

# Introduction and overview

The Food Standards Agency (FSA) commissioned RSM UK Consulting (RSM), Dr Audrey DunnGalvin from University College Cork, and Alizon Draper from the University of Westminster, to carry out a study into the financial burden of living with a food hypersensitivity (FHS) in August 2020. The FSA was established in 2000 as a non-ministerial government department and is responsible for protecting public health in relation to food safety in England, Wales, and Northern Ireland. This includes responsibility for allergen labelling and providing guidance to consumers with food allergies, food intolerance and coeliac disease.

## 1.1 The research programme context

This study is part of a wider research programme being conducted by the FSA. The programme which is part of the [FSA Food Hypersensitivity Strategy 2019-2025](#) aims to increase consumer trust in the information provided to food hypersensitive consumers and through effective enforcement creating confidence, so individuals can make informed choices in their daily lives. Current projects include (but are not limited to):

- a study on the willingness to pay (WTP) and quality of life impacts of FHS. This research will provide data on the management and impacts of FHS on daily lives and monetary valuations for both the financial costs and non-financial costs (pain, grief, and suffering)
- exploratory work on a Food Allergy Safety Scheme to improve choice for the hypersensitive consumer by raising allergy management standards in the food service sector
- **the FOODSENSITIVE study**, led by Aston University, which seeks to understand how FHS impacts people's quality of life. Methods involve two surveys. One survey was designed to capture data on behaviours, attitudes, and quality of life for adults and children. The second survey is designed to capture intangible costs of living with FHS. RSM collaborated with a researcher from the study to plan the timing and content of the study household surveys, to ensure alignment and complementarity with our work

The overarching objective of this research project is to identify and capture all relevant financial (direct and indirect) costs associated with the burden of living with food hypersensitivity, specifically the day-to-day management of food allergies, food intolerance, and coeliac disease i.e. to capture the financial burden of maintaining a symptom-free state. Results from this work will contribute to the development of the FSA's Cost-of-Illness (COI) model for food hypersensitivities, which aims to capture the overall economic burden related to food allergies, food intolerances and coeliac disease.

The study aims to quantify and monetise the financial burden imposed on adults 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 differentials paid for food** between FHS households and non-FHS households
- 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 (food allergy, food intolerance, coeliac disease) and then comparing them to a non-FHS group. Previous studies have focused on coeliac disease and gluten-free products only, so this study is adding new knowledge to the evidence base.

This study includes three FHS cohorts in England, Northern Ireland, and Wales:

- **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

After further in-depth analysis, it was discovered that approximately 92% of reported coeliac disease cases indicated that they were diagnosed by NHS guidelines (blood test and/or gut biopsy). Additionally, approximately 90% of food allergy cases reported to be diagnosed according to NHS guidelines (skin prick test, oral challenge, blood test or a food elimination diet. Both cohorts also included methods of self-diagnosis (approx. 8% and 10% respectively).

## 1.2 Report structure

The rest of the report is made up of nine chapters:

- Chapter 2 explains the methodological approaches used in the study
- Chapter 3 summarises the rapid evidence assessment that was conducted in the initial stages and used to inform survey development
- Chapter 4 summarises the findings from the semi-structured interviews that were conducted in the initial stages and used to inform survey development
- Chapter 5 presents the food consumption costs comparison findings from the quantitative research survey
- Chapter 6 presents the non-food direct costs findings from the quantitative research survey
- Chapter 7 presents the findings of the indirect costs from the quantitative research survey
- Chapter 8 details other findings from the quantitative research survey that were not cost-related
- Chapter 9 sets out a discussion of the findings, limitations, and conclusions of this study