The socio-economic cost of food hypersensitivity on the island of Ireland

The socio-economic cost of food hypersensitivity on the island of Ireland

Publication date: May 2022

Foreword

We would sincerely like to thank all the individuals who completed the surveys (n=4,114) and phone interviews (n=76) and contributed data to this report.

Project Steering Committee:
Dr Ciara Walsh (Project Co-ordinator and Lecturer, Technological University Dublin)
Ms. Eliza Dimla (Postgraduate Student, Technological University Dublin)
Dr Stephen O'Neill (Lecturer, London School of Tropical Medicine)
Ms Laura Carter (Postgraduate Student, National University of Ireland Galway)
Dr Charlene McShane (Lecturer, Queens University Belfast)
Ms Eimear O'Rourke (Research Assistant, Queens University Belfast)
Dr Katarina Domijan (Lecturer, Maynooth University)
Dr James McIntosh (Specialist in Toxicology, ***safe*****food**)
Dr Nadim Akasheh (Medical Consultant, St. James's Hospital, Dublin)
Dr Anne Dee (Public Health Doctor, HSE)
Dr Orla Cahill (TU Dublin)
Dr Michelle Riblet (Director, Scientific Advisory Services (Agri-Food))
Dr Mary Friel (Director, Marel Consulting)

We would also like to thank the following people and organisations for their contribution, assistance or advice at various stages of this study: Ms. Sara Boyd (TU Dublin), Dr Mark Walsh (MU), Dr Pat O'Mahony (FSAI), Ms Sarah Keogh (Coeliac Society of Ireland), and Mr Derek Thompson (Gluten-Free Ireland) and Aisling Naughton.

In addition, we would like to thank the following individuals for their contribution in collecting and organising datasets for this report: Ms Orla Flynn, Ms Lorna Flanagan, Ms Zoe Lim, Ms Orla Delargy, Ms Zainab Abass, Ms Niamh Carroll, Ms Hannah Monahan, Ms Ruta Patel, Mr Daniil Tabolkin, Mr Carlos Martinez and Mr Darragh O'Donoghue.

Glossary

AAI	Adrenaline auto-injector
CSO	Central Statistics Office
CD	Coeliac disease
EYS	Early Years Services
FA	Food Allergy
FH	Food Hypersensitivity
FSAI	Food Safety Authority Ireland
FSA	Food Standards Agency
GB	Great Britain
HSE	Health Service Executive
MDCD	Medically Diagnosed Coeliac disease
MDFA	Medically Diagnosed Food Allergy
NHS	National Health Service
QUB	Queens University Belfast
RASFF	Rapid Alert System for Food and Feed
TUD	Technological University of Ireland

Contents

Executive summary

Food hypersensitivity is a broad term that encompasses food allergies and intolerances, and for the purposes of this research it refers to food allergy, food intolerance and coeliac disease. Food allergy is an adverse immunologic response to a food protein and is characterised by a wide range of symptoms that can range from mild irritation to life-threatening anaphylaxis. Coeliac disease is a chronic inflammatory intestinal disease caused by an autoimmune response to gluten proteins, while food intolerances are metabolic food disorders resulting from genetically determined metabolic deficiencies. Food allergies and intolerances are associated with a variety of symptoms but are generally not considered to be life-threatening. It is estimated that 5% of children and 3% of adults on the island of Ireland suffer from food allergy, while 1% of the population has coeliac disease. The prevalence of food intolerance is harder to estimate due to the diversity of food intolerances, many of which remain ill-defined.

In recent years, research carried out in several Western countries has shown that having a food allergy is associated with increased costs for the affected individuals and their families. This includes direct and indirect financial costs, particularly those associated with healthcare, but also intangible or 'non-monetary' costs due to the impact of food allergy on the individual's overall health status, well-being and quality of life. These studies did not include other hypersensitivities such as coeliac disease or food intolerance. No such studies have to date been carried out on the island of Ireland.

This report details the findings of research carried out in Ireland and Northern Ireland to ascertain the socioeconomic cost of food hypersensitivity in both populations. The principal instrument used for data collection was a suite of online surveys that were active from November 2019 until October 2020. This of course overlapped with the arrival of the SARS-Cov-2 pandemic on the island of Ireland and necessitated measures to ensure the impact of the pandemic on the survey outputs was minimal. This research had three fundamental objectives:

- To determine the direct and indirect socioeconomic cost (including health) of food hypersensitivity on the island of Ireland.
- To determine the intangible costs of food hypersensitivity for consumers on the island of Ireland who experience food hypersensitivity.

- To estimate the prevalence of food hypersensitivity in Ireland and Northern Ireland.

Over 3,000 completed surveys were returned by adults or parents of children with a medically diagnosed food allergy, a medically diagnosed coeliac disease or food intolerance (including a suspected/undiagnosed food allergy). Over 1,000 case-matched control surveys were also collected from individuals who do not experience food hypersensitivity. Direct costs, consisting of healthcare related expenses (medical visits, associated travel, hospital stays, medication, etc.), and indirect costs (due to lost time, missed days, lost earnings, etc.), and the total combined direct and indirect costs, were calculated for food hypersensitive adults and the parents of food hypersensitive children/adolescents in Ireland and Northern Ireland.

The main finding of this research is that for families on the island of Ireland, having a food hypersensitivity is a financial burden. Additional or 'excess' direct and indirect costs associated with food allergy, food intolerance and coeliac disease were determined for self-reporting adults and parents in both jurisdictions. In Ireland, the annual additional direct costs associated with food allergy, reported by adults and parents respectively, were €1,325 and €1,115, while in Northern Ireland these costs were £847 and £1,208. For coeliac disease, these costs were €444 and €903 in Ireland, £737 and £1,608 in Northern Ireland. The direct costs associated with food intolerance in Ireland were €350 for adults, with no real difference recorded by parents, while in Northern Ireland these costs were £377 and £292, respectively. Indirect costs associated with food allergy, food intolerance and coeliac disease were generally lower than direct costs and ranged up to €277/€324 for adults/children in Ireland, £628/£206 for NI adults/children. The main driver of indirect costs was missed days at work/school/college and these costs tended to be higher in Northern Ireland. Additional direct and indirect costs associated with food intolerance were not as pronounced as those associated with food allergy and coeliac disease.

The main driver of direct costs were health care-related expenses, while food costs, lost earnings and missed days were also significant expenses for many of the groups investigated. Annual out-of-pocket costs (mainly non-healthcare) for adults and parents due to food allergy were up to €1,141 in Ireland and £550 in Northern Ireland. The corresponding costs for coeliac disease were €607 and £1,011. Respondents also paid additional annual healthcare costs in association with their local health service. The costs associated with children were greater than those for adults at €940 and £864 for food allergy, and €426 and £679 for coeliac disease in Ireland and Northern Ireland, respectively.

The intangible costs of food hypersensitivity were explored by investigating its impact on quality of life. All groups, regardless of the food hypersensitivity, had a significantly lower quality of life compared to non-food hypersensitive controls. They had significantly higher levels of pain and discomfort, while some of the adult and adolescent groups reported a significantly higher level of anxiety and depression. These findings show how significant the impact of food hypersensitivity can be on health-related quality of life. They also suggest an association between higher levels of 'pain and discomfort' and higher levels of 'anxiety and depression' in the adolescent and adult groups specifically.

Based on these findings, semi-structured telephone interviews were organised with food allergic and coeliac adults and parents to investigate exactly which areas of life were impacted most by food hypersensitivity. Important issues for these groups included the level of awareness and understanding of food hypersensitivity by both the public and the food industry, access to medical specialists, and (at least in the case of food allergic interviewees) the provision of adrenaline auto-injectors in public places. Challenges about the level of awareness and training in educational settings was more of a priority for parents, particularly in Northern Ireland. Access to counselling or psychological services and a recognition of a food hypersensitivity as a disability did not rank highly. The provision of dietetic support was more of an issue for coeliacs. An array of different strategies, ideas and suggestions were proposed by the interviewees to address these challenges. These proposals were further reviewed and considered, in combination with the study findings, in the formulation of key recommendations.

The survey data returned relative prevalence rates for different food allergies which concur with relative prevalence rates from earlier studies. The top trigger foods for food allergy are not all declarable under EU or UK law: peanuts, milk, other nuts, eggs and fruit. These food allergens were also most associated with previous incidences of anaphylaxis among survey respondents. Prevalence rates for kiwi fruit were higher than for many currently declarable foods that cause allergies or intolerances. Across the island of Ireland, the two most reported food intolerances were to milk and cereals containing gluten, followed by fruit, eggs, peanuts and other nuts. This highlights the significance of non-coeliac gluten sensitivity in terms of public health: while it is still a subject of considerable research, non-coeliac gluten sensitivity is suspected to be more prevalent than coeliac disease on the island of Ireland.

In addition to the focus of the research, anonymised food hypersensitivity data from previously published surveys and datasets for the Island of Ireland were reviewed. Prevalence rates documented in the wider literature for Ireland, the UK, Europe and elsewhere were collated. Anonymised food hypersensitivity data was collected from public and private organisations in Ireland and Northern Ireland, and prevalence rates for general food hypersensitivity, food allergy and coeliac disease are reported for over 9,000 children in early years services, more than 3,000 primary and secondary school children, and over 2,000 care home residents. The data generated in this study will contribute to the general body of knowledge for food hypersensitivity on the island of Ireland, and it is hoped that the study findings will assist risk assessors, researchers, regulators, policy makers and other stakeholders in devising measures to improve the lives of food hypersensitive consumers.

Key project recommendations

1. Due consideration should be given to the relative prevalence of medically diagnosed and suspected allergy to kiwi fruit, and possible intolerance to kiwi fruit, by the regulatory authorities on the island of Ireland.
2. Those who suspect they have a food intolerance, or a suspected/undiagnosed food allergy should seek a proper diagnosis either with a qualified medical practitioner or a registered dietitian.
3. Assistance with healthcare costs (and consideration regarding the most effective mechanisms for doing so) should be offered to those with a medically diagnosed food allergy (MDFA) in Ireland and Northern Ireland.
4. Provision of a greater range of more suitably priced gluten-free foods, with additional financial supports (e.g., vouchers or the provision of certain gluten-free foods on prescription, etc.) to parents of medically diagnosed coeliac disease (MDCD) children/adolescents up to 18 years of age in Ireland.
5. Availability of a wider range of gluten-free products, particularly on prescription in Northern Ireland, and/or the provision of tax rebates or vouchers for consumers with MDCD in Northern Ireland.
6. Further examination of the health-related intangible costs associated with food hypersensitivity, as outlined in this report, should be considered, as well as avenues for addressing them.
7. More measures should be developed to promote food industry awareness of food hypersensitivity. This would include an increased focus on food allergens and the prevention of cross-contamination within current food safety training programmes, and compliance with labelling on non-pre-packaged/loose foods.
8. Investigation into mechanisms to prevent misuse/over-use of precautionary allergen labelling (i.e., “may contain” labelling) in the food manufacturing sector should be considered, as well as an exploration of a possible partnership approach with industry and other key stakeholders to address this issue.
9. The development of healthcare pathways (improved access to medical teams, including dietetic support and counselling) for individuals with food hypersensitivity should be considered.
10. Further research is needed into the feasibility, effectiveness and cost-effectiveness of providing adrenaline auto-injectors in controlled environments (similar to Automated

External Defibrillators) such as in schools and early learning and care facilities in Ireland and Northern Ireland.

11. National guidance on the management of food hypersensitivity in educational settings should be developed in Ireland by the Department of Education in conjunction with relevant stakeholders (this is already available in Northern Ireland). This should include advice on the formulation of food allergy polices, individual emergency plans, staff allergen awareness training, storage and use of adrenaline auto-injectors, recommendations regarding school activities, trips, etc.
12. The promotion of public awareness of food hypersensitivities, and the provision of public guidance around the administration of adrenaline auto-injectors, should continue.
13. Nationwide surveys (e.g., TILDA, Healthy Ireland, Growing Up in Ireland, etc.), should include clearly defined food hypersensitivity-related questions developed in consultation with appropriate stakeholders. This will assist the continuing collection of data on these conditions in Ireland and Northern Ireland.
14. Further research into measures to improve food allergen management and the quality of life of food hypersensitive consumers on the island of Ireland is recommended.

Project introduction and background

There is currently no ‘cure’ for a food hypersensitivity (food allergy, food intolerance or coeliac disease). Management of this chronic illness consists of strict avoidance of the “trigger” foods, and medical intervention if accidental consumption occurs (Allen *et al.* 2014; Crevel *et al.* 2008; Helfe *et al.* 2007). While individuals with a food allergy typically do not suffer the symptoms of their disease daily, as with other chronic illnesses, the need for constant vigilance regarding food places a heavy burden on them and their families (Crevel *et al.* 2008; UK Food Standards Agency (FSA), 2002; Miles, 2005). There are many studies highlighting the negative impact of food allergies on the quality of life (QoL) of those affected, their families and caregivers (Sicherer, 2001, Cohen, 2004, Antolin-Amerigo, 2016). For example, Primeau *et al.* (2000) reported significantly more daily disruption in the activities of children with a peanut allergy than for children with rheumatological disease (or other chronic illnesses examined). It is also notable that a study by the FSA found that food allergies were more costly both in terms of money and time (FSA, 2002; Jansson *et al.* 2014; Picarelli *et al.* 2014; Protudjer *et al.* 2015).

While societal costs associated with pediatric food allergy (FA) have been estimated to be in the region of 25 billion dollars in the United States (Gupta *et al.* 2013), there is currently no equivalent estimate available for Europe. A recent study (n=226) in Sweden (Protudjer *et al.* 2015), reported that total household costs (direct and indirect) were higher by €3,961 for a child and €4,792 for an adolescent with FA. Another study examining annual household costs associated with FA and carried out by the same research group (Jansson *et al.* 2014), found the costs to adults with FA to be significantly higher than the control group (by €8,164) and the costs reported for children and adolescents (Protudjer *et al.* 2015). Intangible costs associated with perceptions of well-being were noted in both studies (Jansson *et al.* 2013; Jansson *et al.* 2014; Jansson *et al.* 2015; Protudjer *et al.* 2015; Protudjer *et al.* 2016).

While these studies highlight the burden on individuals and the healthcare sector caused by food allergy, they do not include hypersensitivity, such as coeliac disease and food intolerance, as a parameter in their research. In more specific terms, a review of existing data and literature (particularly regarding prevalence rates), and the calculation of the socio-economic costs associated with having food allergy, coeliac disease, and food intolerance (with consideration of gender, age, jurisdiction etc.), is warranted for the island of Ireland (IoI).

Project aims & objectives

The aim of this study was to examine the socio-economic costs (direct, indirect and intangible) of food hypersensitivity on the IoI.

Definitions

Survey data was gathered from two target groups:

1. adults of 18 years of age or over who have a food hypersensitivity;
2. parents who had a child or adolescent younger than 18 years of age who have a food hypersensitivity.

Throughout the report, these are abbreviated to (a) 'adults' and (b) either 'parents' OR 'children/adolescents', unless separate data are reported for 'children' (0-12 years) and 'adolescents' (13-17 years).

The food hypersensitivities investigated were:

- Medically diagnosed food allergy (MDFA)
- Medically diagnosed coeliac disease (MDCD)
- Food intolerance/suspected or undiagnosed food allergies (FI)

Objectives

To calculate the direct and indirect costs associated with food hypersensitivity in Ireland and Northern Ireland.

- To compare the costs associated with the different food hypersensitivities investigated in the target groups in both jurisdictions.
- To investigate the overall quality of life (QoL), or intangible costs (non-monetary), associated with food hypersensitivity in adults, and similarly for families reporting to have a child/adolescent with one of these conditions.
- To examine available data on food hypersensitivity on the IoI, and to collect related anonymised information from public and private institutions such as early learning services (childcare facilities), schools (primary and secondary) and nursing homes.

- To carry out a review of the peer-reviewed scientific literature for prevalence estimates for MDFA, MDCD and FI in Ireland, UK, Europe and further afield.
- To define the key areas of life impacted for adults and children/adolescents with MDFA or MDCD.
- To examine the challenges faced by adults and families of children/adolescents with MDFA or MDCD and offer possible recommendations or interventions.

1 Literature review

1.1 Introduction

Food allergy is defined as an adverse immunologic response to a food protein. Food-related allergic reactions are associated with a broad range of signs and symptoms that may involve any body system, including the skin, gastrointestinal and respiratory tracts, and cardiovascular system (Waserman *et al.* 2018). The most severe reaction is anaphylaxis, which is defined as a serious allergic reaction (Waserman *et al.* 2018). Food hypersensitivity is a broad term encompassing both food allergies and intolerances (Johansson *et al.* 2001). While the prevalence of these conditions is not widely reported, it is estimated that approximately 1.75 million people have been diagnosed with coeliac disease (AOECS, 2015), and more than seven million have been reported to suffer from food allergies (EAACI, 2015) in Europe alone. In Ireland, statistics show that approximately 5% of children and 3% of adults suffer from food allergies (INDI, 2019). While living with a food hypersensitivity can of itself be challenging, it has been proposed that there is a direct, and often significant, relationship between having such a condition and the expenses incurred by the individuals and their families (Voodrouw *et al.* 2010; Fox *et al.* 2013; Jansson *et al.* 2014; Protudjer *et al.* 2015). Moreover, loss of productivity, missed opportunities and an overall unfavourable impact on QoL have all been reported as important intangible outcomes (Voodrouw *et al.* 2010; Jansson *et al.* 2013; Jansson *et al.* 2014; Jansson *et al.* 2015; Protudjer *et al.* 2015; Voordouw *et al.* 2016). The following is a review of the socio-economic studies that endeavoured to cost food hypersensitivity in Europe and elsewhere. Publications for children/adolescents, adults and families (where reported separately) are presented together. Finally, papers on the quality of life of affected individuals are reviewed.

1.2 Socio-economic costs of food hypersensitivity

Miles *et al.* (2005) developed a framework to measure the costs of having a food allergy, which consisted of three categories: direct costs, indirect costs and intangible costs. The direct and indirect costs can be measured in monetary terms. In contrast, intangible costs are difficult to quantify, as they are the costs associated with impaired QoL because of having a condition such as a food allergy. For this reason, intangible costs are often conveyed through self-reported health status and health-related QoL (HRQoL) assessments. This framework can be adapted to examine the socio-economic costs associated with other food hypersensitivities like food intolerances and coeliac disease.

1.2.1 Direct costs

Direct costs can be defined as the cost to the health service and financial (out-of-pocket) costs that individuals or their families incur because of having a food hypersensitivity. Specifically, direct costs are financial expenditures related to living with, diagnosing, consulting or treating the condition (e.g., medications, hospitalisation, use of emergency services, etc.), and expenses associated with health insurance. Moreover, they include monetary out-goings, such as the cost of travel to visit medical/health care professionals (including costs associated with hospital visits), and visits by medical professionals to a patient's home, e.g., ambulance services (Miles *et al.* 2005). In addition, the cost of health insurance, medication (including over-the-counter and prescribed medicines) and outgoings associated with medical treatment not covered by insurance (and thus paid for by the individual or their family) are included. Other possible considerations include additional expenses associated with food, leisure activities (including travel) and the management of the condition (Miles *et al.* 2005; Voordouw *et al.* 2010; Voordouw *et al.* 2016).

1.2.2 Indirect costs

Indirect financial costs associated with food hypersensitivity are not as readily identifiable as direct costs. They can be defined as time impacts, and losses associated with diminished productivity and earning which can include possible missed opportunities, as well as an overall loss in human capital (Posnett and Jan, 1996, Miles *et al.* 2005). This category also covers aspects such as lost sick (or restricted) days, missed leisure time, or an inability to perform domestic tasks because of illness. Indirect costs may be accrued by both the food hypersensitive individual themselves and their families.   For example, family members may need to be on hand to take care of an infirm individual, resulting in their incurring their own monetary losses. Time spent obtaining medical treatment (consultations or admissions), visiting patients, shopping for suitable foods, or even searching for information on health-related issues, etc., would all be considered indirect costs (Miles *et al.* 2005; Voordouw *et al.* 2010; Protudjer *et al.* 2015; Voordouw *et al.* 2016).

1.2.3 Intangible costs

Intangible costs are defined as a loss of value or utility. These can be difficult to measure in monetary terms but can be examined by reviewing the associated self-reported health status. This includes investigating impact of a food hypersensitivity on the individual's welfare and well-being, their pain/suffering, inconvenience, or diminished QoL (Miles *et al.* 2005; Voordouw *et al.* 2016). Intangible costs are typically examined via a HRQoL assessment (Miles *et al.* 2005) which focuses on an individual's perception of the overall effects of the associated illness and its treatment. This includes aspects of physical, psychological and social well-being and functioning.

Within the European Union's project, "The Prevalence, Cost and Basis of Food Allergy across Europe" (EuroPrevall), Fox *et al.* (2009) designed and validated a questionnaire to measure the socio-economic costs of having a food allergy in the EU. This questionnaire, termed the Food Allergy Socio-Economic Questionnaire (FA-ECOQ), has been utilised in various European studies to determine the socio-economic costs of having a food allergy in various EU countries (Voordouw *et al.* 2010; Fox *et al.* 2013; Cerecedo *et al.* 2014; Jansson *et al.* 2014; Protudjer *et al.* 2015; Voordouw *et al.* 2016).

