

Estimating financial cost to individuals with a food hypersensitivity: Executive summary

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Cynhaliwyd gan: RSM and the Food Standards Agency

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List of acronyms

Acronyms	Definition
CCG	Clinical Commissioning Group
CD	Coeliac Disease
FA	Food Allergy
FBO	Food Business Owner
FHS	Food Hypersensitivity which includes all food allergies, food intolerance and coeliac disease
FI	Food Intolerance
FIO	Food intolerance cohort, includes those with other conditions
FSA	Food Standards Agency
GP	General Practitioners

Acronyms	Definition
MI	Multiple Imputations
ONS	Office for National Statistics
REA	Rapid evidence assessment
RSM	RSM UK Consulting LLP

Executive Summary

Introduction

The Food Standards Agency (FSA) is a non-ministerial government department within the United Kingdom responsible for protecting public health and protecting consumer interests in relation to food in England, Wales, and Northern Ireland.

Food Hypersensitivities (FHS) is a key priority within the FSA as it is an important food-related health issue with a severe and enduring impact for people living with it. FHS includes individuals living with a food allergy, coeliac disease and food intolerance.

It is the responsibility of the FSA to seek ways to understand and reduce avoidable deaths, the negative impact of FHS on both consumers and businesses, and make sure that FHS consumers have access to safe food that is what it says it is on the label, which they can trust. For people with chronic and / or potentially life-threatening FHS, that trust becomes even more important.

FHS places both a public health and financial burden on society. According to the FSA's Food and You 2 Wave 3 Survey ([footnote 1](#)), an estimated 800,000 people are living with a clinically diagnosed food allergy, 300,000 with coeliac disease and 1.2 million living with food intolerance and other FHS conditions in the UK.

The FSA has invested in a programme of research to understand the economic and societal burden of FHS and to explore how people living with FHS are impacted in their daily lives. The FSA commissioned RSM UK Consulting (RSM), Dr Audrey DunnGalvin from University College Cork and Alizon Draper from the University of Westminster to quantify and monetise the financial burden imposed on people living with FHS through their day-to-day management of the physical risks associated with food allergies, food intolerance and coeliac disease.

This is the first study of its kind to consider whether residents in England, Northern Ireland, and Wales who live with any type of FHS condition (food intolerance, coeliac disease or food allergy) results in additional financial burden for their household.

About this study

The aim of the study was to quantify and monetise the financial burden imposed on households with FHS through the day-to-day management of the physical risks associated with food allergies, food intolerance and coeliac disease, by:

- comparing the price paid for food between households with at least one adult above 18 years old living with FHS, to households without FHS
- valuing the direct costs incurred through efforts to manage FHS and remain symptom free (for example, medical and kitchen supplies)
- monetising indirect costs incurred when having to deal with an FHS condition (for example, lost working days)

This study is unique in terms of estimating price differentials for food consumption across different types of FHS and then comparing to a non-FHS comparison group. Previous studies have focused on coeliac disease, specifically the comparison between gluten-free and gluten-containing products, so this study is adding new knowledge to the evidence base.

Scope of analysis

The FHS cohorts used for analysis across England, Wales and Northern Ireland are:

- Food Allergy (FA): Adults above 18 years old that reported living with a food allergy
- Coeliac Disease (CD): Adults above 18 years old that reported living with coeliac disease
- Food Intolerance and Other (FIO): Adults above 18 years old that reported living with food intolerance or other suspected (undiagnosed) FHS ([footnote 2](#))

Further in-depth analysis of these cohorts revealed that approximately 92% of reported coeliac disease cases indicated that their diagnosis was as per NHS guidelines (blood test and/or gut biopsy). Additionally, approximately 90% of food allergy cases reported that their diagnosis was according to recommended NHS guidelines (skin prick test, oral challenge, blood test or a food elimination diet). Notably, both of these cohorts also included non-NHS recognised diagnosis methods (approx. 8% and 10% for CD and FA, respectively).

Methodology

An evidence review was initially completed to scope out and inform the design of the methods used. Additionally, interviews were conducted with people (some interviewees also responded on behalf of their children) living with FHS to inform the development of an online survey examining the direct and indirect costs borne by adults with FHS. The online FHS survey received 1,225 responses from households with an adult that has FHS. The comparator survey (non-FHS group household survey), received 1,530 household responses all of which were from adults. The model was then developed using statistical tests and multivariate regression models, applying the data collected from both surveys.

Key findings

The results of this study show that adults with FHS, regardless of their FHS condition, face an increased financial burden compared to the non FHS group. This study found that compared to households without FHS, on average an FHS household spends an additional 12% - 27% more on weekly food purchases.

In addition, on average FHS households:

- spend £15.22 on monthly medical costs, to manage the symptoms of their condition
- loses approximate 3 paid workdays and 4 unpaid days per year, due to their FHS condition
- spend 40.37 days per year on FHS-related activities including researching, shopping for suitable items and discussing their FHS condition

Broken down by FHS groups, those in the FA group face the highest overall burden, followed by FIO and CD, respectively. The key costs contributing to the higher total cost for the FA group included:

- eating out and takeaway costs for those with FA are 11% more than those with CD
- average monthly medical costs for those with FA are approx. 1.6 to 2.5 times more than those with FIO and CD

This report provides estimates for the financial costs to individuals with an FHS condition however, it does not represent the full cost. The pursuit of safe, allergen-free food environments can lead to social isolation, depression and/or anxiety which pose further costs to individuals that have not been monetised in this study ([footnote 3](#)). A further and more detailed cost breakdown by FHS condition is summarised in the dashboards below.

