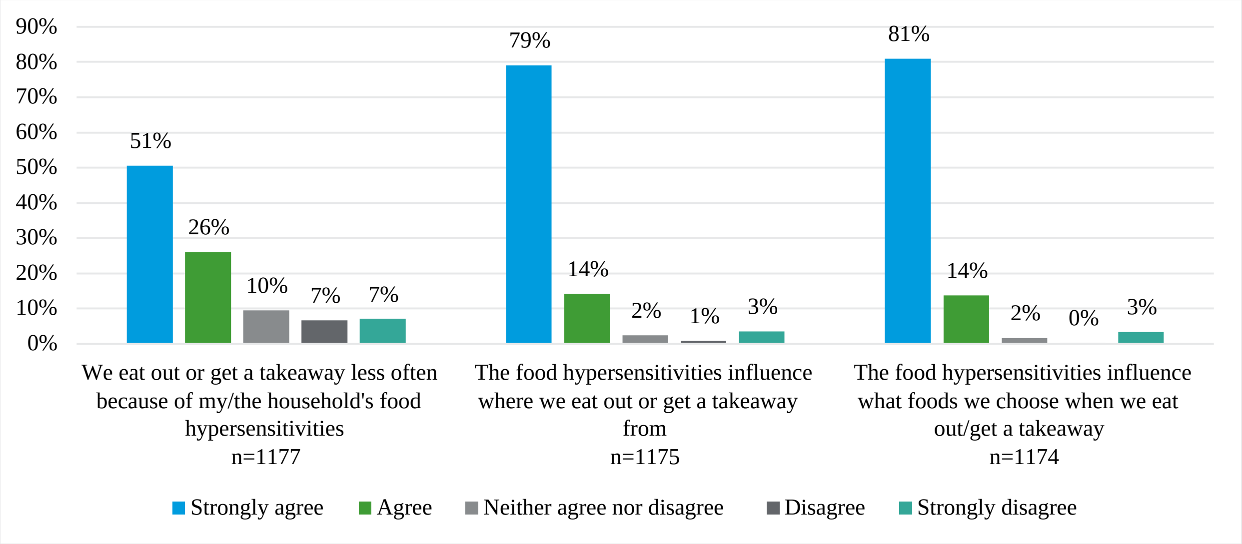
Another 24% of respondents (n=248) said the supply of ‘free from’ products, particularly the essentials, caused a problem for them during the first lockdown. This led some people living with FHS in the survey to bulk purchase essentials (such as GF bread) direct from wholesalers/ producers, to ensure they were well stocked. These supply constraints were reported to particularly impact shielding households and other vulnerable groups who were less able to visit different shops to source allergen free goods.

Additionally, 5% (n=50) of 1,021 respondents said that due to these supply issues, they started shopping at a different supermarket and 2% of respondents (n=22) said that having to track down allergen free foods during Covid-19 meant they spent a lot more time shopping. Only 2% of respondents (n=19) said that the food shortages forced them to cook more food from scratch and some said they had to learn how to cook produce and meals which they would have usually purchased pre-made, which took a considerable amount of time.