Fox *et al.* (2009) examined a wide range of scales used to measure economic welfare and well-being in food allergy patients. This review was conducted to design a disease specific questionnaire which best examined related intangible factors and their overall impact. Notably, Fox *et al.* (2009) reviewed generic scales (which had been previously used in the medical literature to examine disease associated intangible outcomes) to compare the attributes of cases and their control counterparts, e.g., food allergic and non-food allergic individuals. The generic scales that were included were:

1. EuroQol 5-Dimension (EQ-5D) scale (EuroQol Group) to assess health status and health-related quality of life across five non-disease specific dimensions.
2. The five-point perceived health status scale (Benyamini and Idler, 1999) to examine an individual's health-related well-being.
3. The Cantril Ladder (Cantril, 1965) scale of subjective well-being measuring feelings of happiness.
4. The Income evaluation scale (Praag Van and Ferrer-I-Carbonell, 2004) to measure an individual's welfare associated with household income.

In particular, the EQ-5D questionnaire (which consists of five ‘dimensions’ or questions related to various aspects of health) has been widely used to assess health states and health-related quality of life in comparable, but not food hypersensitivity-related, studies (Møller *et al.* 2015; Quaranta *et al.* 2016; Rencz *et al.* 2016; Zrubka *et al.* 2017; Batóg *et al.* 2018 and Prevolnik *et al.* 2019).

The economic costs associated with living with food allergies (including welfare, well-being and economic functioning) have been examined in several EU countries including the UK, Sweden, Greece, Iceland, Poland, Spain, Czech Republic, France, Italy and the Netherlands (Miles *et al.* 2005; Voordouw *et al.* 2010; Fox *et al.* 2013; Cerecedo *et al.* 2014; Jansson *et al.* 2014; Protudjer *et al.* 2015). To date no such study has been conducted on the IoI. More studies of this nature are required to obtain an overview of food hypersensitivity-related costs in the EU to assist affected individuals and their families, and to determine associated governmental and regional costs. Societal costs associated with pediatric food allergies have been estimated to be in the order of 25 billion dollars annually in the United States of America (US) (Gupta *et al.* 2013). Moreover, the economic burden of illness due to food allergies and anaphylaxis in the US was estimated to be in the region of half a billion dollars in 2007 (Patel *et al.* 2011). While there are currently no equivalent estimates available for the EU, the European Academy of Allergy and Clinical Immunology (EAACI) has reported that indirect costs associated with allergic disease (food related, and other sources) for adults and children ranges from 55 to 151 billion euro per annum (EAACI, 2015).

1.3 Studies on the socio-economic costs of food allergies & food hypersensitivities

1.3.1 European studies

In this section, studies on the socio-economic costs of food allergies and other food hypersensitivities in Europe were reviewed. Studies that reported costs in international dollars[1] or pounds sterling were converted to euro for comparison (exchange-rates.org, 2019).

---

[1] The international dollars (I$) (also known as the Geary–Khamis dollar) is an average unit of cost derived by adjusting exchange rates between the US dollar and the local currency to compare values of different currencies based on purchasing power parity and the average commodity prices within each country (Fox *et al.* 2013).

A pilot case-control study by Voordouw *et al.* (2010) used the FA-ECOQ (Fox *et al.* 2009) in the Netherlands (n=99) and the UK (n=91) to examine households with a food allergic individual (adult or child) reporting to be self-diagnosed or clinician-diagnosed. The data from these two countries was studied collectively against control samples (non-food allergic) and reported per household. The difference in annual direct costs per household with a food allergic member (adult or children) compared to non-allergic control households was estimated to be €1,088 (with costs of €8,984 and €7,896, respectively). Statistically significant differences in direct costs appeared to be primarily related to those 'obtaining health care'. In particular, medication ($p < 0.01$) and health care ($p < 0.05$) related costs were significantly higher for households with food allergic members compared to controls. Similarly, the annual difference in total indirect costs (e.g., loss of earnings, costs due to an inability to perform domestic tasks due to ill health, etc.), were reported to be significantly higher among households (€2,571) with food allergic members compared to controls (€9,269 and €6,698, respectively). Lastly, intangible costs (i.e., self-reported health status and well-being) indicated lower overall health status, lower self-perceived health status, and lower well-being[2] for food allergic individuals than controls.

A similar study by Fox *et al.* (2013) investigated the health service cost for food-allergic Europeans across nine European countries collectively (Greece, Iceland, Poland, Spain, Czech Republic, France, Italy, The Netherlands and UK) using the validated questionnaire FA-ECOQ (Fox *et al.* 2009). The participants were recruited through EuroPrevall in a case-control study in four countries (Greece, Iceland, Poland, Spain), and a cases-only study in five countries (Czech Republic, France, Italy, The Netherlands and UK). This study reported that food-allergic adults (n=225, aged 20-54 years) and children (n=270, aged 7-11 years) (self-reported) in the case-control group had higher health care costs than the control group, which were like findings reported by Voordouw *et al.* (2010). The mean annual cost of health care for food allergic adults was estimated to be I$2,016 (international dollars) equivalent to €1,794 based on a US dollar to euros exchange rate in July 2019. This was I$927 (€825) more than the figure recorded for those without food allergy (I$1,089/€969) in the European countries investigated. Similarly, the mean annual cost of health care (I$2,197/€1955) reported for food allergic

---

[2] The well-being of a food allergic individual can be described as the psychological impact of food allergy on the individual and their household. This may include, for example, various limitations caused by health status, such as being unable to perform a job, or restrictions on social life (Kahneman *et al.*, 1999; Praag Van *et al.*, 2004).

children was I$1,334 (€1,187) more than the figure recorded for controls (I$863/€768) on collective examination of the selected countries. Moreover, the mean annual cost of health care for food allergic children (I$2,197/€1,955) was I$181 (€161) more than that reported for food allergic adults (I$2,016/€1,794). While much variation exists between individual healthcare systems in each of the nine European countries studied, this calculation indicates overall higher health care-related costs associated with food allergy in children and adults (case-control group) in Greece, Iceland, Poland and Spain.

In this study, Fox *et al.* assessed whether the severity of symptoms had any impact on the health care costs for allergic people in the two age ranges. Cases of possible and probable food allergy were investigated, and the Mueller Clinical Severity Grading Scale (Muller, 1996) was used to categorise the severity of the reaction. If mild symptoms (e.g., skin rashes) were reported, the severity was categorized as Grade 1; gastrointestinal symptoms or angio-oedema were categorized as Grade 2; respiratory symptoms were categorized as Grade 3. The most severe category was Grade 4 and included reported cardiovascular symptoms and anaphylactic shock. They found that the costs of health care and the severity of the symptoms of a food allergy were significantly related ($P \leq 0.0009$). The cost of health services for those reported to have a 'moderate' food allergy (category 3) were likely to be 68% higher than for those with the 'mildest' symptoms (category 1), while the costs for those with 'severe' food allergies (category 4) were predicted to be twice that of those in category 1 (Fox *et al.* 2013).

Another recent study in Sweden by Protudjer *et al.* (2015) investigated household costs associated with 'objectively' diagnosed allergy to staple foods such as cow's milk, hen's egg and wheat in children (0-12 years) and adolescents (13-17 years). This study examined a group of outpatients (n=144) from an allergy clinic who had a specialist diagnosis of allergy to one (or more) of these staple foods. Notably, most food allergic outpatients had parent-perceived and/or doctor-diagnosed allergies to foods other than the staple foods examined. Protudjer *et al.* reported that mean total household costs (direct plus indirect costs) were significantly ($P < .05$) higher by €3,961 for a food allergic child (€20,819 and €16,858 respectively), and by €4,792 for a food allergic adolescent (€23,468 and €18,676 respectively) (self-reported; n=144), compared to non-allergic controls (age and sex-matched; n=150). It was noted that neither 'concomitant allergic disorders' (asthma, allergic rhinitis, allergic conjunctivitis, eczema), nor the number of offending foods, significantly affected total household costs among children or adolescents. In fact, overall indirect household costs did not differ between cases and controls amongst adolescents. Some clinical factors such as food allergy severity, concomitant allergic disorders and the number of offending foods were statistically associated with higher indirect costs. Further, a history of anaphylaxis was significantly ($P < 0.05$) associated with higher annual direct household costs (mean=€13,016) than no history of anaphylaxis among children (mean=€10,044). When adolescents were examined, a history of anaphylaxis was significantly ($P < 0.05$) associated with higher indirect costs (mean=€11,915) compared to the cost where anaphylaxis was not reported (mean=€7,159). Protudjer *et al.* (2015) indicated that children and adolescents who had experienced anaphylaxis were more likely to carry an adrenaline auto-injector (AAI) which was reported to be associated with 'substantial' out-of-pocket expenses. This study also reported a significantly greater ($P < 0.043$) loss of earnings in households with food allergic adolescents (but not children) than in control households (mean=€1,408 and €544 respectively). Parents perceived their own well-being, as well as that of their child and/or adolescent, to be 'poorer' when compared with parents in households without food allergy.

Jansson *et al.* (2014) investigated household costs among Swedish adults with 'objectively' diagnosed food allergies to cow's milk, hen's egg and/or wheat (n=81) who had been recruited from an outpatient allergy clinic in Sweden. Other self-reported allergies were recorded in this survey, which showed that self-reported allergy to peanut and/or tree nuts was more prevalent among these food allergic adults compared to controls (age and sex-matched; 61.7% vs 3.5%, respectively; $P < 0.001$). The mean annual total household costs (direct plus indirect costs) were significantly higher (by €8,164) for food allergic adults (n=81) than the non-allergic control group (n=85; €23,856 and €15,692, respectively). It was also noted that the presence of concomitant allergic disorders did not affect total costs and that the number of offending foods did not significantly impact total costs like the findings of Protudjer *et al.* (2015) for children and adolescents. However, a self-reported history of anaphylaxis was reported to be associated with significantly higher costs (by €11,199) compared with no history of anaphylaxis (€29,108 and €17,909, respectively). This included direct costs which were significantly higher for cases with a self-reported history of anaphylaxis (€15,487 vs €9,816; $P < 0.05$). The mean annual direct costs of healthcare (€237), medicines (€495) and travel to healthcare professionals (€82) were reported to be significantly higher for those with food allergies than for the non-allergic controls (€60 for healthcare costs, €199 for medicines and €10 for travel to healthcare professionals). These results indicate that food allergy severity may impact direct costs, notably healthcare and medication. Indirect costs were also reported to be significantly higher (by €6,424) for households with food allergic adults, compared to non-allergic controls (€12,822 and €6,398, respectively). This included significantly higher indirect costs associated with time spent performing domestic tasks due to a family member's food allergy, e.g., shopping, preparing food, etc. When intangible costs were considered, adults with a food allergy were reported to have overall lower health status, self-perceived health status and perceptions of well-being than non-allergic controls. In summary, Jansson *et al.* (2014) suggests that food allergies are often an unacknowledged resource burden on affected households.

A study by Cerecedo *et al.* (2014) examined an individual's costs before and after diagnosis using the double-blind placebo-controlled food challenge (DBPCFC) in Spain and Poland as part of the EuroPrevall study. The validated questionnaire FA-ECOQ (Fox *et al.* 2009) was distributed before and after the DBPCFC. Patients were invited to participate on the first day of the DBPCFC (baseline) and were re-evaluated six months later using the same instrument. Specifically, direct and indirect costs were compared before and after the DBPCFC to detect possible differences between tolerant and reactive patients (or parents of tolerant and reactive children). Costs were reported in international dollars with 2007 as the benchmark year. Forty-two patients (31 food allergic children (median age of three years) and 11 food allergic adults (median age of 35 years)) were followed up after the DBPCFC and information on costs was collected before the challenge and six months afterwards. The annual median total direct and indirect costs at baseline for the 42 patients were I$3,289.8/€2,928 and I$5,094.4/€4,534, respectively. Six months after the DBPCFC challenge, patients with a confirmed food allergy were reported to have had significantly higher total costs (median increase of I$813/€724) compared to the total cost spend in 2007 (the benchmark year), while patients negative for food allergy recorded a median decrease in total costs (I$87.3/€78) compared to the 2007 benchmark (P=.031). The amount of money spent on food six months after diagnosis was also significantly higher in those with a confirmed food allergy (P=.040). It was noted that around 70% of the patients were diagnosed as allergic to milk and egg. These two foodstuffs were also reported to be the most frequently 'self-reported' causes of food allergies in the EU based on the EuroPrevall cross-sectional study (McBride *et al.* 2012). Milk and egg are present in many manufactured products and allergic patients need to avoid foods that contain these ingredients even in trace amounts.

In France, Flabbee *et al.* (2008) estimated the economic costs of anaphylaxis, including direct medical expenses (such as treatment, hospitalisation, preventative and long-term care measures) and indirect costs (absenteeism only) for 402 patients (children and adults) with severe anaphylaxis, as documented by the Allergy Vigilance Network (AVN). The global cost was estimated from the national data on hospital admissions for anaphylaxis available for 2003, 2004 and 2005 using International Classification of Diseases (ICD-10) codes for anaphylaxis. Of the 402 patients, 248 patients (96 children and 152 adults) were reported to have experienced food anaphylaxis and 154 cases (17 children and 137 adults) were reported to have experienced drug-related anaphylaxis. From this study, the mean direct cost was reported as €1,580 per patient and the mean indirect cost (based on mean absenteeism of three work/classroom days) was €315. The mean total cost was estimated to be €1,895 for food and drug-related anaphylaxis per patient (€5,610 for the most severe) and €4,053 for Hymenoptera (wasps, bees, etc.) anaphylaxis.

Interestingly, a study by Alanne *et al.* (2012) in Finland reports that having a food allergic infant incurs a higher household cost than other allergic diseases, namely atopic dermatitis and asthma (determined from birth to two years of age). In fact, they determined that the mean total cost per infant was €4,348 with food allergy during the first two years, €425 with atopic dermatitis, €1,858 with asthma, and €50 with healthy infants. The reported mean total cost per infant with food allergy by the first year was €1,791 and €2,556 by second year. The highest direct costs for food allergies were reported to be associated with hospital outpatient care, e.g., food challenges, infant formulae for cow's milk allergies, and indirect costs from travel. This study reported the additional dietary cost for infants with food allergy compared to healthy infants was a median of €778 (mean €2,041) inclusive of the Social Insurance Institution of Finland reimbursement for part of the formulae costs for infants with cow's milk allergy.

A subsequent study (Alanne, 2012) reported that hydrolysed formulas (for infants with cow's milk allergy) were the main factor for increased dietary costs incurred by the families (n=23) with more 'severe' allergy in Finland. Notably, the group examined were not identified as either medically or self-diagnosed. The study reported that infants who used hydrolysed formula (n=12) had a higher daily dietary cost than those (n=11) who had used soy, oat or rice-based alternatives, or were breastfed at 12 months (€3.91 vs. €2.41 per day, respectively; $p=0.015$). In addition, the society's mean contribution (Social Insurance Institution of Finland) for using hydrolysed formula was €8.67 (SD 7.78) and €4.86 (SD 5.15) per allergic child at the ages of 12 and 24 months, respectively.

In the UK, Scott *et al.* (2019) estimated the resource use and associated costs for individuals with peanut allergy compared to matched controls using the data from the UK Clinical

Practice Research Datalink and Hospital Episode Statistics. Individuals with peanut allergy (n=15,483) were matched to two control groups: the first (simple-matched) were matched 1:1 on year of birth, general practice, gender and registration year (n=13,609, 87.9%). The second (atopy-matched) were matched on the same characteristics plus presence/absence of an atopic condition (n=9,320, 60.2%). The prescriptions and primary and secondary care contacts between cases and controls were compared. They reported the total annual incremental health-care costs for peanut-allergic individuals as £253/€293 (atopy-matched) and £333/€386 (simple-matched). This study concluded that individuals with peanut allergy had increased health-care contacts and consequently increased associated costs when compared to their control counterparts.

In more general terms, a study by Voordouw *et al.* (2016) conducted in the Netherlands, Poland and Spain (n=1,558) examined socio-economic costs associated with food hypersensitivity as opposed to having food allergies specifically (as examined in the previous papers reviewed). Voordouw *et al.* reported that the average direct and indirect costs calculated across all countries for families with food hypersensitivity (adults or children) were not higher than for control households. This finding contrasts with previous studies (Voordouw *et al.* 2010; Fox *et al.* 2013; Jansson *et al.* 2014; Protudjer *et al.* 2015) which examined direct and indirect costs associated with food allergies (as opposed to food hypersensitivities). They noted that one of the reasons for the lack of greater incurred costs in the case of food hypersensitive households might be due to a restriction in food choices and related behaviours, including social and recreational activities, leading to fewer expenses when compared to a family without food hypersensitivity (Cornelisse-Vermaat *et al.* 2008 and Voordouw *et al.* 2009). However, Voordouw *et al.* does report higher costs for 'time' spent with, and travelling to visit, health professionals by food hypersensitive members in all the countries examined. In common with previous food allergy studies, they reported that intangible costs for food hypersensitive individuals appear to be higher than those for controls and concluded the associated 'lost opportunities' were 'substantial'. Food hypersensitive individuals were also more likely to report restrictions concerning their job, giving up a job, changing job, restrictions on leisure activities and social life, change of residence, and delayed family expansion, compared to controls. Voordouw *et al.* proposed that having a food hypersensitivity can influence, or limit, life choices associated with schooling, employment and family planning, possibly resulting in unfulfilled aspirations.

1.3.2 World-wide studies

A systematic review conducted by Bilaver *et al.* (2019) assessed the economic burden of food allergies worldwide. Eleven papers were included in this global review (four articles from the US and seven European articles). Four out of seven European articles were part of the EuroPrevall project These articles yielded household-level incremental costs of food allergies using questionnaires that compared households with and without food allergic members in Sweden, Greece, Iceland, Poland and Spain. The generated costs were converted to US dollars (as set in 2018) and were converted to 2019 euro (exchange-rates.org) for comparison. The seven articles that were not part of EuroPrevall all described individual-level or societal-level costs (as opposed to household-level costs) of food allergies. Summary of costs are outlined in Tables 3.3.2a to 3.3.2c for studies in European countries and Tables 3.3.2d to 3.3.2f for the US. This review provided insights into the economic effect of direct medical, out-of-pocket and opportunity costs to individuals and their families with food allergies in the selected countries. Direct medical costs are medical costs borne to the health care system. On the contrary, out-of-pocket costs are expenses associated with the burdens of disease that are not covered by insurance. Bilaver *et al.* define out-of-pocket costs as all health care and non-health care-related costs borne by patients, such as the expense of travel to the physician or hospital, insurance co-payments (co-paid by the insured person and the insurance company), cost of living, medications, specialised foods, health insurance premiums, counselling and special childcare arrangements. They considered opportunity cost as the loss of potential earnings that result from food allergy, for example decreased labour productivity, loss of leisure activity, and increased time spent on any food allergy related household tasks.

Based on the Bilaver review, notable findings included that the mean annual direct medical costs for an individual (US$2,081/€1,852) with food allergy were higher by US$1,275/€1,134 than the mean annual direct medical costs calculated per household with food allergy (US$806/€717). The mean out-of-pocket and opportunity costs for an individual with food allergy were $1,874/€1,668 and $1,038/€924, respectively, while the corresponding costs per food allergic household were $3,339/€2,972 and $4,881/€4,344, respectively. Moreover, household-level out-of-pocket costs were reported to be higher than medical costs (US$3,339/€2,972 compared to US$806/€717), with household-level opportunity costs the most expensive (US$4,881/€4,344). It was noted that direct medical costs are strongly influenced by the specific health care financing systems in place within countries. For this reason, direct medical costs between the European and US studies were difficult to compare in a like-for-like manner. In more general terms, the cost associated with 'special foods' were among the largest proportion of out-of-pocket expenses reported in both Swedish studies (Protudjer *et al.* 2015; Jansson *et al.* 2014) and a US study (Gupta *et al.* 2013), highlighting it as an important factor for consideration as reviewed by Bilaver *et al.* (2019).

In another study by Bilaver *et al.* (2016), the difference in the economic impact of food allergy based on socio-economic status was highlighted. They hypothesised that direct medical and out-of-pocket costs of children with food allergy vary according to socio-economic characteristics (household income, race and ethnicity). Households with food allergic children in the lowest income group incurred 2.5 times the amount of emergency department and hospitalisation costs than higher income strata ($1,021/€909 vs $416/€370; P <0.05). Furthermore, expenses associated with specialist visits were reported to be less in the lowest income group ($228/€203) than the highest income groups ($311/€277; P <0.01). In terms of adjusted mean out-of-pocket costs, there was a significant relationship between increasing family income and increasing out-of-pocket medication. Low-income children had lower spending on specialty care and out-of-pocket expenses but incurred greater costs for emergency department visits and hospitalisation. The low spends on specialist visits and key preventive measures suggest that children in lower-income families may be at a higher risk for accidental ingestions and anaphylaxis because they have less access to specialty care, allergen-free foods and emergency medications such as epinephrine auto-injectors.

Gupta *et al.* (2013) reports that childhood food allergies in the US place a 'considerable' economic burden on families and society. In fact, the overall economic costs of childhood food allergies (consisting of direct medical costs, out-of-pocket expenses, opportunity costs and lost labour productivity) were estimated to be approximately $24.8 (€22.1) billion annually (or $4,184/€3,724 per child per year). Direct medical costs to the US health care system were estimated to contribute to the region of $4.3 (€3.8) billion annually (or $724/€644 per child per year). However, most expenses were associated with lost labour productivity (due to time spent on medical visits), out-of-pocket and opportunity costs, which were collectively estimated to be in the region of $20.5 (€18.2) billion annually (or $3,457/€3,077 per child per year). In more specific terms, lost labour productivity and out-of-pocket costs were reported to be $0.77 (€0.69) billion annually (or $130/€116 per child per year) and $5.5 (€4.9) billion (or $931/€829 per child per year), respectively. Notably, the highest reported cost of $14 (€12) billion (or $2,399/€2,135 per child per year) was due to associated opportunity costs, such as a change/or loss of a job, because of a child's allergy.