Findings

Direct costs: food consumption costs of FHS adults relative to non FHS adults in England, Northern Ireland, and Wales

Note: Weekly groceries costs are costs on any food and non-alcoholic beverages bought from a store/supermarket. This is the primary outcome measure.

Additional direct and indirect financial costs borne by FHS adults living in England, Northern Ireland and Wales.

SUMMARY DASHBOARD

RESULTS: NON-FOOD DIRECT COSTS

Type of cost	FHS Household <i>(aggregate of CD, FA and FIO)</i>	FA	CD	FIO
<i>(mean costs including individuals that reported £0 associated with additional kitchen equipment and medical costs from their FHS condition)</i>				
The average one-off spending by FHS households on additional kitchen equipment cost due to FHS (n=1,225) <i>(eg toasters, chopping boards, breadmakers)</i>	£21.05	£16.12	£26.26	£13.59
The average monthly spending by people living with FHS on medical costs due to FHS (n=1,202) <i>(eg nutritional supplement costs, prescription medication costs, specialist medical costs)</i>	£16.89	£27.98	£11.08	£17.60

RESULTS: INDIRECT COSTS

Type of cost	FHS Household <i>(aggregate of CD, FA and FIO)</i>	FA	CD	FIO
<i>(mean costs including those that did not lose any time due to FHS)</i>				
Paid work days lost by people living with FHS due to FHS per year (n=1,089)	2.67 days	3.77 days	1.74 days	3.81 days
Unpaid work days lost by people living with FHS due to FHS per year (n=1,061)	3.87 days	6.21 days	1.94 days	6.07 days
Extra time spent on researching/planning activities by people living with FHS due to FHS per year (n=1,223)	40.37 days	44.85 days	37.63 days	41.54 days

*Please see Section 6 and 7 for full results

** There is no comparison to the non-FHS group because questions are not relevant to them

Limitations

Whilst this study adds new analysis to the evidence base, there are however several limitations.

1. The data is subject to recall bias (the survey ran between November 2020 to January 2021 and respondents were asked to recall their pre-covid costs).
2. The FHS household survey was disseminated via the partner charities which could have resulted in sampling bias as other members of the population (i.e. adults with FHS that may

not be members of any of our partner charities) were excluded. However, this was done to increase outreach to people living with FHS and maximise sample size for robust statistical analysis. The FHS household survey was largely completed by females (79% of responses) whereas the comparator household survey was more representative of the population (52% of respondents are female). This risk of bias was addressed by a sensitivity analysis.

3. Another limitation is that kitchen equipment costs were monetised by deriving a UK high street average price for all the pieces of equipment named by respondents.
4. Additionally, with the propensity score matching, we were unable to achieve 'perfect' matching which means the matched FHS survey respondents and non-FHS group respondents are not balanced on all demographic and household characteristics. However, the matching method which gave an almost 'perfect' matching while maintaining a large enough sample size was chosen. These limitations are further discussed in Chapter 9 of the report.

Conclusions

The quantitative data shows unequivocally that adults with FHS, regardless of their FHS condition, face an increased financial burden compared to the non FHS group. These costs not only arise from higher food costs, but also higher medical costs (for example, nutritional supplement costs, prescription medication costs, specialist medical costs) ([footnote 4](#)) and lost working/ personal time due to illness and medical appointments, that further increases this burden.

Broken down by FHS groups, those in the FA group face the highest burden, followed by FIO and CD, respectively. This is contributed by those in the FA group having approx. double the eating out / takeaway costs, 1.6 to 2.5 times more in medical costs, and up to a third more in the cost of personal time (including unpaid days lost and extra time lost due to research, planning etc.) compared to FIO and CD. This however is not the full picture, as the pursuit of safe, allergen-free food environments, can lead to social isolation and depression or anxiety.

There is scope for future research that builds on this study's findings. Innovative data collection methods such as big data observations on actual consumer transactions, could enable cost comparisons at a granular level. However, such a study would be challenging to design and gain consent for (since researchers would need to collect individuals' demographic and FHS data alongside expenditure data).

With growing awareness of FHS among food producers/retailers and society, a longitudinal study across multiple time periods that considers the impact of changing attitudes and food environments across time on cost differentials would be an interesting area of research. Other future work could also include examining adults versus parents of children with FHS or studies examining the impact of different FHS conditions on different socio-demographic groups. In addition, the cost of managing an FHS condition compared to other health conditions such as diabetes would provide useful insights into the relative burden of FHS.

1. These are point estimates from the FSA's Food and You 2 Wave 3 Survey. The 95% upper and lower confidence intervals for each of the FHS conditions are as below: Food Allergies 600,000 (lower), 900,000 (upper), Food Intolerance: 1m (lower), 1.4m (upper), Coeliac Disease: 200,000 (lower), 400,000 (upper).
2. The symptoms of food intolerance are similar to many other conditions, making it hard to distinguish, it's likely that a reported food intolerance may be another condition. The accurate identification of conditions and the proportion of food intolerance to other FHS

conditions is unclear which is a caveat of this grouping.

3. The University of Manchester was commissioned by the FSA to conduct research: Impacts of Food Hypersensitivities on Quality of Life (QoL) in the UK and Willingness to Pay (WTP) to Remove those Impacts (September 2022) - to elicit monetised economic values. The study applied an established stated preference approach to identify people's Willingness to Pay (WTP) to remove the symptoms caused by living with FHS in the UK, specifically the day-to-day management of these conditions and the associated inconveniences (social isolation, depression and/or anxiety).
4. Overall, 84% (n = 1,030) of people living with FHS indicated in the FHS online survey say that they do not have private healthcare