8.3 Impact on eating out and takeaway habits

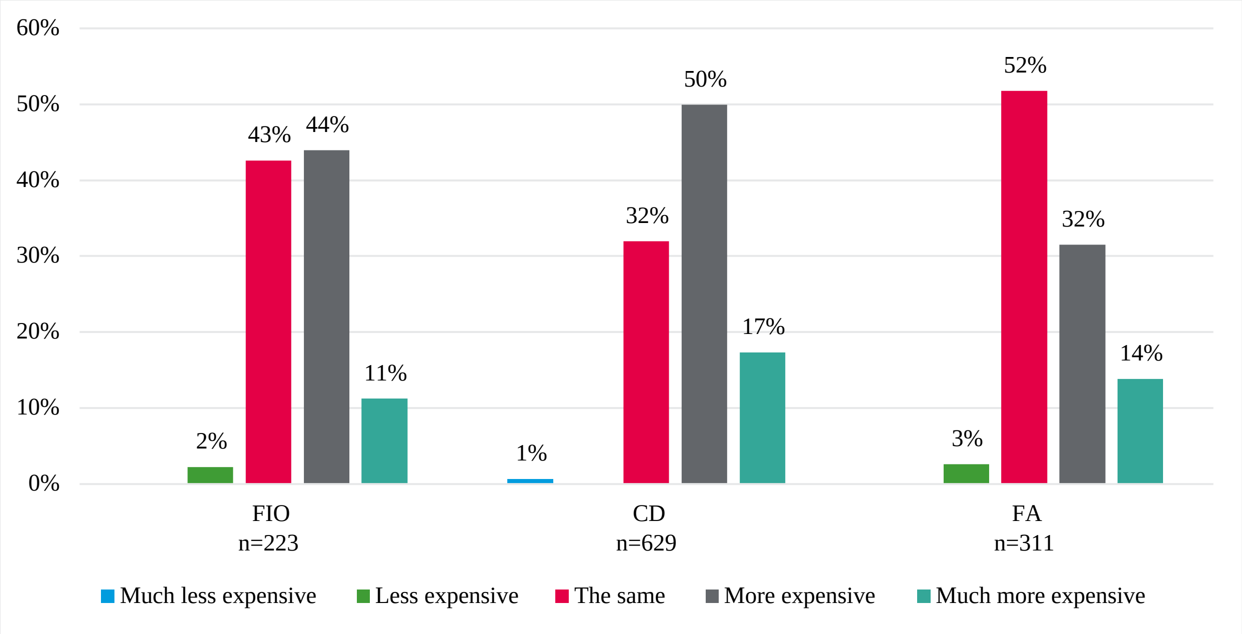
The FHS household survey asked about the extent to which respondents agree with the statements on their eating out / takeaway habits. Results from Figure 8.2 show that having an FHS condition influences the frequency of households’ eating out / takeaway habits, where they eat out / get takeaway, and what foods they choose when eating out / getting takeaway. Overall, 93% (n = 1,093) of 1,175 respondents either agree or strongly agree it influences where they eat out or get takeaway from, and 95% (n=1,115) of 1,174 respondents either agree or strongly agree it influences their food choices when eating out / getting takeaway.

Figure 8.2: Eating out/takeaway habits of respondents (n=1,174 to 1,177) (footnote 1) in England, Northern Ireland, and Wales according to an FHS household survey conducted online between November 2020 and January 2021.



In addition to their perception of how having an FHS condition influences their eating out / takeaway habits, the survey also asked how they think the average price of their meal compares to those without FHS when eating out. Figure 8.3 reveals more respondents from the FIO and CD cohorts (55%, n=123 and 67%, n=423 respectively) think eating out is more expensive with an FHS condition. On the other hand, only 46% in the FA cohort (n=141) believe their food costs more than people living without FHS.

Figure 8.3: Perception of meal prices for people living with FHS compared to those without FHS when eating out (n=1,163) in England, Northern Ireland, and Wales according to an FHS household survey conducted online between November 2020 and January 2021.



We also asked people living with an FHS condition to provide any additional comments on how food hypersensitivity affects their eating out/takeaway habits and received 880 responses. The main impact is around the limits to their social life. Two percent of respondents (n=18) said they have turned down invitations to gatherings due to their condition. Of the 880 respondents, 13% (n=111) acknowledged that eating out is not a spontaneous decision. They must spend time researching options online in advance, discussing suitable meals with food business operators (FBO) by phone, informing serving staff about their allergies on arrival, and reading labels before ordering. Additionally, 8% of respondents (n=68) said they experience worry and anxiety due to a lack of trust in FBOs around preventing exposure to allergens through ingredients and cross-contamination.