Interestingly, caregivers reported a willingness to pay (WTP) of approximately $20.8 (€18.5) billion annually ($3,504/€3,119) per child per year) for an effective food allergy treatment. These WTP estimates are remarkably like the total costs borne by families associated with out-of-pocket expenses, lost labour productivity and lost opportunity minus direct medical costs, suggesting possible avenues for future exploration in this area.

Summary tables based on studies of socio-economic costs of food allergies in Europe

Table 1.3.2a: Direct medical costs borne by the health care system per food allergic patient per year in European countries. 2018 US$ and 2019 euro (converted) (adapted from Bilaver *et al.* 2019)

State	Country	Primary care consultations	Private specialists & examination	Inpatient hospital stays	ED visits	Hospital Outpatient care	Medica-tion	Travel costs	Infant formula	Disability allowance	Total ($)	Total (€)
Alanne *et al.* 2012 (first year of life)	Finland	$91.76/ €81.67	$108.04/ €96.16	NR	NR	$627.50/ €558.48	$47.36/ €42.15	$185/ €164.65	$1,011.38/ €900.13	$238.28/ €212.07	$2,309.32	€2,055.29
Alanne *et al.* 2012 (second year of life)	Finland	$7.40/ €6.59	$158.35/ €140.93	NR	NR	$741.45/ €659.89	$47.36/ €42.15	$187.95/ €167.28	$1,712.30/ €1,523.95	$688.17/ €612.47	$3,542.98	€3,153.25
Flabbee *et al.* 2007 (children)	France	NR	NR	NR	NR	NR	NR	NR	NR	NR	$2,624.59	€2,335.89
Fox *et al.* 2013 (children)	Multiple EU countries	NR	NR	NR	NR	NR	NR	NR	NR	NR	Greece: $153.41 Iceland: $112.01 Poland: $1,654.58 Spain: $1,199.24	Greece: €136.53 Iceland: €99.71 Poland: €1,472.58 Spain: €1,067.32

State	Country	Primary care consultations	Private specialists & examination	Inpatient hospital stays	ED visits	Hospital Outpatient care	Medica-tion	Travel costs	Infant formula	Disability allowance	Total ($)	Total (€)
Fox *et al.* 2013 (adults)	Multiple EU countries	NR	NR	NR	NR	NR	NR	NR	NR	NR	Greece: $253.24 Iceland: $1,065.31 Poland: $2,208.55 Spain: $233.76	Greece: €225.38 Iceland: €948.13 Poland: €1,965.61 Spain: €208.05

*Abbreviations: ED, emergency department; NR, not reported. [a]Direct medical costs are those borne by the health care system associated with the prevention, diagnosis and treatment of food allergies. **All costs were converted to 2018 US dollars and 2019 euro (1 US Dollar=€0.89, exchange-rates.org).

Table 1.3.2b: Out-of-pocket costs[a] 2018 US$ and 2019 Euro (converted)**) of food allergy in European countries (adapted from Bilaver *et al.* 2019)

Study	**Country**	**Travel for visits**	**Cost of living**[b]	**Medications**	**Diet and food**	**Health insurance**	**Total ($)**	**Total (€)**
Flabbee *et al.* 2007 (children)	France	NR	NR	NR	NR	NR	$2,342.45	€2,084.78
Cerecedo *et al.* 2014	Spain and Poland	$3.29/ €2.93	NR	$301.09/ €267.97	$2,742.42/ €2,440.75	NR	$4,005.33	€3,564.74
Jansson *et al.* 2014	Sweden	$88.79/ €79.02	$1,427.92/ €1,270.85	$360.01/ €320.41	Included in cost of living	$24.33/ €21.65	$2,116.02	€1,883.26
Protudjer *et al.* 2015 (children 0-12 years old)	Sweden	$56.70/ €50.46	$2,702.48/ €2,405.21	$423.03/ €376.50	Included in cost of living	−$168.3/ -€149.79	$3,031.03	€2,697.62
Protudjer *et al.* 2015 (adolescents 13-17 years old)	Sweden	$24.72/ €22.00	$3,504.95/ €3,119.41	$543.69/ €483.88	Included in cost of living	$85.77/ €76.34	$4,204.18	€3,741.72

*Abbreviations: ED, emergency department; NR, not reported.

** All costs were converted to 2018 US dollars and 2019 euro (1 US Dollar=€0.89, exchange-rates.org).

[a] The definition of out-of-pocket costs can vary to include or exclude healthcare expenses. In this instance 'out-of-pocket' costs include those borne by patient associated with the prevention, diagnosis and treatment of food allergies, and all costs associated with protecting the child from exposure to allergens, including special childcare arrangements. This definition includes medication in this instance. Both articles by Alanne *et al.* 2012 are excluded from the table because they only present out-of-pocket costs related to infants' diets during a very narrow period of infancy and early childhood.

[b] Includes costs of food.

Table 1.3.2c: Opportunity costs of food allergy in European countries (adapted from Bilaver *et al.* 2019)

Study	**Country**	**Opportunity Costs, 2018 US$ and 2019 euro (converted) *Total lost labour productivity and/or time costs ($)**	**Opportunity Costs, 2018 US$ and 2019 euro (converted) *Total lost labour productivity and/or time costs (€)**
Alanne *et al.* 2012 (first year of life)	Finland	$141.96	€126.34
Alanne *et al.* 2012 (second year of life)	Finland	$134.92	€120.07
Cerecedo *et al.* 2014	Spain and Poland	$6,202.43	€5,520.16

* All costs were converted to 2018 US dollars and 2019 euro (1 US Dollar=€0.89, exchange-rates.org).

Summary Table based on Studies of Socio-economic Costs of Food Allergies in the United States

Table 1.3.2d: Direct medical costs* per Patient with FA Per Year, 2018 US$ and 2019 Euro (converted)** (borne by the health care system) of food allergy in the US (adapted from Bilaver *et al.* 2019)

Study	Country	Primary care consultations	Private specialists and examination	Inpatient hospital stays	ED visits	Hospital outpatient care	Total ($)	Total (€)
Gupta *et al.* 2013	USA	$103.25/ €91.89	$212.11/ €188.78	$352.39/ €313.63	$144.77/ €128.85	NR	$812.51	€723.13
Miller *et al.* 2016	USA	NR	NR	NR	NR	NR	$1,113.74	€991.23

Abbreviations: ED, emergency department; NR, not reported.

[x] Hospital outpatient care, medication, travel costs, infant formula and disability allowance were not included in the costs analysis

* Direct medical costs are those borne by the health care system associated with the prevention, diagnosis, and treatment of food allergies. The article by Bilaver *et al.* 2016 is excluded from the table because it focuses on direct costs by race, ethnicity and income, and uses the same database as the articles by Gupta *et al.* 2013. The article by Patel *et al.* 2011 is excluded from the table because individual-level direct medical costs attributable to FA were not reported.

** All costs were converted to 2018 US dollars and 2019 euro (1 US Dollar=€0.89, exchange-rates.org).

Table 1.3.2e: Out-of-pocket costs* (costs borne by patient) of food allergy in the US (adapted from Bilaver *et al.* 2019) From Gupta *et al.* 2013 Study United States

Out of pocket cost of the patient (individual-level) 2018 US$ and 2019 euro (converted)*	Euro	Dollar
Visits to physicians or ED (including co-payments)	€164.80	$185.17
Travel (for visits)	€24.97	$28.06/
Medications	€117.86	$132.43/
Diet and food	€284.66	$319.84/
Childcare, schools, camps, and/or counselling	€310.63	$349.02/
Total ($)	-	$1,405.06
Total (€)	€1,250.50	-

Abbreviations: ED, emergency department.

* All costs were converted to 2018 US dollars and 2019 euro (1 US Dollar=€0.89, exchange-rates.org).

* Out-of-pocket costs include those borne by patient associated with the prevention, diagnosis and treatment of food allergies, and all costs associated with protecting the child from exposure to allergens, including special childcare arrangements. The article by Bilaver *et al.* 2016 is excluded from the table because it focuses on out-of-pocket costs by race, ethnicity and income, and uses the same database as the article by Gupta *et al.* 2013.

* All costs were converted to 2018 US dollars and 2019 euro (1 US Dollar=€0.89, exchange-rates.org).

Table 1.3.2f: Opportunity costs of food allergy in the US (adapted from Bilaver *et al.* 2019) From Gupta *et al.* 2013 Study United States

Opportunity cost	Dollar	Euro
Total lost labour productivity and/or time costs ($) Opportunity costs, 2018 US$ and 2019 euro (converted)**	$2,838.18	
Total lost labour productivity and/or time costs (€) Opportunity costs, 2018 US$ and 2019 euro (converted)**	-	€2,525.98

* All costs were converted to 2018 US dollars and 2019 euro (1 US Dollar=€0.89, exchange-rates.org).

1.4 Quality of life of food allergic individuals and their family

Brazier *et al.* (2007) refers to HRQoL as the impact of the health aspects of an individual's life on that person's quality of life, or overall well-being. Contrary to direct and indirect cost, intangible costs such as the loss of HRQoL are typically not experienced in monetary terms. However, their influence can still be very pronounced in the lives of food allergic individuals (Bollinger *et al.* 2006; Flokstra-De Blok *et al.* 2010; Jansson *et al.* 2013; Jansson *et al.* 2015; DunnGalvin *et al.* 2015; Protudjer *et al.* 2016). The negative impact of food allergies on the QoL of those affected and their families (Jansson *et al.* 2013; Jansson *et al.* 2014; Protudjer *et al.* 2015; Jansson *et al.* 2015) should be considered.

1.4.1 Family studies

DunnGalvin *et al.* (2015) reviewed the literature (examining both quantitative and qualitative research findings) to provide an in-depth picture of the impact of food allergy on the concerns and everyday lives of children, teens, adults and parents. They proposed that food allergy has a 'strong' impact on HRQoL in terms of social, dietary and psychological factors. In particular, it was noted that food restrictions and avoidance extend far beyond 'mealtimes', as food is such an integral part of daily life. For example, social events are experienced differently by people with food allergy; sometimes they give rise to feelings of isolation or exclusion. Moreover, food allergies were reported to compound existing psycho-social stress in a household (e.g., normal developmental changes), potentially leading to adverse effects on overall HRQoL.

Flokstra-De Blok *et al.* (2010) compared the HRQoL of food allergic adults (n=72), children (n=79) and adolescents (n=74) with the general population and other chronic diseases by using a generic HRQoL questionnaire in the Netherlands. Food allergic adolescents and adults were reported to have 'impaired' QoL and significantly lower scores on 'bodily pain' (P=0.020) when compared to the general population. In fact, adults and adolescents with food allergies were reported to have 'poorer' overall health and HRQoL, than their non-food allergic counterparts. Moreover, adults with food allergy reported poorer HRQoL than that of adults with diabetes mellitus, but better HRQoL than adults with rheumatoid arthritis, asthma and irritable bowel syndrome.

Bollinger *et al.* (2006) conducted a study to evaluate the impact of food allergy on the daily activities of food allergic children and their families in the US. Among 87 families, more than 60% of caregivers reported that a child's food allergy significantly affected their meal preparation, while 41% of parents reported that their stress levels were significantly affected. The causes were reported to be ‘cost’ (leading factor), correct allergen labelling, and the potential for cross-contamination and accidental allergen exposure outside of the home, e.g., schools, parties, etc. In addition, Bollinger *et al.* reported that 49% of parents indicated that their child’s food allergy impacted on the type of social activities that each family could engage in. In more general terms, 34% of respondents reported that their child’s attendance at school was affected, with 10% noting that they would choose to homeschool their children because of their food allergy.

Following a world-wide literature review by Antolin-Amerigo *et al.* (2016), this research group described the factors that may influence the quality of life of patients (children, adolescents and adults) with regard to food allergy. Sicherer, Noone & Muñoz-Furlong (2001) noted that food allergic children with multiple food allergies (greater than two) had lower QoL scores compared to those with one or two food allergies. Food allergies were also reported to affect the QoL scores for adolescents, resulting in social isolation, depression, difficulties in school performance and leisure activities, along with the fear of allergic reactions (Cumming *et al.* 2010; MacKenzie *et al.* 2010; Sommer *et al.* 2014). Uncertainty and anxiety were reported to account for the greatest impact on HRQoL in the food-allergic adults reviewed (Flokstra-de Blok *et al.* 2009; Goossens *et al.* 2014; Antolin-Amerigo *et al.* 2015). In fact, Antolin-Amerigo *et al.* (2016) noted that the fact that neither the time of onset, nor the predictability of the intensity of the allergic reaction, can significantly influence QoL. The constant threat of allergen exposure and the need for vigilance in the avoidance of specific foods were reported as important influencing factors (de Blok *et al.* 2007; Goossens *et al.* 2014).

1.4.2 Adult studies

Jansson *et al.* (2013) investigated HRQoL in Swedish food allergic adults to at least one staple food: cow’s milk, hen’s egg or wheat. The group involved (n=79; 28 males, 51 females, mean age=41 years) was recruited at an outpatient clinic where they had been medically diagnosed with a food allergy. The respondents completed a disease-specific food allergy quality of life survey FAQLQ-AF (EuroPrevall) containing a total of 29 questions which assesses HRQoL in four areas: Allergen Avoidance and Dietary Restrictions (AADR), Emotional Impact (EI), Risk of Accidental Exposure (RAE), and Food Allergy-related Health (FAH). Out of the four areas examined, AADR had the largest negative impact on HRQoL, while health concerns associated with having a food allergy (FAH) was reported as having the least impact. Notably, previous episodes of anaphylaxis (and particularly the prescription of an AAI), was associated with an overall ‘low’ HRQoL. Moreover, this paper proposes that both the severity of the food allergy and the presence of associated allergic disorders can have a ‘profound impact’ on HRQoL, for example, asthma in combination with food allergy.

A further study by Jansson *et al.* in 2014 on food allergic adults (n=81, and a control group of n=85) reported that food allergic adults in Sweden experienced overall lower health status and self-perceived health status than their non-allergic counterparts. In fact, adults with an allergy to at least one of the staple foods of cow’s milk, hen’s egg or wheat reported significantly reduced and impaired HRQoL (as determined by EQ-5D).

1.4.3 Children and adolescent studies

Jansson *et al.* (2015) investigated the factors that affect HRQoL in households with a child or adolescent with objectively diagnosed allergy to at least one of the staple foods: cow’s milk, hen’s egg or wheat. In this study, adolescents and parents of food allergic children completed the FAQLQ. In total, 85 children (0-12 years) and 58 adolescents (13-17 years) cases, as well as 94 children and 56 adolescents controls, participated. Dietary restrictions (AADR) had the largest negative impact on HRQoL experienced by the adolescents, while concern for accidental exposure (AE) had the least. Children who had previous anaphylaxis ($p < 0.001$) and an AAI prescription ($p < 0.05$) had a lower HRQoL: this trend was not observed in the adolescents. The variations in findings reported between children and adolescents indicate that consideration should be given to the age of the patient when managing patients with food allergies.

Protudjer *et al.* (2015) reported that food allergic children and adolescents (n=144, a control group of n=150) in Sweden had a ‘poorer’ perception of their own well-being in parent-reported studies than their peers without this condition. They also reported that food allergic children and adolescents experienced overall lower health status and self-perceived health status than their non-allergic counterparts (as determined by EQ-5D).

A later study by Protudjer *et al.* (2016) investigated the association between objectively-diagnosed allergy to cow’s milk, hen’s egg and/or wheat and HRQoL amongst adolescents aged 13-17 years (n=58) in Sweden using the disease-specific Food Allergy Quality of Life Questionnaire-Teenager form (FAQLQ-TF) by EuroPrevall (18 females and 40 males). The food allergies impacted on the adolescents’ lifestyles and were associated with poorer than average overall HRQoL. The mean score for overall HRQoL for adolescents was 4.70/7.00 (based on the FAQLQ-TF scale of 1-7, where 1 corresponds to the best HRQoL and 7 corresponds to worst HRQoL (self-reported)). Factors such as 'emerging independence' and 'the need for support' (e.g., eating out, emotional issues surrounding communication, and understanding/acknowledgment of food allergies by others, etc.) were noted. Females were reported to have 'clinically worse' HRQoL compared to their male counterparts. However, this was not reported to be statistically significant (mean difference=0.71; p <0.07). HRQoL tended to be lower amongst those with multiple food allergies (three or more) or those with an AAI prescription. Interestingly, the number and types of symptoms, including a history of anaphylaxis, were not associated with a decrease in HRQoL score.

1.5 The socio-economic costs of Coeliac disease

Food intolerances, also known as metabolic food disorders, occur because of genetically determined metabolic deficiencies that affects the ability to metabolize a specific substance in foods, or heightens sensitivity to a particular foodborne chemical (Taylor & Baumert, 2020).

Coeliac disease is a chronic inflammatory intestinal disease caused by an autoimmune response to gluten proteins, which occurs in genetically susceptible individuals (Cappaci *et al.* 2018). Sources of gluten include wheat, barley and rye and repeated consumption results in intestinal mucosal damage and other symptoms. Management of the condition requires a strict life-long gluten-free (GF) diet. Coeliac disease can manifest at any age with a variety of symptoms (Caio *et al.* 2019).

Non-coeliac gluten sensitivity is diagnosed in individuals who do not have coeliac disease or a wheat allergy but who have intestinal symptoms, extraintestinal symptoms, or both, relating to the ingestion of gluten-containing foods. Notably, there are also symptomatic improvements on withdrawal of gluten-containing products from the diet (Leonard *et al.* 2017).

An overall prevalence rate of 1% for coeliac disease in EU populations has been suggested (Mustalahti *et al.* 2010; Caio *et al.* 2019) and rates of 0.5-1% have been reported in the Irish and UK populations (FSAI, 2015; Irish College of General Practitioners (ICGP), 2015; Coeliac Society of Ireland (CSI), 2019; Coeliac UK, 2019). In a systematic review and meta-analysis, Singh *et al.* (2018) reported that coeliac disease had a global prevalence of 0.7% (n=138,792) when based on biopsy-confirmed results, and up to 1.4% when based on serological test results (n=275,818). Prevalence rates have been reported to be statistically significantly higher in females (Singh *et al.* 2018).

Picarelli *et al.* (2014) reported that each year of delay in diagnosing coeliac disease is ultimately associated with higher medical care costs. The medical costs of laboratory tests and medical surveys were collected from coeliac disease patients (n=28) in Italy and the US over a three-year period prior to their receiving the 'correct diagnosis'. The total pre-diagnosis expenditure was €408 in Italy and $8,748 (€7,786) in the US. The mean cost proposed was €136 in Italy and $2,916 (€2,595) in the US for each year of delay in diagnosis. This study agrees with another US study by Long *et al.* (2010), which examined the impact of coeliac disease diagnosis on direct medical costs borne by 133 index cases versus 133 controls cases over one year, pre- and post-diagnosis. The average total costs were reduced by $1,764 (€1,570) in the year following diagnosis (pre- and post-diagnosis costs of $5,023 (€4,470) and $3,259 (€2,901), respectively; 95% confidence interval of difference $688 (€612) to $2,993 (€2,664)), highlighting the importance of a timely and correct diagnosis of this condition.

Another study by Violato *et al.* (2012) reported higher health costs for coeliacs pre- and post-diagnosis in an examination of 3,646 medically diagnosed coeliac disease (MDCD) and 32,973 non-coeliac controls in UK primary care, as extracted from the General Practice Research Database (GPRD) between 1987–2005. Contrary to reports by Picarelli *et al.* (2014) and Long *et al.* (2010), Violato *et al.* reported that the average annual healthcare costs per coeliac disease patient increased by £310 (€360) p.a. after diagnosis (£340 (€394) pre-diagnosis versus £650 (€754) post-diagnosis). This calculation was based on the average costs to the individual for a maximum of 10 years post diagnosis. These differences were mainly driven by higher costs for tests and referrals (70% and 50%, respectively, compared with matched controls), while consultation and prescription costs contributed to a lesser extent (less than 40% higher than for controls).

Similarly, Long *et al.* (2010) reported that MDCD individuals (n=153) in a US study experienced higher out-patient costs (mean difference of $1,457 (€1,297); P=0.016) and higher total costs (mean difference of $3,964 (€3,528); P=0.053) than non-coeliacs (n=153) when examined over a four-year timeframe. These higher totals costs were reported to be associated with out-patient costs, radiological costs, laboratory service use and office visits. In summary, higher costs (mainly attributed to healthcare) have been associated with coeliac disease pre- and-post diagnosis (Long *et al.* 2010; Violato *et al.* 2012; Picarelli *et al.* 2014).

1.5.1 Availability and cost of gluten-free products

Previous studies have reported a lack of palatability regarding substitute gluten-free (GF) products which can affect adherence to a strict GF diet (Roma *et al.* 2010 and Crocker *et al.* 2018). In addition, a review of 110 products available in UK supermarkets in 2017 (Allen & Orfila, 2018) found that GF products were reported to be significantly lower ($p < 0.01$) in protein and higher in fat and fibre ($p < 0.05$) than their conventional counterparts. Similarly, Fry *et al.* (2018), in an examination of these macronutrients in 1,724 products in the UK, observed higher levels of fat, sugar and salt in GF bread (and some crackers) compared to standard foods. Allen & Orfila (2018) reported that only 5% of GF bread products in the UK were fortified with micronutrients such as calcium, iron, nicotinic acid/nicotamide and thamin, and 28% with calcium and iron. Thompson (1999, 2000) reported that only 9-23% of GF bread products in the United States were fortified with thiamin, riboflavin and niacin, and no fortification in US GF pasta products was recorded. These recent studies have demonstrated low intakes of micronutrients in the diets of coeliacs (Kinsey *et al.* 2008; Wild *et al.* 2010; Ohlund *et al.* 2010; Abenavoli *et al.* 2015), which is of particular concern for growing children.

In more general terms, many studies have demonstrated that adherence to a GF diet significantly increases the cost of food for adherents, with prices often two to three times greater than for similar non-GF products (Lee *et al.* 2007; Burden *et al.* 2015; Panagiotou and Kontogianni, 2017; Fry *et al.* 2018; Allen & Orfila, 2018; Hanci and Jeanes, 2019; Lee *et al.* 2019). The cost of maintaining a strict GF diet can be prohibitive, with 33% of participants reporting cost as the reason for dietary non-compliance in a study of several US cities (sample size unknown) in 2016 (Lee *et al.* 2019). One key reason for the cost difference is that naturally gluten-free grains and flours (e.g., quinoa, millet, teff, sorghum, buckwheat) currently available on the market are not as mainstream as their gluten containing counterparts. For example, if we examine a staple food like bread, Allen & Orfila, (2018) reported the average increase in the cost of GF bread alternatives in the UK was 220-314% (white (+307%), brown (+314%) and seeded (+220%)). In addition, the cost of GF pasta was found to be 70% higher than the cost of standard pasta. GF products were significantly more expensive across all four product categories than the standard equivalents. Two further UK studies (Burden *et al.* 2015; Hanci & Jeanes, 2019) reported GF products being up to 400% more expensive than their wheat-based counterparts.

In addition to the higher cost of GF food, many reports discuss the limited availability of GF products on the market. Notably, Allen & Orfila, (2018) reported GF foods are less available and more expensive than gluten-containing products in the UK supermarkets. A total of 110 products were examined in the cost and nutritional analysis section of this study, and significantly more 'standard' products were found to be available across all categories. In fact, the mean number of standard products ranged from 23 to 62 per category, while the mean number of GF products available ranged from 4 to 11. There was a significantly lower number of GF white breads, brown breads and pasta available compared to standard alternatives ($p \leq 0.01$). Therefore, the increased economic burden of coeliac disease and the reduced availability of products may increase the likelihood of some coeliacs being unable to comply with a GF diet.

1.5.2 Measures to address the cost of gluten free food

Designated schemes exist in some countries to assist coeliacs with the cost of GF foods. For example, coeliacs in Ireland and Canada receive tax deductions to subsidise the additional cost of GF foods. In the UK, coeliacs are eligible to access GF core staples on prescription. The National Health Service (NHS) spends about £195 (€226) per patient per annum to cover the costs of prescribed foods (NICE, 2015). Cappaci *et al.* (2018) noted there is suggestive evidence that the price paid by the NHS is higher than the shelf price of the same GF products sold in supermarkets (Department of Health, 2017b). In fact, in March 2017 the Department of Health launched a public consultation on whether to end or reduce GF food prescriptions in England (Department of Health, 2017a) given the increased availability of GF foods on the market. The cost of GF prescriptions in the UK is estimated to be £25.7 (€29.8) million (2015 data).

In Italy, law no.123 from 2005 recognises coeliac disease as a 'social disease' and ensures the free distribution of GF foods. Capuozzo *et al.* (2013) stated that the pharmaceutical service in Italy produced a booklet composed of 12 coupons corresponding to the months of the year. The value in euro for each coupon varied according to the age and gender of the patient, based on pre-determined expenditure patterns associated with an individual's demand for GF products. The value of each coupon for each age group was as follows: €45 for children aged 6 months to one year (both sexes), €62 for children aged 1-3.5 years (both sexes), €94 for children aged 3.5-10 years (both sexes), and for those 10 years or older the value of each coupon corresponds to €140 for males and €99 for females (most likely because of higher consumption patterns among males). It was reported that patients with coeliac disease can buy GF foods using these coupons in any Italian pharmacy.

These subsidy schemes can be beneficial to coeliacs, given the reported higher costs associated with GF products. From this perspective, they should be monitored to ensure that they accurately reflect the expenditure incurred because of the disease and can adequately support a GF diet where cost would otherwise be an obstacle.

1.5.3 Quality of life in coeliac disease

Many studies have reported a GF diet to be burdensome, restrictive and challenging to adhere to, which can cause difficulties in various aspects of daily life, including travelling, shopping and eating meals outside of the home (Sverker, Hensing & Hallert, 2005; Whitaker *et al.* 2009; Shah *et al.* 2014; Black & Orfila, 2011). In fact, Altobelli *et al.* 2013 reported frustrations felt by MDCD children and adolescents (n=140) following a restrictive diet in an Italian study. Notably, nearly 20% of participants reported feeling 'different from others' and 'misunderstood' because of their condition.

A survey by MacCulloch and Rashid (2014) evaluating GF diets in children and adolescents reported good adherence at home and in school, but low adherence at social events. Significant barriers to good adherence were reported to be the availability of GF products, appropriate labelling of food and the cost. Roma *et al.* (2010) reported that the main causes of non-adherence to GF diets in children (n=73) were poor palatability (32%), issues dining outside home (17%) and poor availability of products (11%). Furthermore, Wagner *et al.* (2008) reported that non-adherent adolescents had more physical problems, a higher burden of illness, higher feelings of "ill-health" and more family problems than their adherent counterparts.

Similarly, for adults (and as previously described), non-adherence to a GF diet can be associated with higher costs of GF alternatives and a limited availability of suitable products (Allen & Orfila, 2018; Lee *et al.* 2019), thereby affecting the individual's sense of well-being and overall HRQoL. Crocker *et al.* (2020) reported that healthcare experiences can affect the HRQoL of adults (≥18 years) with coeliac disease. A cross-sectional postal survey was completed by 268 members of Coeliac UK in 2014. A Coeliac Disease Assessment Questionnaire (CDAQ) of 53 questions was used, and four key healthcare associated areas were found to significantly impact the HRQoL of coeliacs. These were: information provision, general practitioners' knowledge, communication with health professionals, and access to prescriptions ($p < 0.05$). Crocker *et al.* noted that 'poorer' experiences of healthcare services were related to a worse overall HRQoL. Therefore, improving services in these key areas may help to ameliorate the deleterious effects on HRQoL reported in this study.

In summary, coeliacs have been reported to have a reduced HRQoL because of their condition (Ciacci and Zingone, 2015; Wagner *et al.* 2008; Crocker *et al.* 2020). In particular, the condition has had an impact emotionally, economically, psychologically, and on interpersonal relationships (Martínez-Martinez *et al.* 2019; Crocker *et al.* 2020). Mechanisms to support coeliacs regarding their healthcare requirements, and to address the cost and availability of GF foods, could greatly improve their quality of life.

2 Study methodologies

A comprehensive examination of the socio-economic cost of food hypersensitivity on the IoI was undertaken (as described in the Project Aims & Objectives) under the following headings:

- Food Hypersensitivity Survey Design, Collection & General Analysis
- Calculation of Socio-economic Costs Associated with Food Hypersensitivity on the IoI (presented as direct and indirect Costs, and as healthcare and out-of-pocket costs)
- Calculation of the Socio-economic Cost of Food Hypersensitivity on the IoI - intangible costs (EQ-5D) and effect on QoL
- Completion of Priority Setting Interviews of Individuals with MDFA or MDCD (and parents thereof) in Ireland and Northern Ireland
- Collection and Examination of Food Hypersensitivity Datasets in Public and Private Institutions
- Prevalence Rates for MDFA and MDCD on the IoI reported in the literature

2.1 Methodology for food hypersensitivity survey design, collection and analysis

In this study, the age groups examined were adults aged ≥18 years, children aged 0 to 12 years, and adolescents aged 13 to 17 years. Excess costs (compared to controls) were reported for adults and combined for children and adolescents due to the small number of respondents for the adolescents' group.

Surveys targeting adults or parents of children/adolescents with food hypersensitivities were developed by our team (scientists, medics and health economists) to be completed by respondents under the following headings:

1. Individuals with **medically diagnosed food allergies - MDFA** (as diagnosed by a healthcare professional via any or all the following methods: skin-prick test, blood tests, oral food challenge and trial elimination diet)
2. Individuals with **medically diagnosed coeliac disease - MDCD** (as diagnosed by a healthcare professional via blood tests and/or gut biopsy)

3. Individuals with **food intolerances or suspected/undiagnosed food allergies - FI** (not medically diagnosed)
4. Individuals with **no known food hypersensitivities** (i.e., control group). This survey was launched independently as a 'cost of living and health care' survey and contained corresponding questions to the other surveys

Eight surveys were designed to accommodate groups 1-4 as outlined above. Respondents fell into two categories: -

1. Individual adults reporting their own experiences of having food hypersensitivity.
2. Parents reporting their own and/or their household's experiences due to having a child/adolescent with food hypersensitivity. If more than one child/adolescent in a household was affected, the reporting parent was asked to complete the survey with reference to the eldest child/adolescent.

The questions for the surveys were based on the validated Food Allergy Economic Questionnaire (FA-ECOQ) developed by Europrevall (Fox *et al.* 2009), peer-reviewed papers (Miles *et al.* 2005; Voordouw *et al.* 2010; Fox *et al.* 2013; Cerecedo *et al.* 2014; Jansson *et al.* 2014; Protudjer *et al.* 2015; Voordouw *et al.* 2016), and on discussion with the project steering committee. The eight surveys proposed were reviewed by academics, medical consultants, scientists and stakeholders, including regulators and food hypersensitivity patient representative groups. The agreed surveys were then piloted for the purposes of validation with a test group of 104 individuals, which included both food hypersensitive and non-food hypersensitive adults, and parents of children/adolescents with food hypersensitivity. All feedback was considered by the project team. The final surveys were ethically approved by ethics committees in the Technological University Dublin (TU Dublin) and Queens University Belfast (QUB). The questionnaires had a completion time of between 30 – 40 minutes and 10 – 15 minutes for each control survey. They consisted of:

- 38 to 39 questions for respondents with MDFA (adults or parents)
- 31 to 32 questions for respondents with MDCD (adults or parents)
- 26 questions for respondents with FI (adults or parents)
- 20 to 21 questions for the control (non-food hypersensitive) adult and parent surveys.

Additional questions were added if, for example, an individual with MDFA also indicated that they were MDCD, or had additional food intolerances etc. This was made possible by using a sophisticated electronic platform (LimeSurvey) which not only added necessary questions where relevant, but also redirected respondents if they were completing the wrong survey. For instance, if a food hypersensitive respondent started to complete the control survey they would, based on information given in the initial line of questioning, be automatically redirected to the correct survey. The control study questionnaire (non-hypersensitive) was launched online, independent to the food hypersensitivity surveys in Ireland and Northern Ireland and titled 'Cost of Living and Healthcare'.

2.1.1 Methodology – survey distribution and collection

This survey set was available online on the LimeSurvey Platform via an electronic link. The online surveys were launched in November 2019 and ran until October 2020, with the focus on achieving target numbers for analysis in certain (low number) categories in the final few months of this study, i.e., the parental surveys for children with MDCD and FI. The Covid-19 pandemic began in Ireland and Northern Ireland in early March 2020, at which time additional wording was added to the surveys to request that respondents completing cost questions did so from a pre-Covid perspective. This wording was included to try to ensure that the pandemic (and possible associated changes in spending) had minimum impact on the overall study.

A Facebook page called the ‘Food Hypersensitivity Study’ (and an associated TU Dublin email address) were set up to promote these surveys, distribute the link online, and serve as a hub for respondents’ queries and questions. The survey link was forwarded to stakeholders in Ireland and Northern Ireland to circulate it widely. These stakeholders included the Coeliac Society of Ireland, Gluten Free Ireland, Coeliac UK, Irish Allergy Support Group, and Allergy Mums UK. The questionnaire was also promoted by ***safe*****food** on their Facebook page and by intermittent paid advertising on Facebook. Similarly, the project team attended various public events to distribute (and collect) hard copies of the surveys and to circulate fliers to members of the public regarding this study. These events included food hypersensitivity conferences, events, and meetings of associated support groups (including a radio broadcast in January 2020) in Ireland and Northern Ireland. No public events were attended by the project team from March 2020 onwards, at which point all survey promotion occurred online.

A total of 4,114 surveys were collected during this study (Table 2.1.1a) with 1,872 test surveys completed in Ireland (1,404 collected from adults and 468 from parents (Table 2.1.1b). A corresponding set of 699 control surveys (non-food hypersensitive) were collected in Ireland, from 557 adults and 142 parents. Regarding Northern Ireland, a total of 1,129 test surveys were completed with 834 collected from adults and 295 from parents. In addition, 414 control surveys (non-food hypersensitive) were collected in Northern Ireland from 229 adults and 185 parents.

Table 2.1.1a: Proposed study sample numbers and achieved study sample numbers in a food hypersensitivity survey carried out between November 2019 and October 2020 in Ireland and Northern Ireland

Groups to be examined	**Original proposed survey sample no.**	**Achieved survey sample numbers**
Children/Adolescents (<18) with MDFA - Ireland	≥125	258
Children/Adolescents (18) with MDFA - Northern Ireland	≥125	168
Total	≥250	426
Adults ≥18) with MDFA – Ireland	≥125	194
Adults (≥18) with MDFA - Northern Ireland	≥125	124
Total	≥250	318
Children/Adolescents and Adults with MDCD - Ireland	>100	774
Children/Adolescents and Adults with MDCD - Northern Ireland	>100	261
Total	≥200	1,035
Children/Adolescents and Adults with FI - Ireland	This group was not originally proposed for inclusion	646
Children/Adolescents and Adults with FI - Northern Ireland		576
Total		1,222
Control Group: Children/Adolescents - Ireland	≥125	142
Control Group: Children/Adolescents - Northern Ireland	≥125	185
Total	≥250	327
Control Group: Adults - Ireland	≥125	557
Control Group: Adults - Northern Ireland	≥125	229
Total	≥250	786
TOTAL	1,200	4,114

*MDFA: medically diagnosed food allergy; MDCD: medically diagnosed coeliac disease; FI: Food intolerance or suspected/undiagnosed food allergy.

Table 2.1.1b: A detailed breakdown of the survey sample numbers of food hypersensitive individuals (and parents thereof) collected between November 2019 and October 2020 in Ireland and Norther Ireland (n=4,114)

Collected survey sample for adults and parental surveys	**N**
Medically Diagnosed Food Allergy ADULT Surveys (MDFA) – Ireland	194
Medically Diagnosed Coeliac Disease ADULT Surveys (MDCD) – Ireland	623
Food Intolerance & Suspected Food Allergies ADULT Surveys (FI) – Ireland	587
ADULT Non-food hypersensitive controls – Ireland	557
Medically Diagnosed Food Allergy PARENTAL Surveys (MDFA) – Ireland	258
Medically Diagnosed Coeliac Disease PARENTAL Surveys (MDCD) – Ireland	151
Food Intolerance & Suspected Food Allergies PARENTAL Surveys (FI) – Ireland	59
PARENTAL Non-food hypersensitive controls – Ireland	142
Medically Diagnosed Food Allergy ADULT Surveys (MDFA) – Northern Ireland	124
Medically Diagnosed Coeliac Disease ADULT Surveys (MDCD) – Northern Ireland	195
Food Intolerance & Suspected Food Allergies ADULT Surveys (FI) – Northern Ireland	515
ADULT Non-food hypersensitive controls – Northern Ireland	229
Medically Diagnosed Food Allergy PARENTAL Surveys (MDFA) – Northern Ireland	168
Medically Diagnosed Coeliac Disease PARENTAL Surveys (MDCD) – Northern Ireland	66
Food Intolerance & Suspected Food Allergies PARENTAL Surveys (FI) – Northern Ireland	61
PARENTAL Non-food hypersensitive controls – Northern Ireland	185
TOTAL	4,114

*MDFA: medically diagnosed food allergy; MDCD: medically diagnosed coeliac disease; FI: Food intolerance or suspected/undiagnosed food allergy.

2.1.2 General analysis of the survey data

General analysis of the survey data was carried out on the 3,001 specific food hypersensitive surveys collected during this study. The findings of the general analysis are presented in Chapter 3 of this report and in Annexes 1-6. These Annexes present specific information recorded on each survey group by condition (MDFA, MDCD and FI) for Ireland and Northern Ireland. Parental surveys and adult surveys are also separated. As the dataset collected is quite large, a highlights section summarising the findings for each of the six survey groups has been included with the associated figures and graphs in each of the relevant Annexes, as detailed in Table 2.1.2.

Table 2.1.2: Index of general analysis annexes, based on food hypersensitivity survey data collected in Ireland and Northern Ireland between November 2019 and October 2020

Food hypersensitivity survey analysis
Annex 1: MDFA Parental Surveys in Ireland and Northern Ireland
Annex 2: MDFA Adults Survey in Ireland and Northern Ireland
Annex 3: MDCD Parental Surveys in Ireland and Northern Ireland
Annex 4: MDCD Adults Survey in Ireland and Northern Ireland
Annex 5: FI Parental Survey in Ireland and Northern Ireland
Annex 6: FI Adults Survey in Ireland and Northern Ireland

* MDFA: Medically Diagnosed Food Allergy; MDCD: Medically Diagnosed Coeliac disease; FI: Food intolerance or suspected/undiagnosed food allergy.

2.1.3 Statistical analysis of the survey data

Statistical analysis was carried out on various findings of the study, including differences in gender. The statistical tests used include the Pearson chi-squared test, the two-sample t-test, Kruskal-Wallis rank sum test, and Pairwise Wilcoxon rank sum tests, with Benjamini-Hochberg (1995) corrections for multiple testing.

2.2 Calculation of socio-economic costs associated with food hypersensitivity on the island of Ireland (direct and indirect Costs)

2.2.1 Summary of the calculation of direct and indirect costs

The socio-economic costs of food hypersensitivity were calculated as either mean direct, indirect, or total (direct + indirect) increased costs associated with each food hypersensitivity examined (MDFA, MDCD and FI), compared to non-food hypersensitive control groups that were reweighted to match with each food hypersensitivity group. This data was collected from 4,114 surveys collected in Ireland and Northern Ireland (Table 2.2.1a) for:

- Adults (≥18 years) with a food hypersensitivity, and
- Children/adolescents (<18 years) with a food hypersensitivity

Direct costs to the health service associated with health care utilizations (e.g., visits to medical practitioners, hospital stays) as well as costs incurred by the individual (e.g., travel costs, costs for alternative therapies and medication costs) are detailed in Table 2.2.1a. Indirect costs include loss of earnings associated with health care utilization, absences from work/education, and increases in the time spent food shopping. Non-medical out-of-pocket costs (typically borne by respondents) and healthcare costs (shared by respondents and the health service) reported by adults and parents are detailed in Table 2.2.1b, and additional (incremental costs) are presented in Table 4.1.2c and Table 4.2.2c.

The inclusion of surveys on cost analysis was based on the respondent completing financial questions. If this information was incomplete or skipped, the survey was removed from the overall dataset used for the analysis. The final number of surveys which were viable for cost analysis was 3,731, as outlined in Table 2.2.2a. The costs presented are the reported additional expenses incurred by food hypersensitive individuals and their families because of their condition. No monetary value was calculated for intangible costs but the EQ-5D results, and an analysis of the QoL of those affected (section 2.3.), are presented in Chapter 4.

Table 2.2.1a: Direct and indirect costs calculated for each food hypersensitivity

Direct costs
Visits to GPs, Consultants/Specialists, Nurses, Nurses (Outpatient Clinic), Dieticians/Nutritionists, Pharmacists, Physiotherapists, Other Health Professionals, Alternative Therapists
Travel costs associated with visits to GP, Consultant/Specialist, Nurses, Nurses (Outpatient Clinic), Dieticians/Nutritionists, Pharmacists, Physiotherapists, Other Health Professionals, Alternative Therapists
Outpatient attendance: Day unit
Emergency Department attendance with or without subsequent admission to a ward
Ambulance (A&E); Ambulance (Hospital Admission)
Prescribed medicines; Over-the-counter medicines
Private health insurance
Food Cost
Indirect Costs
Time spent food shopping and preparing food
Days missed from work/school/college
Lost earnings associated with healthcare visits

Table 2.2.1b: Healthcare and out-of-pocket costs for each food hypersensitivity

Healthcare costs* (incurred by respondents and the health service)
Visits to GPs, Consultants/Specialists, Nurses, Nurses (Outpatient Clinic), Dieticians/Nutritionists, Pharmacists, Physiotherapists, Other Health Professionals
Outpatient attendance: Day unit
Emergency Department attendance with or without subsequent admission to a ward
Ambulance (A&E); Ambulance (Hospital Admission)
Total prescribed medicines
Out-of-Pocket Costs (typically incurred by respondents alone)
Visits to other alternative therapists
Over-the-counter medicines
Private health insurance
Food cost*
Travel costs associated with visits to GP, Consultant/Specialist, Nurses, Nurses (Outpatient Clinic), Dieticians/Nutritionists, Pharmacists, Physiotherapists, Other Health Professionals, Alternative Therapists
Time spent food shopping and preparing food
Days missed from work/school/college
Lost earnings associated with healthcare visits

* A tax rebate for gluten-free foods is available for MDCD individuals in Ireland. Respondents were asked if they claimed this tax-rebate, and it was deducted from the overall cost to the respondent when reported (29% MDCD adults and 30% for MDCD child/adolescents) to give an accurate reflection of food costs incurred because of this condition. However, the cost prior to this deduction is also included in the text. In addition, certain gluten-free foods are available on prescription in Northern Ireland; these were not captured as part of this study.