The anxiety is heightened for those who experience severe reactions to food allergens. Five percent of respondents (n=46) reported having a past reaction to an allergen while eating out, despite some being assured by the FBO that the food was safe and allergen free. For these reasons, 8% of respondents (n=71) said they completely forego eating out and eating takeaways, preferring the safety of home-cooked food instead. An alternative is to eat at formal dining establishments or get takeaways from chains as there is typically more comprehensive and up-to-date allergen information available, as reported by 3% of respondents (n=24). Some 1% of respondents (n=11) said they rely on FHS networks (for example, Coeliac UK, friends with FHS) for FBO recommendations. Another 1% of respondents (n=12) said they keep emergency rations in their bag when they eat out in case there are no safe options available.

Additionally, we asked respondents to provide any additional comments as to whether Covid-19 had any impact on their eating out/ takeaway habits during November 2020 to January 2021 and received 398 (32%) responses. Figure 8.4 below sets out the types of changes these respondents experienced due to Covid-19.

Figure 8.4: Impact on COVID-19 on eating out/takeaway habits (n=398) in England, Northern Ireland, and Wales according to an FHS household survey conducted online between November 2020 and January 2021

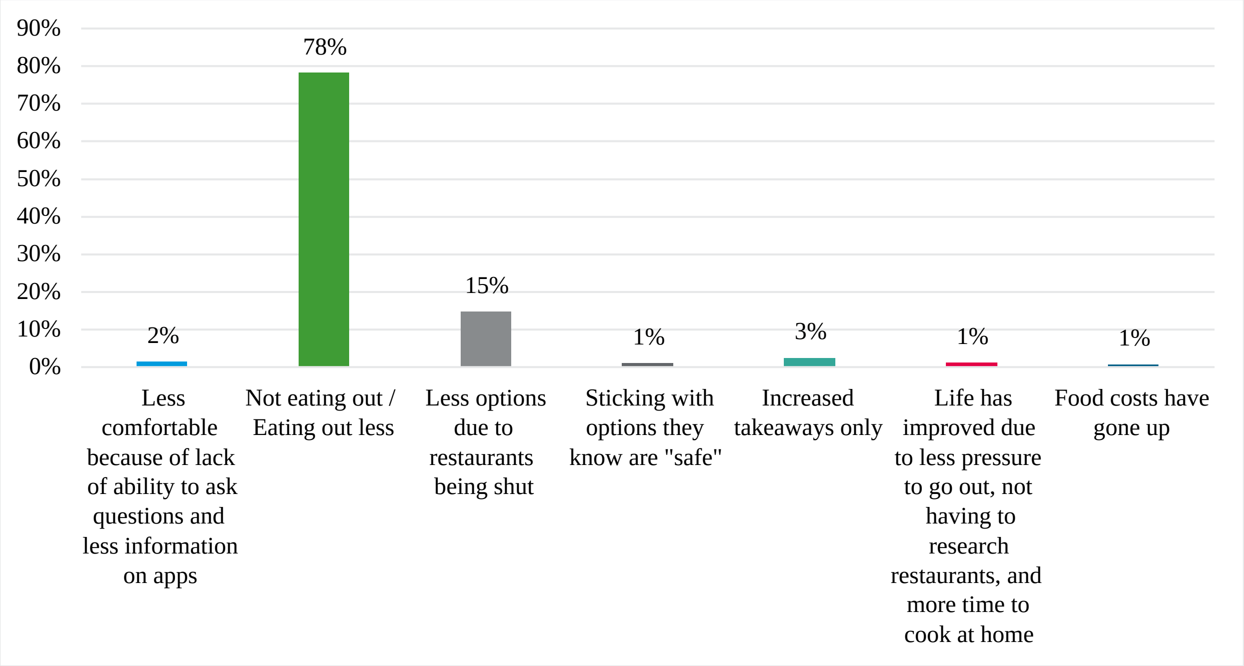


Figure 8.4 shows that the largest impact of Covid-19 is that respondents reduced or stopped eating out / ordering takeaway. Interestingly, 15% of impacted respondents (n=59) felt there were less options available for people living with FHS, due to the closure of their ‘go-to’ safe restaurants/ takeaways or the removal of allergen free options from slimmed down menus due to Covid-19 restrictions on FBOs.