2.2.2 Detailed explanation of the calculation of direct & indirect costs

There is no common uniform database that covers unit costs in Ireland. Consequently, information on unit costs comes from a variety of Irish data sources. Where necessary, unit cost data obtained prior to 2019 was adjusted using an appropriate inflation index (Central Statistics Office (CSO), 2020) to reflect costs for 2019. Labour costs were calculated using consolidated salary scales available from the Health Service Executive (HSE, 2019) for public-sector employees, with associated non-pay costs estimated according to the methods outlined by the Health Information and Quality Authority (HIQA, 2019). Day unit and hospital admission costs were sourced from the HIPE dataset (HIPE, 2018). GP and consultant visits, outpatient attendance, accident and emergency and ambulance costs were sourced from previous Irish publications and were updated to 2019 figures (Connolly *et al.* 2014; Brick *et al.* 2015; Gannon *et al.* 2006).

Unit costs for Northern Ireland were based on the 2018/2019 financial year. Staff costs, outpatient attendance, day unit visits and hospital admission costs were obtained from Health Resource Groups (HRG) unit cost schedules for 2018/2019, which can be found on the Northern Ireland Department of Health website. An average for Northern Ireland based on these was used in this analysis. The average cost per GP visit was provided by the Information & Analysis Directorate, Department of Health, Northern Ireland. In the absence of Northern Ireland -specific data, the cost of an ambulance journey, consultant visit and the average cost per hour of a pharmacist were sourced from Personal Social Services Research Unit data (PSSRU, 2019) in England. Accident and emergency and minor injury unit attendance costs were sourced from England NHS Reference Costs (NHS Reference Costs, 2019).

The survey elicited respondents' use of health services, visits to alternative therapists, use of prescribed and over-the-counter medications, their cost of living and their quality of life as measured by the EQ5D-3L (The EuroQoL group, 1990). Medications were costed based on information from the British National Formulary (https://bnf.nice.org.uk/) after converting it to euro.

The reported annual household medical insurance policy cost was divided by the household size to obtain the cost per person. For the valuation of travel costs in both Ireland and Northern Ireland, a car was the assumed mode of transport; the methodology used was like Hanly *et al.* (2013) whereby the number of miles/kilometres travelled were multiplied by the average cost per mile/kilometre for the year (Hanly *et al.* 2013; AA, 2019; HM Revenue and Customs, 2019).

The reported annual cost of gluten-free products was adjusted to account for any tax relief claimed when reported by respondents. The annual cost for food shopping was calculated based on respondents' reported weekly figures. Loss of earnings associated with outpatient, day unit, emergency department and hospital admissions were directly elicited from respondents. Time costs associated with shopping and preparation of food and absences from work/college were given a valuation based on the national minimum wage in 2019 (€9.80 for Ireland (www.gov.ie) and £8.21 for Northern Ireland (www.gov.uk). The exact breakdown of public/private sector employees was not known, so therefore the cost of 'lost days/earnings' has been calculated for all regardless of employer. However, this figure has been calculated conservatively at the rate of minimum wage per hour.

The analysis considered respondents for whom complete information for the costing was available: 2,361 and 1,370 individuals for Ireland and Northern Ireland, respectively. Of these, 1,854 and 947, respectively, were adults, in Ireland and Northern Ireland, respectively, while less responses were obtained for the parental surveys, with 507 and 423, respectively. The respondents tended to be female (Table 2.2.2a), particularly in the MDFA group where the ratio of female to male responses was 167:15 in Ireland and 103:8 in Northern Ireland. In the parental surveys, the responses concerning adolescents (13 to 17 years) were less frequent than those for children (0 to 12 years).

Table 2.2.2a: Sample size for each group by jurisdiction used in the calculation of direct and indirect costs for food hypersensitivity in Ireland and Northern Ireland based on survey data collected between November 2019 and October 2020 (n=3,731)

ADULTS	**Ireland**	**Northern Ireland**	**Parental**	**Ireland**	**Northern Ireland**
Total controls	**531**	**204**	**Total controls**	**130**	**165**
Control males	70	23	Controls aged 0-12 years	101	108
Control females	461	181	Controls aged 13-17 years	29	57
Total MDFA	**178**	**111**	**Total MDFA**	**173**	**147**
MDFA males	15	8	MDFA aged 0-12 years	147	128
MDFA females	163	103	MDFA aged 13-17 years	26	19
Total MDCD	**609**	**173**	**Total MDCD**	**148**	**60**
MDCD males	110	20	MDCD aged 0-12 years	104	40
MDCD females	499	153	MDCD aged 13-17 years	44	20
Total FI	**536**	**459**	**Total FI**	**56**	**51**
FI males	48	32	FI aged 0-12 years	44	37
FI females	488	426	FI aged 13-17 years	12	14
TOTAL	**1,854**	**947**	**TOTAL**	**507**	**423**

*MDFA: medically diagnosed food allergy; MDCD: medically diagnosed coeliac disease; FI: Food intolerance or suspected/undiagnosed food allergy.

Table 2.2.2b. summarises the characteristics of the groups considered for Ireland. In the adult sample, respondents with FI or MDFA tended to be younger than those in the control or MDCD groups and were more likely to be female. Respondents in the control group were less likely to report suffering from other long-term illnesses, health problems or disabilities which limited daily activities. For the parental responses, we find that responses for the MDFA and FI group tended to be younger than in the other groups. The responses in the parental groups are more likely to be for male children/adolescents than in the corresponding adult groups. We again find that other long-term illnesses are less prevalent in the control group than in the other groups.

Table 2.2.2b: Characteristic of each group for Ireland used in the calculation of direct and indirect costs for food hypersensitivity in Ireland based on reported data from a survey run between November 2019 and October 2020 (n=2,361)

Ireland	**Adult controls**	**Adult MDFA**	**Adult MDCD**	**Adult FI**	**Parental controls**	**Parental MDFA**	**Parental MDCD**	**Parental FI**
Average age (years)	41.45	31.20	47.28	32.08	8.35	7.00	9.99	7.50
Percentage of females	87%	92%	82%	91%	55%	43%	63%	59%
Average no. of males aged 18+	1.12	1.09	1.03	1.13	0.98	0.95	1.11	1.07
Average no. of females aged 18+	1.35	1.75	1.30	1.70	1.13	1.07	1.16	1.25
Average no. of males aged 13-17	0.14	0.12	0.11	0.11	0.12	0.14	0.30	0.11
Average no. of females aged 13-17	0.19	0.19	0.13	0.12	0.18	0.19	0.37	0.21
Average no. of males aged 0-12	0.48	0.13	0.24	0.18	0.96	0.95	0.65	0.73
Average no. of females aged 0-12	0.48	0.24	0.23	0.13	0.91	0.80	0.91	0.79
Percentage with other long-term illness	10%	33%	34%	26%	5%	29%	25%	23%
Percentage of urban	47%	53%	45%	49%	45%	46%	41%	46%
Sample size	**531**	**178**	**609**	**536**	**130**	**173**	**148**	**56**

MDFA: medically diagnosed food allergy; MDCD: medically diagnosed coeliac disease; FI: Food intolerance or suspected/undiagnosed food allergy.

* ‘Other long-term illness’ and ‘Urban’ are based on the average of all responses with Yes=1 and No=0

Similarly, Table 2.2.2c summarises the characteristics of the groups considered for Northern Ireland. Among the adults, the age and gender pattern across groups was like that in Ireland, although the control pool tended to be older than in Ireland and MDCD respondents tended to be younger. In the parental surveys, MDCD respondents tended to be the oldest group, with the MDFA group the youngest group. The gender breakdowns were relatively like those in Ireland. The rate of other long-term illnesses was higher among the control pools (adult and parental) in Northern Ireland than was the case for Ireland but the rates in the other groups were quite similar between the jurisdictions, except for MDCD, where respondents in Northern Ireland were less likely to report suffering from other illnesses.

Table 2.2.2c: Characteristic of each group for Northern Ireland used in the calculation of direct and indirect costs for food hypersensitivity in Northern Ireland based on reported data from a survey run between November 2019 and October 2020 (n=1,370)

Northern Ireland	**Adult Controls**	**Adult MDFA**	**Adult MDCD**	**Adult FI**	**Parental Controls**	**Parental MDFA**	**Parental MDCD**	**Parental FI**
Average age (years)	47.04	32.09	40.91	34.71	9.79	6.29	10.85	8.37
Percentage of females	89%	93%	88%	93%	51%	44%	65%	53%
Average no. of males aged 18+	1.01	1.04	0.96	1.02	0.87	0.87	0.88	0.94
Average no. of females aged 18+	1.32	1.57	1.35	1.46	1.08	1.10	1.10	1.06
Average no. of males aged 13-17	0.09	0.11	0.16	0.12	0.18	0.16	0.37	0.29
Average no. of females aged 13-17	0.10	0.13	0.11	0.09	0.29	0.15	0.35	0.35
Average no. of males aged 0-12	0.19	0.21	0.24	0.21	0.91	0.97	0.60	0.80
Average no. of females aged 0-12	0.18	0.16	0.30	0.25	0.79	0.83	1.02	0.92
Percentage with other long-term illness	24%	32%	34%	30%	10%	21%	12%	20%
Percentage of urban	39%	43%	46%	46%	42%	42%	20%	41%
Sample size	**204**	**111**	**173**	**459**	**165**	**147**	**60**	**51**

MDFA: medically diagnosed food allergy; MDCD: medically diagnosed coeliac disease; FI: Food intolerance or suspected/undiagnosed food allergy.

* ‘Other long-term illness’ and ‘Urban’ are based on the average of all responses with Yes=1 and No=0

2.2.3 Survey selection for costs analysis and data cleaning

A total of 3,001 food hypersensitivity surveys and 1,113 control surveys were completed during this study (n=4,114). While data from all surveys were applicable in the general analysis section, i.e., type of food hypersensitivity, associated foods etc., certain pertinent questions required responses for costs analysis. Careful examination of each survey led to the selection of all suitable surveys for monetary cost calculations where these questions had not been omitted/skipped over. This reduced the overall number of surveys that could be used in the calculation of direct and indirect costs by condition for this study task.

Further examination of this group by the project Steering Committee led to the removal of three outliers (three additional surveys) from the overall cost analysis presented in this report. These three respondents reported 40, 70 and 77 days in hospital in the last 12 months (at €904 per night in Ireland and £597/€663 in Northern Ireland; HIPE, 2018; DoH (Northern Ireland) Trust Reference Costs 2018/2019). However, these respondents reported no previous adverse reaction to food, e.g., anaphylaxis, during this timeframe. In addition, all three reported co-morbidities (long-term illness not specified) and being on disability allowance. Nonetheless, data which includes these three outliers is presented in Annex 7 (Table 7.A.5 and Table 7.A.7)

After careful examination, a total of 2,701 food hypersensitivity questionnaires and 1,030 control surveys were deemed to be suitable for the calculation of direct and indirect costs by condition (n=3,731) in this study (Table 2.2.2a).

2.2.4 Statistical analysis of direct, indirect and total costs

A linear regression model is estimated with the cost of interest as the dependent variable (Y) and an indicator (D) for whether the individual is in the treated group (D=1) or the control (D=0). The coefficient on this indicator represents the difference in mean costs between the groups. By weighting the data using entropy balancing, we ensure that the groups are comparable in terms of their characteristics. The coefficient therefore represents the incremental cost for the treated group relative to the cost for a comparable group of the controls. We also include the covariates in the regression models to account for any residual confounding not controlled for by the entropy balancing. The standard error and confidence interval can be recovered from the regression output and capture the uncertainty of the incremental costs.

2.3 Calculation of the Socio-economic Cost of Food Hypersensitivity on the Island of Ireland - intangible costs and effect on QoL

The non-monetary cost was calculated when examining intangible costs or the effects of food hypersensitivity on the QoL of food hypersensitive individuals and their families. These aspects were examined by integrating the standard EQ-5D questionnaire in all surveys. In addition, a specific food hypersensitivity question (designed as part of this study) to examine the areas of life affected by MDFA, MDCD and FI was included in all surveys.

2.3.1 EQ-5D: standardised health-related quality of life questionnaire

Background to the EQ-5D

EQ-5D is a standardised health-related quality of life questionnaire developed by the EuroQol Group, designed for self-completion by respondents. The EuroQol Group is a network of international multidisciplinary researchers from Europe, North America, Asia, Africa, Australia and New Zealand (www.euroqol.org). EQ-5D consists of the EQ-5D descriptive system that measures health-related quality of life, and the EQ VAS (a self-rating of overall health-related quality of life). EQ-5D is widely used in clinical trials, observational studies and other health surveys. This questionnaire is applicable to a wide range of health conditions and treatments. It provides a simple descriptive profile and a single index value for health status that can be used in the clinical and economic evaluation of health care as well as in population health surveys.

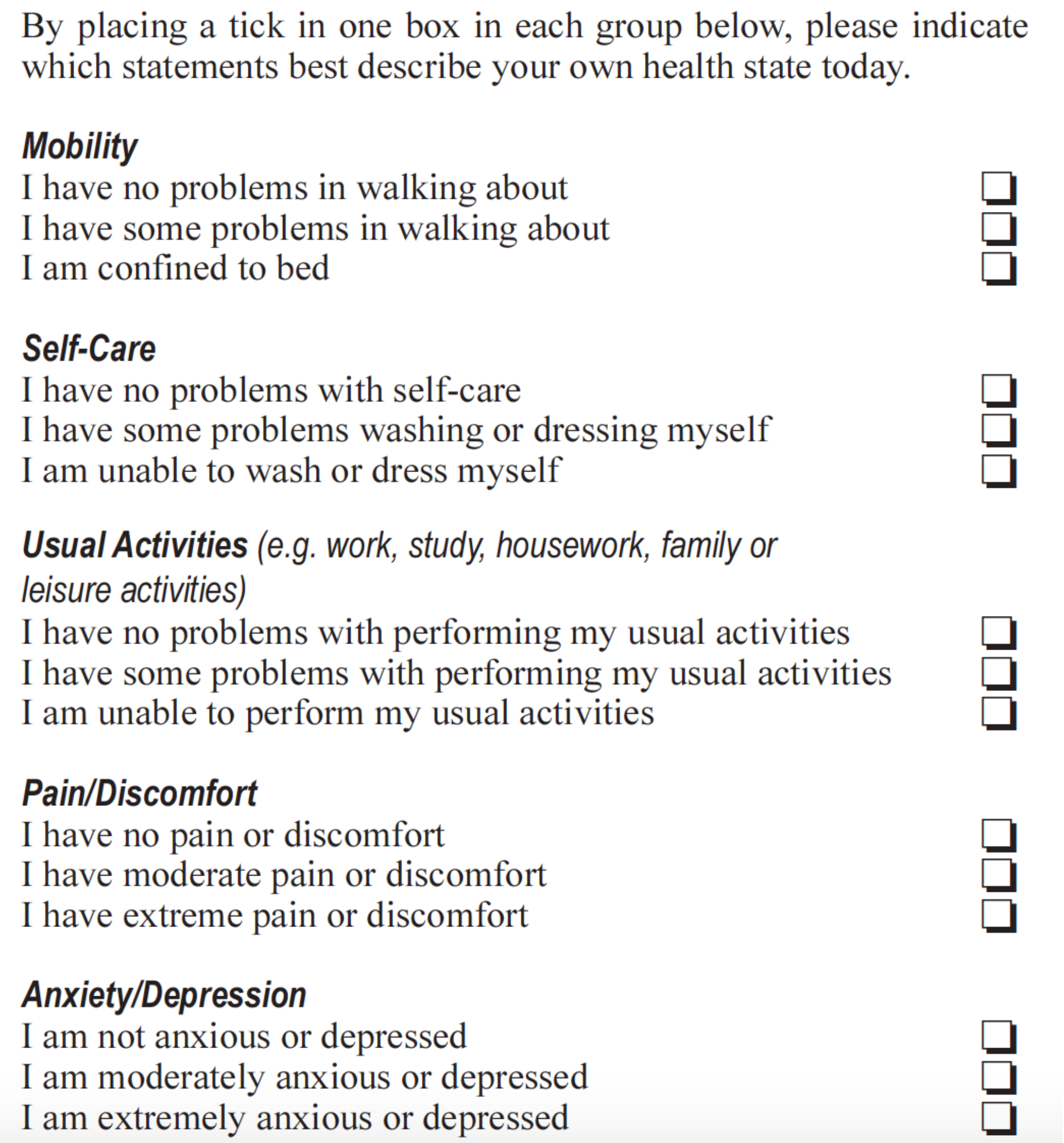
EQ-5D use in this food hypersensitivity survey study

Permission was sought and received from the EuroQol Group to include EQ-5D-3L for adults (≥18 years) and EQ-5D-Y proxy version 1 for completion by parents of children and adolescents in these surveys.

EQ-5D-3L for adults (≥ 18 years)

The EQ-5D descriptive system is comprised of five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has three reporting levels: no problems, some problems, or severe problems (Figure 2.3.1a). The respondents were asked to indicate their health status by ticking the box against the most appropriate statement in each of the five dimensions. A single index value of the health status for each of the different food hypersensitive groups was calculated (EuroQol Group, 1990 and 2004) as well as an EQ VAS.

Figure 2.3.1a: EQ-5D-3L for adults (≥ 18 years), as included in all food hypersensitive and control surveys in this study.



By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility

I have no problems in walking about ☐
I have some problems in walking about ☐
I am confined to bed ☐

Self-Care

I have no problems with self-care ☐
I have some problems washing or dressing myself ☐
I am unable to wash or dress myself ☐

Usual Activities *(e.g. work, study, housework, family or leisure activities)*

I have no problems with performing my usual activities ☐
I have some problems with performing my usual activities ☐
I am unable to perform my usual activities ☐

Pain/Discomfort

I have no pain or discomfort ☐
I have moderate pain or discomfort ☐
I have extreme pain or discomfort ☐

Anxiety/Depression

I am not anxious or depressed ☐
I am moderately anxious or depressed ☐
I am extremely anxious or depressed ☐

Image Source: https://euroqol.org/wp-content/uploads/2016/10/Measuring_Self-Reported_Population_Health_-_An_International_Perspective_based_on_EQ-5D.pdf

The EQ VAS records the respondents' self-rated health on a vertical, 20 cm visual analogue scale where the endpoints are labelled 'Best imaginable health state' and 'Worst imaginable health state' (Figure 2.3.1b). This information can be used as a quantitative measure of health outcome as judged by the individual respondents. In summary, the following three parameters were examined from our survey results:

1. Each of the five dimensions for each of the different food hypersensitive adult groups (MDFA, MDCD and FI) were compared against their control counterparts.

2. A single index value of the health status was calculated for each of the different food hypersensitive adult groups and their control counterparts, based on the responses from participants on the five dimensions.
3. A self-rated health-related quality of life (EQ VAS) score was calculated for each of the different food hypersensitive groups and the control group based on adult participants rating of health status between 0 and 100.

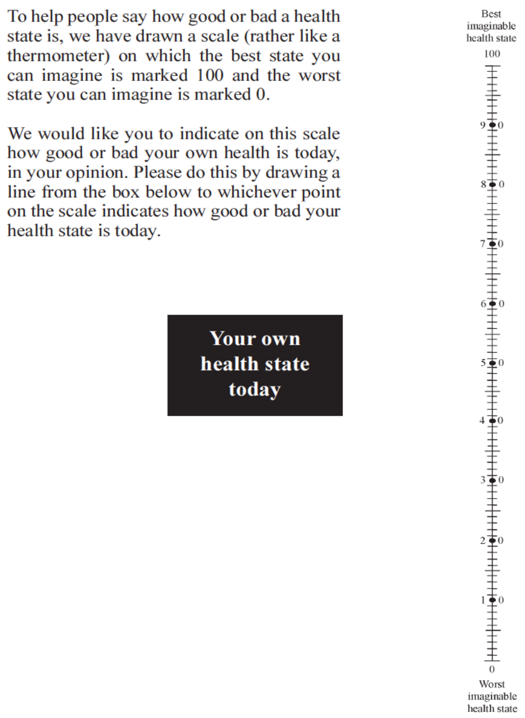
EQ-5D-Y proxy version 1 (<18 years)

The EQ-5D-Y proxy version 1 was completed by parents of food hypersensitive children (0-12 years) and adolescents (13-17 years) in the same way as EQ-5D-3L for adults (≥18 years). The proxy rating involved the respondents (parents) rating the health of their child/adolescent. Results were reported for the same three parameters as for the EQ VAS scoring.

2.3.2 Food hypersensitivity study question

In preparation for the release of the surveys to determine the socio-economic cost of food hypersensitivity on the IoI, a question was prepared to highlight the key areas of life affected by food hypersensitivity. This question was designed with the assistance of food hypersensitive individuals and with reference to the literature. The areas of life selected were amended and added to following the pilot study, in which draft questionnaires were completed by 104 individuals. The final question consisted of 25 options by which the respondent could tick the areas affected in their life, or that of their child/adolescent, because of their food hypersensitivity. The options included the following: cost, time, the ability to eat out, social life, travel life, relationships, household tasks, social activities/interactions, sports, public transport, childcare, their choice of job, and their choice of school. The areas of life affected, as reported by the 4,114 main survey respondents, are detailed by condition, jurisdiction (Ireland and Northern Ireland) and status (whether they completed the questionnaire as a food hypersensitive adult or as a parent of a food hypersensitive child/adolescent).

Figure 2.3.1b: Self-rated health-related quality of life (EQ VAS) as included in all food hypersensitive and control surveys in this study.



To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

Your own health state today

Image Source: https://euroqol.org/wp-content/uploads/2016/10/Measuring_Self-Reported_Population_Health_-_An_International_Perspective_based_on_EQ-5D.pdf

2.3.3 Statistical analysis of EQ-5D

The following tests were used for statistical analysis of the EQ-5D data:

1. Two-sample t-test
2. A Kruskal-Wallis rank sum test was performed to test whether there was a difference in the medians (location parameters) of the distributions of reported health status between the control, MDFA, MDCD and FI groups for children, adolescents and adults.
3. Pairwise Wilcoxon rank sum tests with Benjamini-Hochberg (1995) corrections for multiple testing were carried out to test for differences in reported health status between controls and MDFA, MDCD and FI children, adolescents and adults.

   Statistical analysis for self-reported and parent-reported health status was completed for respondents who have no other health problems in addition to food hypersensitivity.

2.4 Completion of priority setting interviews of MDFA and MDCD adults and parents in Ireland and Northern Ireland

2.4.1 Priority setting interview study design

Food hypersensitivity surveys were completed by 744 MDFA and 1,035 MDCD adults and parents, as detailed in Chapter 2. Based on the findings of these surveys, including feedback collected and reviewed from open questions requesting additional information and opinion in the associated surveys, eight areas of concern were reported. Similar feedback was recorded by MDFA and MDCD adults and parents, allowing the same headings to be used for the further examination of both affected groups (points 1 to 7), except for point 8 (on adrenaline auto-injector availability).

1. Awareness and training regarding food allergy/coeliac disease in an educational setting
2. Public and food industry awareness and understanding of food allergy/coeliac disease
3. Cost and availability of medication and supplements to treat food allergy/coeliac disease
4. Accessing medical teams, e.g., consultants, specialist nurses etc., to treat food allergy/coeliac disease
5. Dietetic support for food allergy/coeliac disease
6. Counselling/psychological services for food hypersensitive individuals and their families
7. Recognition of food allergy/coeliac disease as a ‘disability’
8. Adrenaline auto-injectors to be made available in all public spaces in case of emergency (like automated external defibrillators, AED)

An interview plan was formulated to investigate perceived challenges or key issues for food hypersensitive individuals, and proposed solutions about these headings, with point 8 only under consideration by MDFA adults and parents. Priority Setting Interviews were selected as a precise mechanism for ranking and comparing feedback of the test groups based on similar studies reported in the literature (Aldiss *et al.* 2019; Ghisoni, 2017; Jones, 2015; Wilson *et al.* 2009). A target schedule was proposed, which focused on arranging an equivalent number of interviews for MDFA and MDCD individuals in Ireland and Northern Ireland, with representation from both food hypersensitive adults and parents of food hypersensitive children/adolescents (Table 2.4.1). This would allow future comparisons between both jurisdictions, conditions (MDFA and MDCD), and age groups (adult/parents). An ethical approval application was prepared and completed prior to commencing phone interviews. This ethical application was approved by the ethics committees of TUD and QUB.

Table 2.4.1: Priority setting interviews sampling plan based on condition (MDFA or MDCD) and age category (adult or parent of child/adolescent) in Ireland and Northern Ireland, carried out between August 2020 and November 2020

Priority setting interviews	**Target interviews Ireland**	**Completed interviews Ireland**	**Target interviews Northern Ireland**	**Completed interviews Northern Ireland**
Adults with MDFA	10	10	10	10
Adults with MDCD	10	10	10	10
Parents of children/adolescents with MDFA	10	10	10	10
Parents of children/adolescents with MDCD	5-10	10	5-10	6
TOTAL	**35-40**	**40**	**35-40**	**36**

2.4.2 Priority setting interview completion

Participants were invited to take part in the priority setting interviews by means of paid advertisements on Facebook. Respondents were emailed a participant information leaflet and a consent form to be completed prior to interview. Each priority setting interview lasted approximately 30 minutes and all researchers involved in the field work (n=3) received prior interview training. All interviewers completed a survey-style questionnaire (semi-structured interview) to record details of the discussion throughout the phone call. The interviewees' answers were transcribed for future reference, but the interviews were not recorded. This survey focused on (i) key issues and (ii) possible solutions regarding the associated 7/8 areas of concern. Post-interview, participants were requested to complete a short online anonymous survey which included ranking the topics discussed from most important to least important.

A total of 76 phone interviews – 40 in Ireland and 36 in Northern Ireland – were completed (Table 2.4.2) between July and December 2020. All interviewees were adults and reported having MDFA or MDCD themselves, or they were a parent of a child/adolescent with either condition. All participants reported to be resident in Ireland or Northern Ireland at the time of interview. All recorded data was anonymised and participants received a gratuity for their assistance with this project task.

Table 2.4.2: Priority setting interviews sampling plan based on condition (MDFA or MDCD) and age category (adult or parent of child/adolescent with either condition) in Ireland and Northern Ireland, carried out between August 2020 and November 2020

Priority setting interviews carried out in Ireland & Northern Ireland	**Age profile and gender information**
Adults with MDFA – Ireland	Ten adults from Ireland participated in this interview process. All participants were females, with 70% (n=7) of these females aged between 21-29 and 30% (n=3) aged between 30-39 years.
Adults with MDFA – Northern Ireland	Ten adults from Northern Ireland participated in this interview process. All participants were females with 50% (n=5) aged between 21-29 and 50% (n=5) aged between 30-39 years.
Adults with MDCD – Ireland	Ten adults from Ireland participated in this interview process. Seventy percent (n=7) of participants were female and 30% (n=3) were male. The age profile was as follows: 21-29 years (30%, n =3), 30-39 years (20%, n=2), 40-49 (20%, n=2), 50-59 (20%, n=2), 60+ (10%, n= 1).
Adults with MDCD – Northern Ireland	Ten adults were interviewed from Northern Ireland: 80% were female (n=8) and 20% male (n=2). The age profile was as follows: 21-29 years (10%, n=1), 30-39 years (30%, n =3), 40-49 (20%, n=2), 50-59 (20%, n=2), 60+ (20%, n=2).
Parents of children/adolescents with MDFA – Ireland	Ten parents of children/adolescents (seven female and three male) from Ireland reporting to have MDFA children/adolescents were interviewed. Twenty percent (n=2) of children were between 0-5 years, 60% (n =6) between 6-12 years, and 20% (n=2) were adolescents between 13-17 years.
Parents of children/adolescents with MDFA – Northern Ireland	Ten parents of children/adolescents (seven female and three male) from Northern Ireland reporting to have MDFA children were interviewed. Sixty percent (n=6) of these children were between 0-5 years, 20% (n=2) between 6-12 years, and 20% were adolescents (n=2) between 13-17 years.
Parents of children/adolescents with MDCD – Ireland	Ten parents (eight female and two male) from Ireland reporting to have MDCD children/adolescents were interviewed. Forty percent (n=4) of these children were between 6-12 years of age and 60% (n=6) were adolescents between 13-17 years.

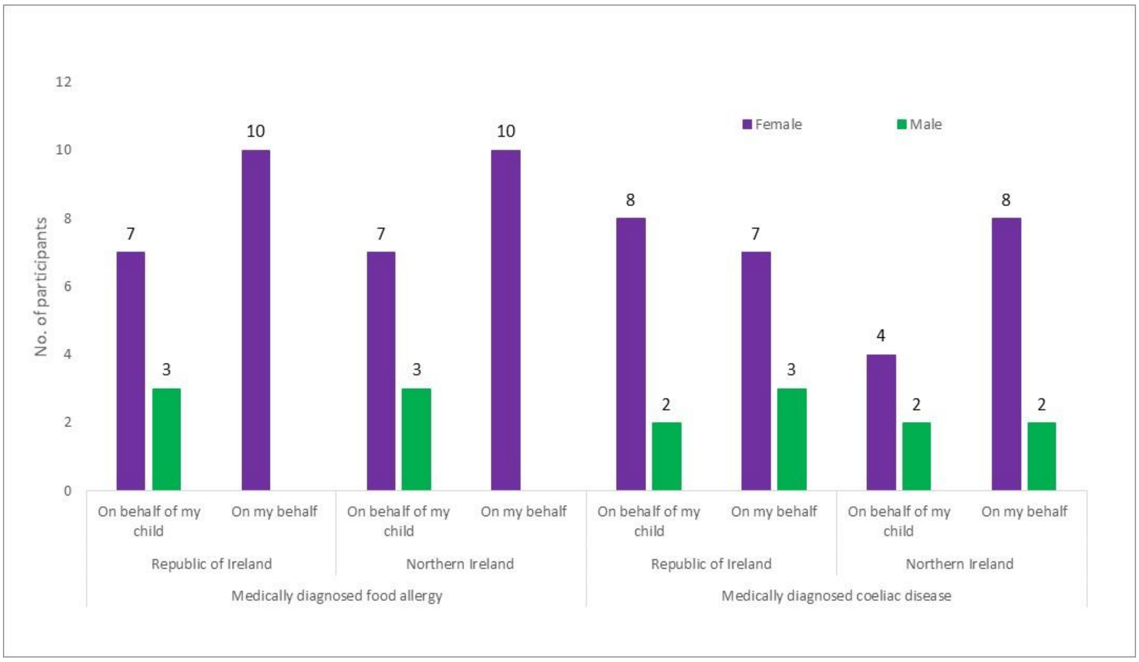
Parents of children/adolescents with MDCD – Northern Ireland	Six parents from Ireland reporting to have MDCD children/adolescents (four female and two male) were interviewed. Eighty three percent (n=5) of these children were between 6-12 years and 17% (n=1) were adolescents between 13-17 years.

*MDFA: medically diagnosed food allergy; MDCD: medically diagnosed coeliac disease

2.4.3 Priority setting interview results overview regarding gender and age

A target of 10 interviews was agreed for each target group listed in Table 2.1.2. However, an exception of 5-10 interviews was set for parents of children/adolescents with MDCD (10 achieved in Ireland and six in Northern Ireland), as this group was the most difficult to locate. A breakdown by gender revealed that 35 females (88%) and five males (12%) completed the priority setting interviews for the 'adults' group. There were 26 females (72%) and 10 male children (28%) represented in the parental MDFA and MDCD interviews (Figure 2.4.3.).

Figure 2.4.3: Breakdown by gender of the number of adults or children/adolescents (parental interviews) with MDFA or MDCD who completed the priority setting phone interviews carried out between August 2020 and November 2020 (n=76)



2.5 Collection and examination of datasets in public and private institutions

This task targeted existing databases of information on food hypersensitivity in early years service (EYS) providers, childcare facilities, primary and secondary schools, and nursing homes. Surveys were sent via email to target institutions in Ireland and Northern Ireland. These questionnaires were designed to collect information on (i) gender, (ii) age range, and (iii) associated trigger foods (where applicable) of hypersensitive children and elderly adults. Additional information on carrying an adrenaline auto-injector, or having experienced previous adverse reactions to food on-site, was requested. These surveys also sought information on all of the individuals in attendance at, or residing within, these institutions/facilities, i.e., one completed survey could contain relevant information on several hundred individuals.

2.5.1 Survey of early year services (EYS) providers in Ireland and Northern Ireland

There are approximately 1,300 EYS in Ireland. The contacts details of registered EYS are provided by Tusla on their website by county, and 800 of these facilities were contacted at random across all counties in Ireland (taken from https://www.education.ie/en/Publications/Statistics/Data-on-Individual-Schools)[3]. In total, 95 nurseries and 480 pre-schools are registered with the Department of Education in Northern Ireland (http://apps.education-ni.gov.uk/appinstitutes/default.aspx)[4]. A random sample of 342 were contacted and were also requested to complete the food hypersensitivity survey with anonymous information on attendees in their services.

- https://www.tusla.ie/services/preschool-services/list-of-pre-school-services-by-county/
- http://apps.education-ni.gov.uk/appinstitutes/default.aspx

2.5.2 Survey of primary & secondary schools in Ireland and Northern Ireland

There are currently a total of 3,926 schools under the remit of the Department of Education and Skills in Ireland. They consist of 3,106 primary schools, 134 special schools and 722 post-primary schools. Except for nursery and pre-school facilities, there are 983 schools under the

---

[3] https://www.education.ie/en/Publications/Statistics/Data-on-Individual-Schools/

[4] http://apps.education-ni.gov.uk/appinstitutes/default.aspx

remit of the Department of Education in Northern Ireland. These consist of 801 primary schools, 40 special schools, 130 secondary schools and 12 preparatory schools.

Twenty schools (10 primary and 10 secondary) were randomly selected from every county in Ireland and Northern Ireland. However, for the more heavily populated counties such Dublin, Cork, Galway, Limerick and Antrim, up to 40 schools were targeted (20 primary and 20 secondary). In total, 600 schools were contacted in Ireland, and 136 schools in Northern Ireland, by email, and were requested to provide anonymous food hypersensitivity information on all the pupils attending their facilities. Contacted schools and their details were found via the Department of Education and Skills website for Ireland, and for the Department of Education website for Northern Ireland.

2.5.3 Survey of nursing homes in Ireland and Northern Ireland

According to Nursing homes Ireland (NHI), there are over 400 nursing homes in Ireland providing care for over 25,000 people. All the 432 organisations listed on the NHI website in 2019 were contacted via email regarding completion of the food hypersensitivity study (https://nhi.ie/find-a-nursing-home/)[5]. The number of nursing home facilities in Northern Ireland could not be confirmed; however, an online directory (carehome.co.uk) of nursing homes in Northern Ireland was used to find contact details for this study (https://www.carehome.co.uk)[6]. A total of 212 nursing homes were contacted in Northern Ireland using this website. All these facilities were requested to provide anonymous food hypersensitivity information on their residents.

2.5.4 Collection of food hypersensitivity surveys from public and private institutions

A follow-up email was sent to EYS, schools and nursing homes approximately one month after the initial questionnaire email. Many surveys were completed with regard to the specific number of individuals in each organisation with a food hypersensitivity, but not all respondents gave further details regarding trigger foods or the availability of adrenaline auto-injectors etc., as requested. Response rates and their breakdown per county are provided for EYS, schools and nursing homes. The percentage of reported food hypersensitivities (FA, CD and FI) are presented in Tables 6.1.1a, 6.2.1 and 6.3.1. Where possible, information regarding gender is included for this data. Information on associated trigger foods and adrenaline auto-

---

[5] https://nhi.ie/find-a-nursing-home/

[6] https://www.carehome.co.uk

injectors is also included if reported, as were records of any previous incidences of adverse reactions to food on-site. The total number of organisations who participated in this survey was 214 and the total number of individuals represented was 14,889 throughout the IoI. It is worth noting that schools (particularly secondary) were less likely than nursing homes and EYS to have a record of a mild food hypersensitivity, particularly when food is not always provided on-site.

2.5.5 Examination of food hypersensitivity datasets on the island of Ireland

During this study, databases were sought with information on food hypersensitivity for the IoI. The percentages of reported food hypersensitivity, the breakdown by age and gender and the associated trigger foods (where available) are reported.

Statistical analysis carried out on the food hypersensitivity datasets included:

- *Growing Up in Ireland* studies were statistically analysed by the two-sample test for equality of proportions with continuity correction.
- HIPE 2 data was statistically analysed by Pearson Chi-squared test.

A summary of the databases reviewed are as follows and are presented in Section 6.5:

6.5.1 Self-reported food hypersensitivity data from registered students (19,929 students) attending TU Dublin (2018-2019): This dataset includes the self-reported food hypersensitivity data (often including the trigger food) by gender for 19,929 students registered in the academic year 2018/2019.

6.5.2 The Growing Up in Ireland study from the Economic & Social Research Institute (ERSI): This includes the percentage of reported food hypersensitivity on a group of 11,134 infants when they are nine months old, three years old (n=9,783) and five years old, between 2008-2013 (https://www.growingup.ie/about-growing-up-in-ireland/)[7]. The gender of each of the food hypersensitive groups (wave 1, 2, and 3) is also examined.

---

[7] https://www.growingup.ie/about-growing-up-in-ireland/

6.5.3 Central Statistics Office (CSO) survey for 5,348 secondary school students from 155 secondary schools (2015): This includes the breakdown of specific food allergies within this group (www.censusatschool.ie)[8].

6.5.4 Dining out: The challenge for those with a food allergy or food intolerance in the Republic of Ireland and Northern Ireland (2013): This includes information of trigger foods associated with food hypersensitivity for 241 individuals in Ireland and 111 in Northern Ireland (https://www.safefood.net/getmedia/62903d02-8532-4659-a7e6-59ba365ec00f/Final-report-ROI-Jan2015.aspx?ext=.pdf

[1] https://www.safefood.net/getmedia/3f1e9d08-a448-47c9-bfbb-0305513ef6b7/Final-report-NI-Jan2015.aspx?ext=.pdf)[9,10].

Available at the following links:

- https://www.safefood.net/getmedia/62903d02-8532-4659-a7e6-59ba365ec00f/Final-report-Ireland-Jan2015.aspx?ext=.pdf
- https://www.safefood.net/getmedia/3f1e9d08-a448-47c9-bfbb-0305513ef6b7/Final-report-NI-Jan2015.aspx?ext=.pdf

6.5.5 FSAI Food Allergy Survey (2011): The FSAI carried out an online food allergy and intolerance survey in Ireland (n=509) as part of their "Monitoring & Surveillance Series Food Allergens & Labelling Survey". Associated food allergens are reported. Available at:

- https://www.fsai.ie/resources_publications/allergen_labelling_2011.html.html

6.5.6a Irish Hospital Inpatients Enquiry (HIPE 1) data for Ireland: Information on the predominant food associated with food anaphylaxis between 1995 to 2004.

6.5.6b Irish Hospital Inpatients Enquiry (HIPE 2) data for Ireland: HIPE 2 is a dataset of the number of individuals discharged from hospital because of food anaphylaxis (principal

---

[8] www.censusatschool.ie
[9] https://www.safefood.net/getmedia/62903d02-8532-4659-a7e6-59ba365ec00f/Final-report-ROI-Jan2015.aspx?ext=.pdf
[10] https://www.safefood.net/getmedia/3f1e9d08-a448-47c9-bfbb-0305513ef6b7/Final-report-NI-Jan2015.aspx?ext=.pdf

diagnosis) between 2008 and 2018. Figures on hospital discharge numbers, associated age categories and gender are reviewed.

6.5.7 Data from a study on the Incidence and Prevalence of Coeliac Disease in the UK (per region) Over Two Decades (1990-2011): Population-Based Study: This study provides information on the prevalence of coeliac disease (per 100,000 population) in Northern Ireland, England, Scotland and Wales in 2011. This data is also examined regarding gender and the age of individuals diagnosed with coeliac disease (https://journals.lww.com/ajg/Fulltext/2014/05000/Incidence_and_Prevalence_of_Celiac_Disease_and.22.aspx)[11].

6.5.8 Coeliac Society of Ireland dataset of 2,899 individuals with medically diagnosed coeliac disease in 2019: The Coeliac Society of Ireland 2019 dataset includes information on 2,899 members (by gender) reported to be medically diagnosed with coeliac disease. This information was also available by age category: infants and young children (0 to 3 years), children (4-12 years), adolescents (13-17 years), adults (18-64 years) and adults (>65 years).

2.6 Prevalence rates for MDFA and MDCD reported in the literature

An internet search was carried out to find reported prevalence values for MDFA and MDCD in the published literature and from known institutions. This review was carried out on PubMed, Science Direct, Wiley Online Library and Google Scholar. Tables 6.6a to 6.6i were prepared, considering previous published prevalence figures by the European Academy of Allergy and Clinical Immunology (EAACI) in 2014. A total of 130 peer-reviewed papers were included, ranging from 1973 to 2021, as well as data reported by 26 institutions on food hypersensitivity. The prevalence values for MFDA in children/adolescents are outlined in Table 6.6a, with data for peanuts, eggs and milk allergy presented in Table 6.6b, and data for other food groups in Table 6.6c. The food allergy prevalence values for children/adolescents and adults (where all ages were reported together) are included in Table 6.6d. Food allergy prevalence values for adults only are included in Table 6.6e, and food allergy in adults by different food groups in Table 6.6f.

---

[11] https://journals.lww.com/ajg/Fulltext/2014/05000/Incidence_and_Prevalence_of_Celiac_Disease_and.22.aspx

In addition to peer-reviewed papers, prevalence data for children, adolescents and adults from food allergy studies reported by certain worldwide institutions are presented in Tables 6.6g to 6.6h. The prevalence values reported for coeliac disease in children, adolescents and adults from peer-reviewed papers and certain institutions are presented in Table 6.6i.

3 General analysis of food hypersensitivity survey data

Six food hypersensitivity surveys targeting (a) adults and (b) parents of children/adolescents with:

- medically diagnosed food allergy (MDFA),
- medically diagnosed coeliac disease (MDCD) and
- food intolerance and suspected/diagnosed food allergy (FI),

were released in Ireland and Northern Ireland in November 2019 and ran until October 2020. A total of 3,001 specific food hypersensitive surveys were collected during this study, and an additional 1,113 surveys from non-food hypersensitive controls (total n=4,114). More detailed information on these specific surveys per group is available in Table 2.1.1b.