8.4 Impact on holidays

We asked FHS respondents how their condition impacts their holidays and trips away, and received a total of 1,017 responses. Many respondents told us that travelling with a FHS is a challenge, including work trips and conferences. Foreign holidays can be particularly stressful and require considerable advance planning for people living with FHS. Although foreign holidays are a luxury rather than an essential, they are life enhancing and bring benefits that are more difficult to access for people living with FHS.

The most common way that an FHS impacts on holidays is the reduced choice of accommodation options, with 26% of respondents (n=263) citing this as an issue. Many respondents (22%, n=220) prefer to stay in self-catering accommodation rather than hotels, because they have access to a private kitchen where they can prepare their own meals. Some people living with FHS noted that planning their eating habits on holiday to stay safe requires extra effort, from the deep clean of the kitchen on arrival to shopping and cooking throughout the stay. Skipping meals to stay safe or using emergency rations from home when safe options are unavailable was reported by 1.8% respondents (n=18).

Living with an FHS also affects where people choose to holiday, with 22% of respondents (n=228) citing this as an issue. Locations are selected depending on how likely it is that dietary restrictions can be accommodated. Many respondents (16%, n=160) said they select destinations based on factors such as awareness and culture of food safety, food safety regulations, and language spoken. Some people choose to revisit a destination where they have previously felt safe. Several respondents said they feel safe while travelling in EU countries (1%, n=13) due to harmonized allergen labelling while others said they prefer visiting English-speaking countries (1%, n=12) as it is easier to read food labels in English.

Moreover, the type of food people typically eat is another consideration and some respondents said they would avoid destinations where an allergen is commonplace in the local cuisine (for example sesame seeds in China or Israel); with 1% of respondents (n=10) identifying Asia as an area they would not travel to due to the cuisine. Conversely some respondents choose locations where the local cuisine makes it easier to avoid an allergen (for example, countries with a Mediterranean diet where gluten-free dishes are widely available).

A notable number of respondents (7%, n=68) raised concerns about the safety of flying with a severe food allergy and some people (1%, n=13) choose not to fly due to the risk. Although it was noted that airlines have improved their food options for certain diets in recent years (vegetarians, vegans, halal etc) the provision of allergen and GF free foods for people living with FHS was felt to have ‘worsened over time’. Another challenge is ensuring that airlines and cabin crew notify passengers of severe allergies and ban certain food items on individual flights. Another barrier is the paperwork required to keep EpiPens in hand luggage: a letter from the GP needs to be purchased for each flight and airline permission is needed in advance to carry an EpiPen.

People living with FHS typically do more preparation when going on holiday than non FHS, particularly abroad. Several respondents (37%, n=378) indicated that they have to spend a significant amount of time on planning and research such as choosing a location / destination. This means checking online reviews for guidance/ feedback from fellow people living with FHS; reading blogs to identify ‘safe’ restaurants; and speaking to hotels beforehand to discuss menus and cross contamination policies. Many people said they typically research catering options before booking and do not book if there is uncertainty. Those at risk of severe reactions said they research medical facilities prior to booking and this determines where they stay. A common activity for 8% of respondents (n=82) before travel to a non-English speaking destination, is learning key words and phrases in the local language or buying translation cards from Allergy UK or Coeliac UK. Items reportedly taken on holiday by people living with FHS include pre-packaged safe foods (emergency rations for when safe food is unavailable), toasters / toaster bags and even mini fridges.

Lastly, a number of respondents (17%, n=174) felt that it is often more expensive for people living with FHS to go on holiday, particularly outside the UK. Hotels that have good allergy policies in place and cater to restrictive diets are often at the premium end of the market and prohibitively expensive to families and others on moderate incomes. Some holidaymakers with severe food allergies will only travel on certain airlines which charge higher fares. When flying, it may be necessary to purchase extra luggage capacity to transport packaged foods and other items for preparing food safely (16% of respondents (n=165) mentioned taking food from home on holiday). Travel insurance was reported to be higher by 1% of respondents (n=12), due to their risk of a severe reaction to food.