A large amount of data was gathered from each of the surveys. A detailed breakdown of this data is available in Annexes 1-6. A summary of each of the six datasets is presented in this chapter as well as a review of some of the key findings regarding trigger foods, age and gender.

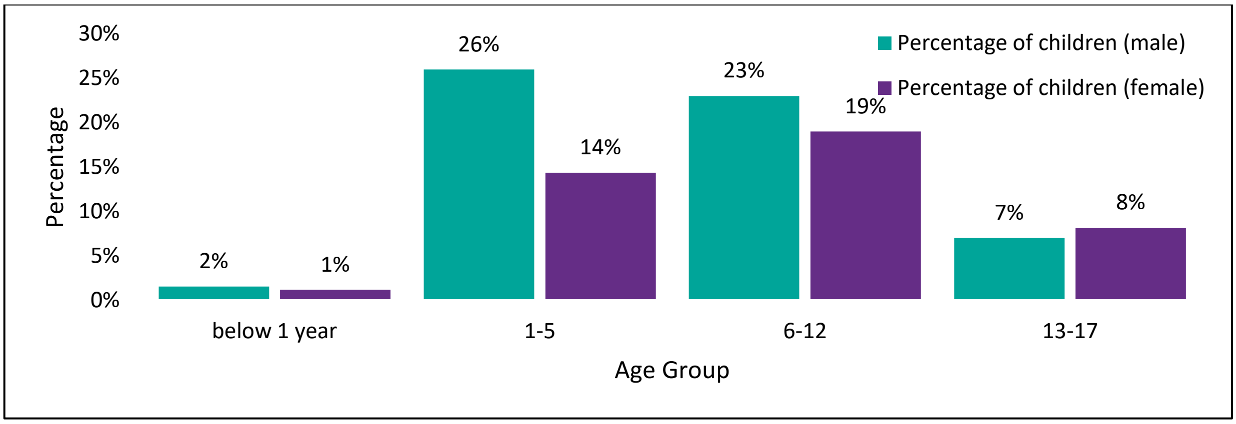
3.1 Food hypersensitivity information for adults, children and adolescents in Ireland and Northern Ireland

3.1.1 Summary information on children and adolescents with MDFA from parental surveys carried out in Ireland and Northern Ireland

3.1.1a Summary of the MDFA parental survey in Ireland

This group consisted of the responses from 258 parents of children/adolescents with MDFA in Ireland. The overall gender breakdown was 57% (n=148) male parents and 43% (n=110) female parents. Forty-three per cent (n=111) of children were reported to be in the $\leq$5 years of age category (28% males & 15% females), and 84% (n=218) were reported to be $\leq$12 years (50% males & 34% females). The remaining 16% (n=40) were adolescents aged between 13-17 years (7% males & 8% females) (Figure 3.1.1a). All of the children and adolescents in this study were required to have been medically diagnosed with a food allergy by at least one of the HSE/NHS recognised diagnostic test methods by a recognised healthcare professional: 80% (n=206) of parents reported their child/adolescent to have had a confirmatory blood test, 79% (n=205) a positive skin prick test, 39% (n=101) reported diagnosis by food oral challenge, and 25% (n=64) via trial elimination diet. Regarding the number of tests used to make a diagnosis, 21% of parents (n=54) reported diagnosis by one of the HSE/NHS tests, 41% (n=106) by two tests, 30% (n=78) by three tests, and 8% (n=20) by all four tests. Approximately 1 in 10 (9.5%; n=25) parents reported their child to have had an anaphylactic reaction over the 12 months prior to completing this survey, with 9% (n=24) reporting one episode, and 0.4% (n=1) reporting two episodes. More details on this group are available in Annex 1 to this report.

Figure 3.1.1a: Percentage breakdown of children and adolescents, by gender and age, with MDFA in the parental survey carried out in Ireland between November 2019 and June 2020 (n=258).

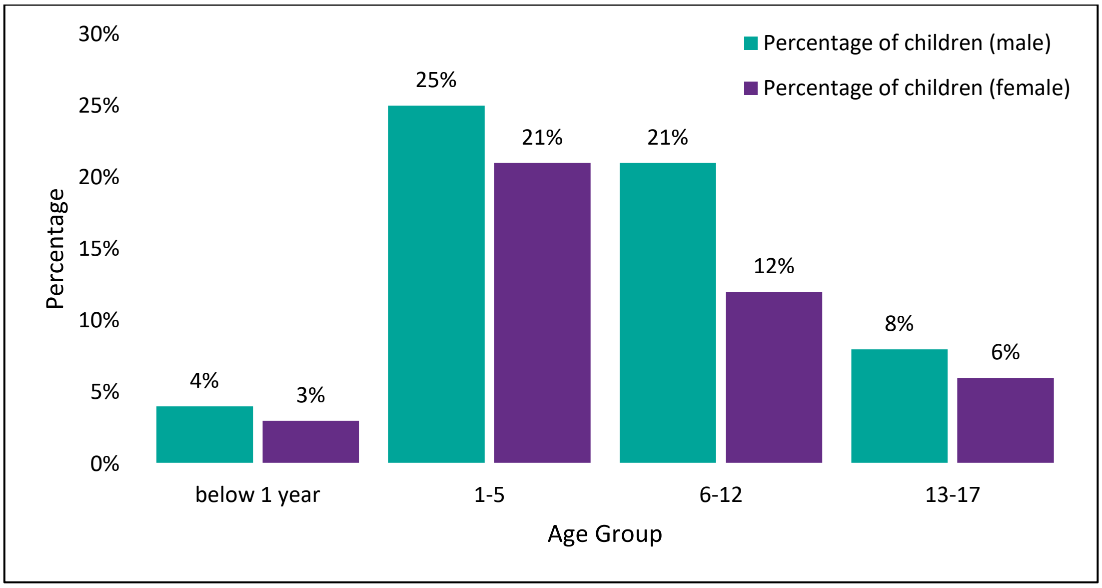


*Associated number of children and adolescents reported by their parents to have MDFA: <1 year=four males and three females; 1–5 years=67 males and 37 females; 6–12 years=58 males and 49 females; 13–17 years=19 males and 21 females.

3.1.1b Summary of the MDFA parental survey in Northern Ireland

This group consisted of responses from 168 Northern Irish parents of children/adolescents with MFDA. The overall gender breakdown of the responding parents was 58% (n=97) males and 42% (n=71) females. Notably, 52% (n=88) of children were reported to be ≤5 years of age (29% males and 24% females) and 87% (n=145) to be ≤12 years (50% males and 36% females); with approximately 13% (n=23) of adolescents in the 13-17 years age category (8% males and 6% females) (Figure 3.1.1b). Regarding the tests used for diagnosis of MDFA, 58% (n=97) of parents reported their child/adolescent to have had a confirmatory blood test and 71% (n=120) a positive skin prick test. Forty-four per cent (n=74) reported diagnosis via trial elimination diet and 38% (n=64) by oral food challenge. In addition, 26% (n=43) reported diagnosis by one of these tests, 46% (n=78) by two tests, 19% (n=32) by three tests, and 9% (n=15) by all four tests. Lastly, 10% (n=17) of parents surveyed reported their child to have had an anaphylactic reaction over the 12 months prior to completing this survey, with 7% (n=11) reporting one episode and 4% (n=6) reporting two episodes. More details on this group are available in Annex 1 of this report.

Figure 3.1.1b: Percentage breakdown of children and adolescents, by gender and age, with MDFA in the parental survey carried out in Northern Ireland between November 2019 and June 2020 (n=168)



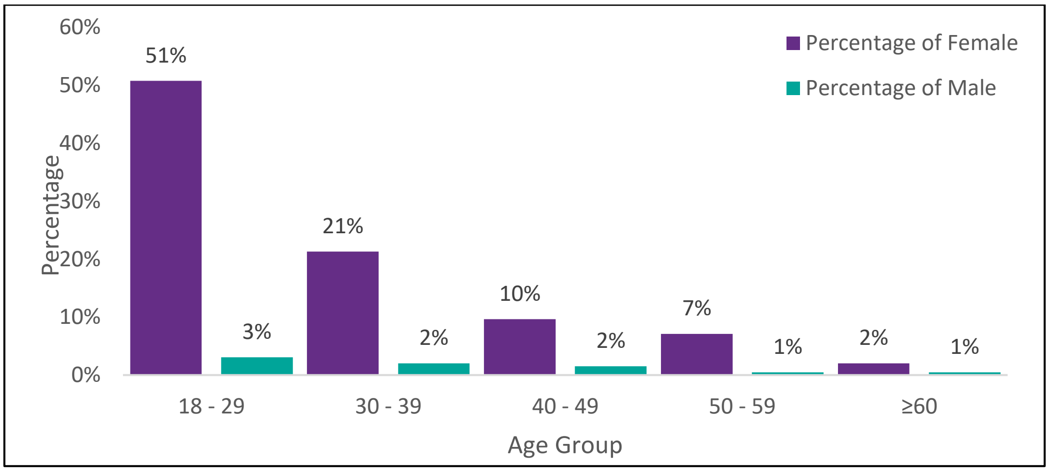
*Associated number of children and adolescents reported by their parents to have MDFA: <1 year=six males and five females; 1–5 years=42 males and 35 females; 6–12 years=36 males and 21 females; 13–17 years=13 males and 10 females.

3.1.2 Summary Information on adults reported to have MDFA in a survey carried out in Ireland and Northern Ireland

3.1.2a Summary of the MDFA adult survey in Ireland

This group consisted of responses from 194 adults in Ireland. The overall gender breakdown was 91% (n=178) female, and 9% male (n=16). Just over half of all respondents (54%, n=105) were in the 18-29 years age category (51% females and 3% males), 77% (n=150) were aged between 18-39 years (females 72% and males 5%), and 23% (n=44) were aged ≥40 years (19% females and 4% males) (Figure 3.1.2a). Regarding the tests used in the medical diagnosis of food allergy, 71% (n=137) reported having had a confirmatory blood test, 60% (n=116) a positive skin prick test, 46% (n=90) were diagnosed via trial elimination diet and 26% (n=51) by food oral challenge. In addition, 34% (n=66) were diagnosed by one test, 36% (n=70) by two tests, 23% (n=44) by three tests, and 7% (n=14) by all four tests. Regarding serious allergic reactions, 9.5% (n=18) of all respondents reported to have had an anaphylactic reaction over the 12-months prior to completing this survey, with 5% (n=9) reporting 1 episode, 1.5% (n=3) reporting 2 episodes, and 2% (n=4) reporting 3 episodes. More details on this group are available in Annex 2 of this report.

Figure 3.1.2a: Percentage breakdown of adults, by gender and age, with MDFA in a survey carried out in Ireland between November 2019 and June 2020 (n=194)



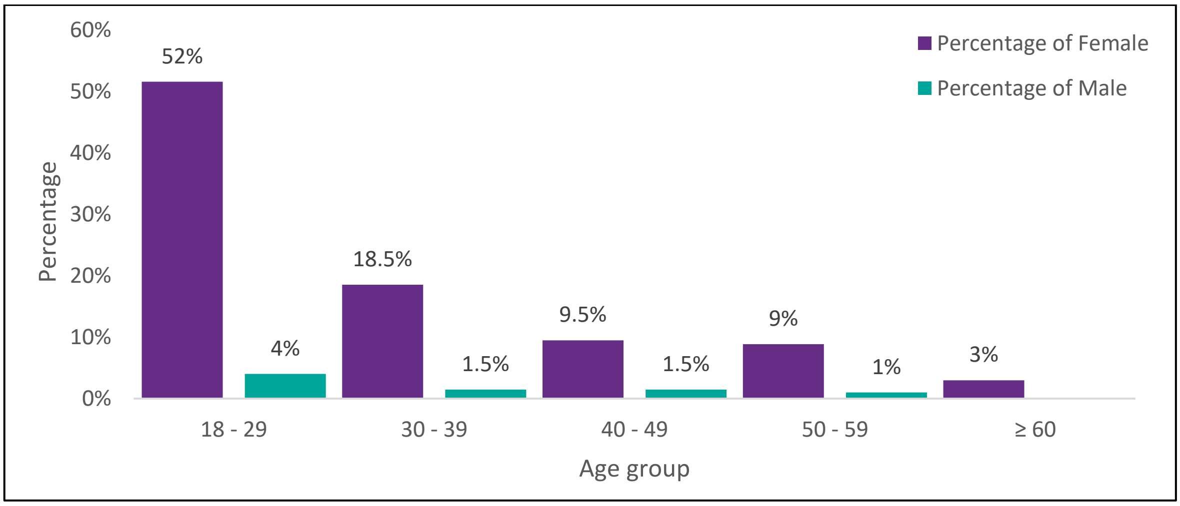
*Associated number of individuals who reported their age group: 18–29 years=99 females and six males; 30–39 years=41 females and four males; 40–49 years=19 females and three males; 50–59 years=14 females and two males; ≥60 years=five females and one male.

3.1.2b Summary of the MDFA adult survey in Northern Ireland

This group consisted of responses from 124 adults in Northern Ireland. The overall gender breakdown was 92% (n=114) female and 8% male (n=10). Just over half (56%, n=69) of all respondents were in the 18-29 years category (52% females and 4% males), 76% (n=94) were 18-39 years (females 70.5% and males 5.5%); and 24% (n=30) were ≥40 years (21.5% female and 2.5% male) (Figure 3.1.2b).

When the tests used in the diagnosis of MDFA were examined, 77% (n=96) reported to having had a confirmatory blood test, 54% (n=67) a positive skin prick test, 35% (n=44) were diagnosed by trial elimination diet, and 26% (n=32) by food oral challenge. Overall, 37% (n=46) were diagnosed by one diagnostic test, 38% (n=47) by two tests, 21% (n=26) by three tests, and 4% (n=5) by all four tests. Finally, 13% (n=15) of respondents reported to have had an anaphylactic reaction over the 12 months prior to completing this survey, with 8% (n=10) reporting one episode, 2% (n=2) reporting two episodes, and 3% (n=3) reporting an anaphylactic reaction on three or more occasions. Notably, one individual reported seven instances of anaphylaxis over this period. More details on these groups are available in Annex 2 of this report.

Figure 3.1.2b: Percentage breakdown of adults, by gender and age, with MDFA in a survey carried out in Northern Ireland between November 2019 and June 2020 (n=124)



*Associated number of individuals who reported their age group: 18–29 years=64 females and five males; 30–39 years=23 females and two males; 40–49 years=12 females and two males; 50–59 years=11 females and one male; ≥60 years=four females.

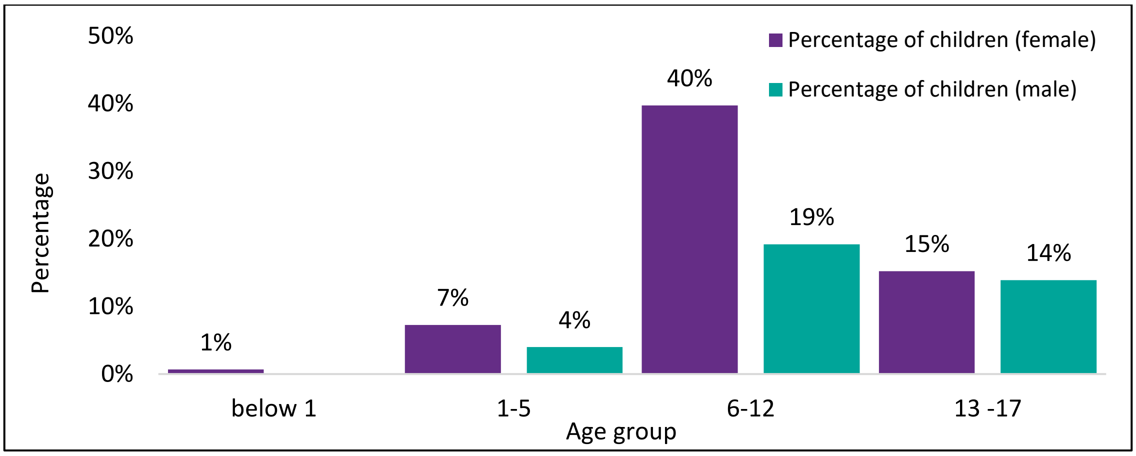
3.1.3 Summary Information on children and adolescents reported to be MDCD in a parental survey carried out in Ireland and Northern Ireland

3.1.3a Summary of the MDCD parental survey in Ireland

This group consisted of responses from 151 parents of children/adolescents with MDCD in a parental survey in Ireland. The overall gender breakdown of children and adolescents was 63% (n=95) females and 37% (n=56) males. Only 12% (n=18) of children were reported to be in the ≤5 years age category (8% females and 4% males), with just 1% of females being younger than 1 year. 71% (n=107) of children were ≤12 years (48% females and 23% males). The other 29% (n=44) were adolescents aged 13-17 years (15% females and 14% males) (Figure 3.1.3a).

All the children and adolescents in this study were required to have been positively diagnosed by at least one of the HSE/NHS recognised diagnostic test methods and by a healthcare professional. Ninety-three per cent (n=140) of parents reported their child as having had a confirmatory blood test and 66% (n=99) a gastrointestinal endoscopy and biopsy. Forty per cent (n=61) were diagnosed by one diagnostic test and 60% (n=90) by both tests. More details on this group are available in Annex 3 of this report.

Figure 3.1.3a: Percentage breakdown of children and adolescents, by gender and age, with MDCD in a parental survey carried out in Ireland between November 2019 and October 2020 (n=151)



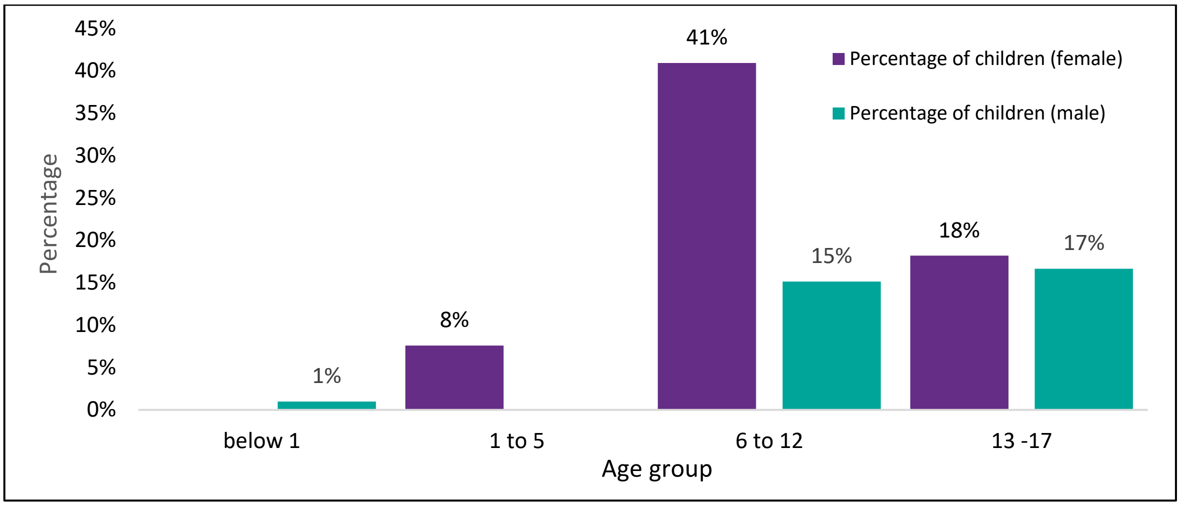
*Associated number of children and adolescents reported by parents to have MDCD: <1 year=one female and zero males; 1-5 years=11 females and six males; 6-12 years=60 females and 29 males; 13-17 years=23 females and 21 males.

3.1.3b Summary of the MDCD parental survey in Northern Ireland

This group consisted of responses from 66 parents of children/adolescents with MDCD in a parental survey in Northern Ireland. The overall gender breakdown was 67% (n=44) female and 33% (n=22) male. Only 8% (n=5) of children – all female – were aged 1 to 5 years, and 1% (a male) was less than 1 year old. 65% (n=43) were ≤12 years of age (26% females and 16% males). The other 35% (n=23) were adolescents in the 13-17 years age category (females 18% and males 17%) (Figure 3.1.3b).

Regarding diagnosis, 92% (n=61) were diagnosed by a confirmatory blood test and 42% (n=28) by gastrointestinal endoscopy and biopsy. Sixty-two per cent (n=41) were diagnosed by one test and 38% (n=25) by both tests. More details on this group are available in Annex 3 of this report.

Figure 3.1.3b: Percentage breakdown by parents of children and adolescents, by gender and age, who were reported to have MDCD in a parental survey carried out in Northern Ireland between November 2019 and October 2020 (n=66)



*Associated number of children and adolescents reported by their parent to have MDCD: 0-5 years=five females and 1 male; 6-12 years=27 females and 10 males; 13-17 years=12 females and 11 males.