8.5 Non-continuing costs at diagnosis

Respondents were asked whether there were any one-off time and/or financial costs at the time of their diagnosis. Table 8.1 below summarises the common non-recurrent costs.

Table 8.1: Common non-recurrent costs around the time of diagnosis (n=453) in England, Northern Ireland, and Wales according to an FHS household survey conducted online between November 2020 and January 2021.

Costs around time of diagnosis	Examples of the costs
Some of the common non-recurrent costs around the time of diagnosis	disposal of foods that contain the allergen(s), travel to appointments around the time of diagnosis including time and costs (petrol, train fares and parking), the cost of tasting new ‘free from’ products to see if they are palatable.
Less common one-off costs around the time of diagnosis	buying food for skin prick tests or oral food challenges, which were thrown away, time spent cooking items for the infant milk and egg ladders, purchasing of FHS recipe books, charity membership, training and events run by Coeliac UK, Anaphylaxis Campaign or Allergy UK, deep cleaning the kitchen, time spent educating family and friends about the condition, costs for associated legal actions: Local Education Authority tribunal to access appropriate education and a family court case, private dental care for discoloured/ damaged teeth caused by FHS, overnight accommodation required for longer trips associated with diagnosis (appointments and stays in medical facilities).

8.6 Other findings: public attitudes towards FHS, mental health impact, impact on friends and families and GF food on prescription withdrawal

Participants were asked to share additional information on the burden of living with FHS. We received 598 responses and the majority of these emphasised the financial burden of living with FHS (which has been covered in the analysis of other survey questions, so is not repeated here). Additional themes were raised including public attitudes towards FHS; mental health impacts; impacts on friends and family (footnote 2). These findings are summarised in the table 8.2 below.

Table 8.2: Other findings from the FHS household survey: (n=598) in England, Northern Ireland, and Wales according to an FHS household survey conducted online between November 2020 and January 2021.

Findings	FHS household survey responses
Public attitudes towards FHS	A lack of public awareness for FHS was raised by 7% of respondents (n=43). People living with FHS said they have experienced intolerant/ impatient attitudes and had hurtful comments directed towards them. The risk of food contamination is not always taken seriously, and some people living with an FHS condition said they have experienced a lack of support in the workplace. For those living with coeliac, gluten intolerance can be dismissed as a mild condition or lifestyle choice. Respondents said they had been accused of following a fad diet, being picky or awkward.
Mental Health impact	Overall, 8% of respondents (n=45) mentioned mental wellbeing/ psychological issues as an additional impact arising from their FHS condition. For 3% of respondents (n=17) their mental health was said to have declined as a direct result of their FHS, leading to stress / anxiety and depression. A few people living with FHS emphasised that the emotional burden is higher than the financial burden and they feel at greater risk of poor mental health outcomes due to social isolation and exclusion.
Impacts on friends and family	Overall, 6% of respondents (n=33) acknowledged that their FHS condition also has a big impact on immediate friends and family. Relationships can be affected too, from minor irritation to feelings of burden causing a great strain on relationships. These issues were reported by 3% of respondents (n=15) who said their FHS condition had negatively affected their relationships with family and friends. Some respondents said their partners follow restrictive diets to minimise the risk of cross contamination for people living with FHS.

Findings	FHS household survey responses
Food on prescription withdrawal	The withdrawal of GF food on prescription in England for people on restrictive diets was raised as a concern by 3% of respondents (n=20). In recent years, increasing numbers of Clinical Commissioning Groups (CCGs) have declined to fund gluten free food on prescription for those living with coeliac disease (or limited the amount available). Half of these respondents also said the withdrawal of free prescriptions has caused them a greater financial burden.

1. Sample sizes vary because some respondents did not provide a response to the particular statement

2. The FSA has also commissioned the FOODSENSITIVE study led by Aston University, which seeks to understand how FHS impact people’s quality of life. One of the surveys is designed to capture the intangible costs of living with FHS.