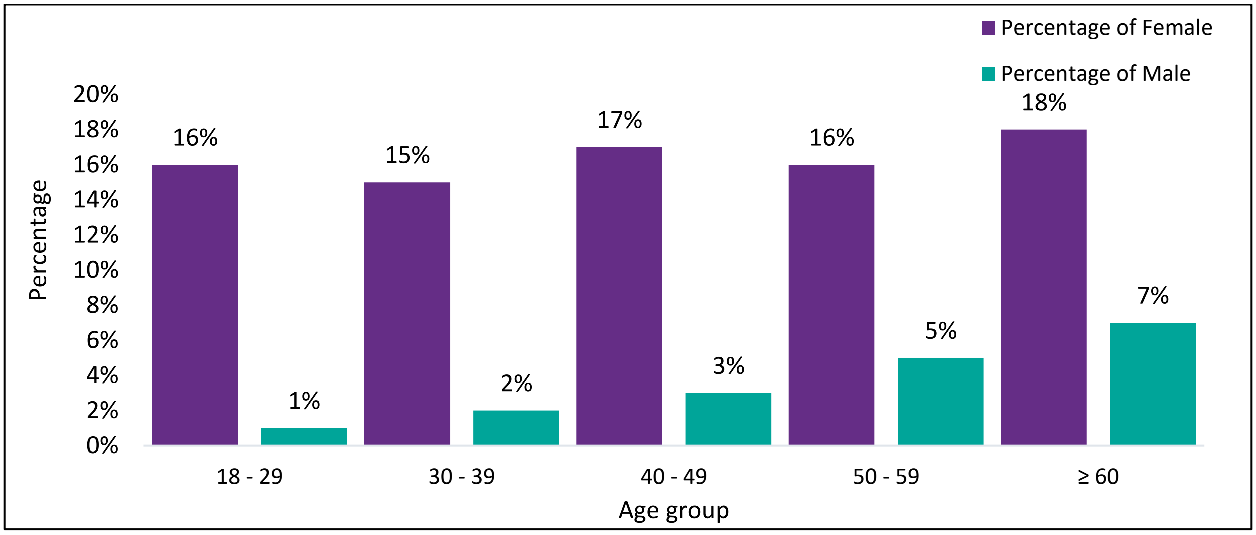
3.1.4 Summary information on adults reported to be MDCD in a survey carried out in Ireland and Northern Ireland

3.1.4a Summary of the MDCD adult survey in Ireland

This group consisted of responses from 623 adults with MDCD in Ireland. The overall gender breakdown was 82% (n=511) female and 18% male (n=112). Only 17% (n=106) of respondents were in the 18-29 years category (16% females and 1% males). An additional 17% (n=105) of all respondents were aged between 30-39 years (15% females and 2% males), with 66% (n=412) being ≥40 years (51% females and 15% males) (Figure 3.1.4a).

Regarding the tests used in the diagnosis of coeliac disease, 47% (n=509) had a confirmatory blood test and 53% (n=570) a gastrointestinal endoscopy and biopsy. Twenty-seven per cent (n=168) were diagnosed with one of these tests and 73% (n=455) by both tests. More details on this group are available in Annex 4 of this report.

Figure 3.1.4a: Percentage breakdown of adults, by gender and age, with MDCD in a survey carried out in Ireland between November 2019 and June 2020 (n=623)

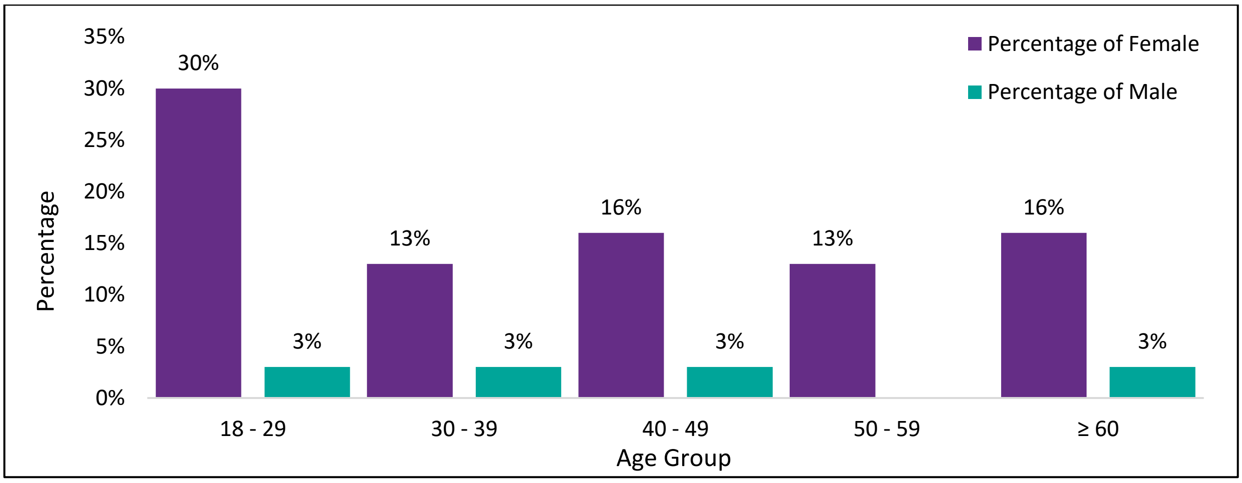


*Associated number of individuals who reported their age group: 18–29 years=100 females and six males; 30–39 years=93 females and 12 males; 40–49 years=107 females and 20 males; 50–59 years=100 females and 28 males; ≥60 years=111 females and 46 males.

3.1.4b Summary of the MDCD adult survey in Northern Ireland

This group consisted of responses from 195 adults with MDCD in Northern Ireland. The overall breakdown of this group was 88% (n=171) female and 13% male (n=24). A third (33%) of all respondents (n=63) were in the 18-29 years age category (30% females and 3% males), and 16% (n=31) were aged 30-39 years (females 13% and males 3%), with 52% (n=101) aged ≥40 years (45% females and 7% males) (Figure 3.1.4b). Regarding the tests used in the diagnosis of coeliac disease, 85% (n=166) had a confirmatory blood test and 90% (n=175) a gastrointestinal endoscopy and biopsy. A quarter (25%, n=49) of all respondents were diagnosed by one test and 75% (n=146) by both tests. More details on this group are available in Annex 4 of this report.

Figure 3.1.4b: Percentage breakdown of adults, by gender and age, with MDCD in a survey carried out in Northern Ireland between November 2019 and June 2020 (n=195)



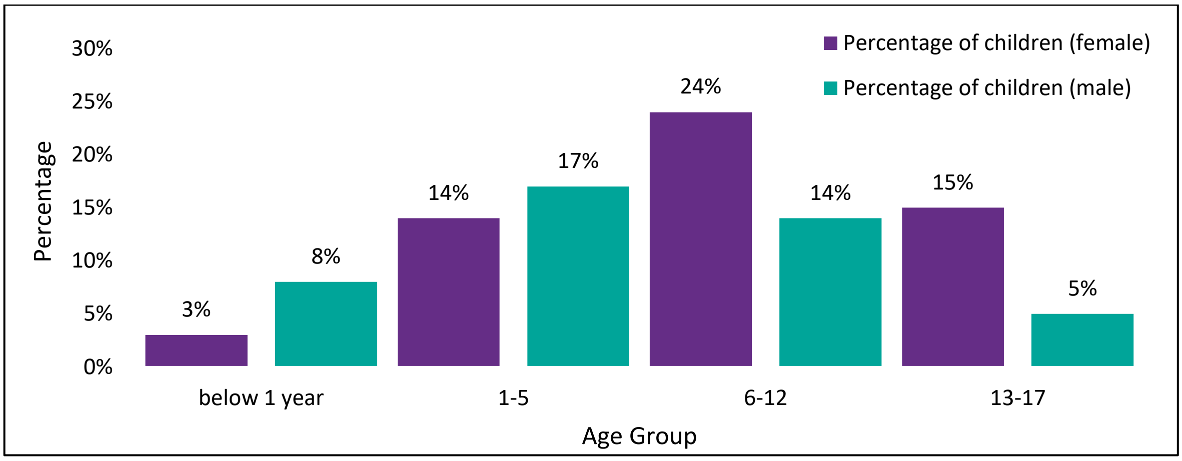
*Associated number of individuals who reported their age group: 18–29 years=58 females and five males; 30–39 years=26 females and five males; 40–49 years=31 females and six males; 50–59 years=25 females and two males; ≥60 years=31 females and six males.

3.1.5 Summary information on children & adolescents reported to have a food intolerance or suspected/undiagnosed food allergy (FI) in a parental survey carried out in Ireland and Northern Ireland

3.1.5a Summary of the FI parental survey in Ireland

This group consisted of responses from 59 parents of children/adolescents with FI in a parental survey in Ireland. The overall gender breakdown was 56% (n=33) females and 44% (n=26) males. Forty-two per cent (n=25) of children were in the ≤5 years category (17% females and 25% males), 80% (n=47) were ≤12 years (41% females and 39% males), and 20% (n=12) of adolescents were 13-17 years (15% females and 5% males) (Figure 3.1.5a). More details on this group are available in Annex 5 of this report.

Figure 3.1.5a: Percentage breakdown of children and adolescents, by gender and age, reported to have FI in the parental survey carried out in Ireland between November 2019 and June 2020 (n=59)

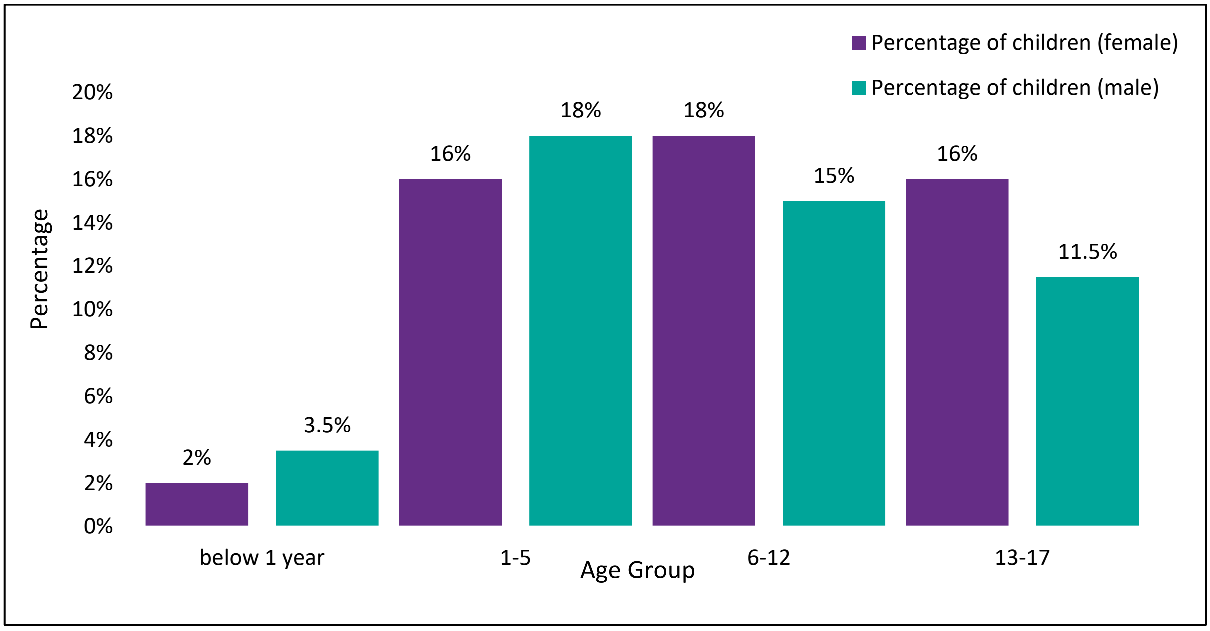


*Associated number of children and adolescents reported by their parents to have FI: <1 year=two females & five males; 1–5 years=eight females and 10 males; 6–12 years=14 females and eight males; 13-17 years=nine females and three males.

3.1.5b Summary of the FI parental survey in Northern Ireland

This group consisted of responses from 61 parents of children/adolescents with FI in a parental survey in Northern Ireland. The overall gender breakdown was 52% (n=32) females and 48% (n=29) males. In terms of age breakdown, 39% (n=24) of children were ≤5 years of age (18% females and 21.5% males), 73% (n=44) were ≤12 years (females 36% and males 36.5%), and 27% (n=17) of adolescents were 13-17 years (16% females and 11.5% males) (Figure 3.1.5b). More details on this group are available in Annex 5 of this report.

Figure 3.1.5b: Percentage breakdown of children and adolescents, by gender and age, who were reported to have FI in a parental survey carried out in Northern Ireland between November 2019 and June 2020 (n=61)



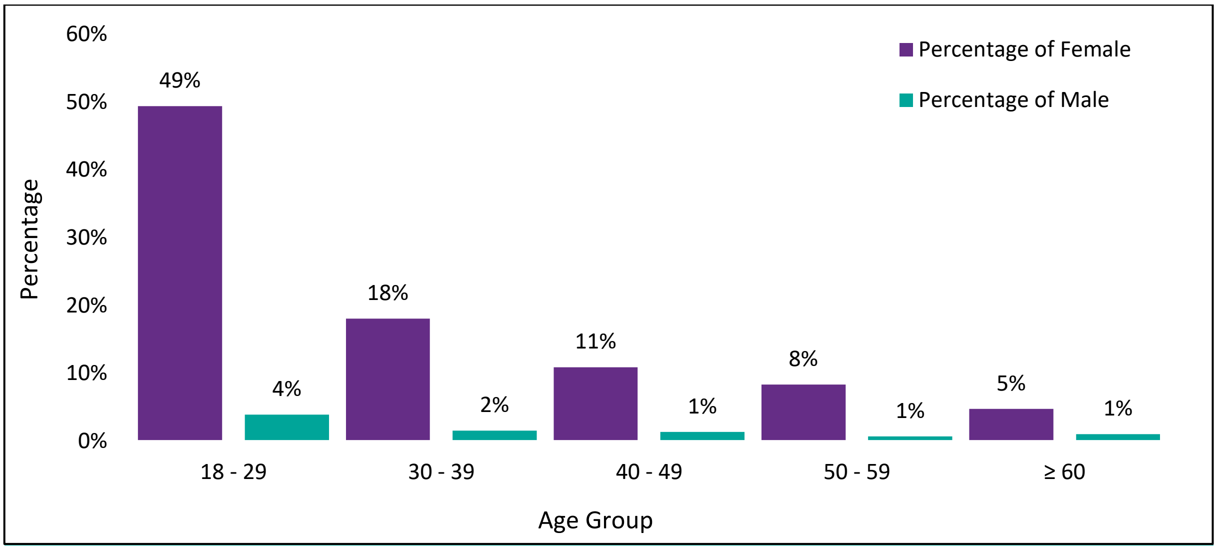
*Associated number of children and adolescents reported by their parents to have FI: <1year=one female and two males; 1–5 years=10 females and 11 males; 6–12 years=11 females and nine males; 13-17 years=10 females and seven males.

3.1.6 Summary information on adults reported to be FI in a survey carried out in Ireland and Northern Ireland

3.1.6a Summary of the food intolerance or suspected/undiagnosed food allergy (FI) adult survey in Ireland

This group consisted of responses from 587 adults with FI in a survey in Ireland. The overall gender breakdown was 91% (n=537) female and 9% male (n=50). Over half of all respondents (53%, n=113) were in the 18-29 years category (49% females and 4% males), while 73% (n=228) of all respondents were aged 18-39 (females 67% and males 6%), with 27% (n=159) being ≥40 years (24% females & 3% males) (Figure 3.1.6a). More details on this group are available in Annex 6 of this report.

Figure 3.1.6a: Percentage breakdown of adults, by gender and age, with FI in a survey carried out in Ireland between November 2019 and June 2020 (n=587)

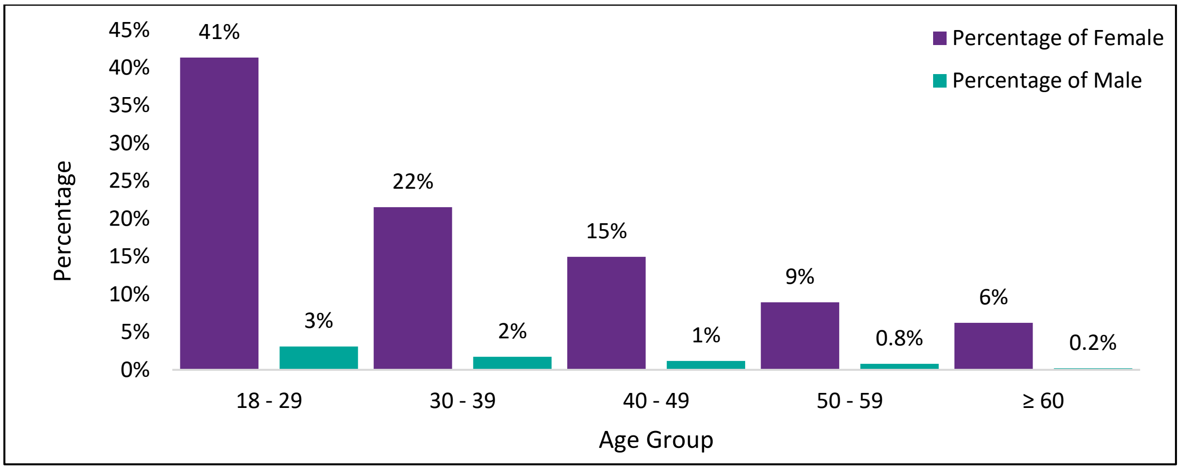


*Associated number of individuals who reported their age group: 18–29 years=290 females and 23 males; 30–39 years=106 females and nine males; 40–49 years=64 females and eight males; 50–59 years=49 females and four males; ≥60 years=28 females and six males.

3.1.6b Summary of the food intolerance or suspected/undiagnosed food allergy (FI) in adults in Northern Ireland

This group consisted of responses from 515 adults with FI in a survey in Northern Ireland. The overall gender breakdown was 93% female (n=479) and 7% male (n=36). In terms of age breakdown, 44% (n=229) of respondents were in the 18-29 years age category (41% females and 3% males). In fact, 68% (n=349) of respondents were aged 18-39 (females 63% and males 5%), with 32% (n=166) being ≥40 years (30% females and 2% males) (Figure 3.1.6b). More details on this group are available in Annex 6 of this report.

Figure 3.1.6b: Percentage breakdown of adults, by gender and age, with FI in a survey carried out in Northern Ireland between November 2019 and June 2020 (n=515)



*Associated number of individuals who reported their age group: 18–29 years=213 females and 16 males; 30–39 years=111 females and nine males; 40–49 years=77 females and six males; 50–59 years=46 females and four males; ≥60 years=32 females and one male.

3.2 A review of trigger foods, gender and age category associated with reported medically diagnosed food allergy (MDFA)

3.2.1 Reported medically diagnosed food allergies (MDFA) for children and adolescents (parental survey) in Ireland (n=258) and Northern Ireland (n=168)

Peanuts (52%), milk (45%), eggs (42%) and 'other nuts' (37%) were the four most reported MDFA in children (n=363) in Ireland (n=218) and Northern Ireland (n=145) (Table 3.2.1). In fact, the prevalence of allergy to these four foods was significantly greater (at the 5% significance level) than all other MDFA reported in the child groups. These findings agree with a previous ***safe*****food** study carried out in 2013, which indicated that the most reported food allergies in children between 0-12 years (n=107 in Ireland; n=77 in Northern Ireland) were peanut, eggs, milk and 'treenuts'. In addition, many Irish and UK sources have highlighted peanuts, milk, eggs and nuts as the most prevalent allergies affecting infants and young children in both countries (Colver, 2005; McClain *et al.* 2014; Kelleher *et al.* (2016); MacGiobuin, 2017; IFAN, 2019). The fifth most reported MDFA in this age group was to fruit, at 15% (kiwi 4% and other fruit 11%), followed closely by soybeans (11%) and fish (10%) (Figure 3.2.1).

Table 3.2.1: The five most reported MDFA among children (n=363), adolescents (n=63) and adults (n=355) reported in a food hypersensitivity survey carried out in Ireland and Northern Ireland between November 2019 and October 2020.

Prevalence	**MDFA children (males and females) (n=363)**	**MDFA adolescents (males and females) (n=63)**	**MDFA adults (males and females) (n=318)**
1st	Peanuts (52%)	Peanuts (57%)	Peanuts (39%)
2nd	Milk (45%)	Other Nuts (43%	Other nuts (31%)
3rd	Eggs (42%)	Eggs (29%)	Milk (29%)
4th	Other nuts (37%)	Milk (24%)	Cereals containing gluten (23%)/ Fruit*(23%)
5th	Fruit (15%)	Fish/Fruit (14%)	Eggs (17%)

*Fruit: consists of kiwi and other fruits (Children: 4% kiwi and 11% other fruits; Adolescents: 6% kiwi and 8% other fruits; Adults: 8% kiwi and 15% other fruits).

Similarly, peanuts (57%), other nuts (43%), eggs (29%) and milk (24%) were the four most reported MDFA for adolescents (13-17 years) in both groups (Ireland n=40 and Northern Ireland n=23) (Table 3.2.1). Milk allergy moved from the second most reported MDFA in children to fourth place for adolescents. In fact, an overall percentage decrease is noted in MDFA to milk in adolescents (24% on average) compared to children (45% on average) ($p < 0.001$).

Egg allergy remained the third most reported MDFA in adolescents (as in children), but the mean percentage is lower in adolescents (29% on average) than in children (42% on average). Similarly, allergy to ‘other nuts’ moved from the fourth most reported MDFA in children (37% on average) into second place for adolescents (43% on average). While many children are reported to outgrow allergies to milk and eggs (EFSA 2014) (a trend supported by the reported percentages of MDFA in this study), this is not as common for allergies to peanuts, tree nuts, fish or shellfish (FSAI, 2011). The European Food Safety Authority has previously reported that 75% of allergic reactions in children have been attributed to eggs, peanuts, milk, other nuts and fish (EFSA, 2014).

3.2.2 Reported medically diagnosed food allergies (MDFA) among adults self-reported by survey in Ireland (n=194) and Northern Ireland (n=124)

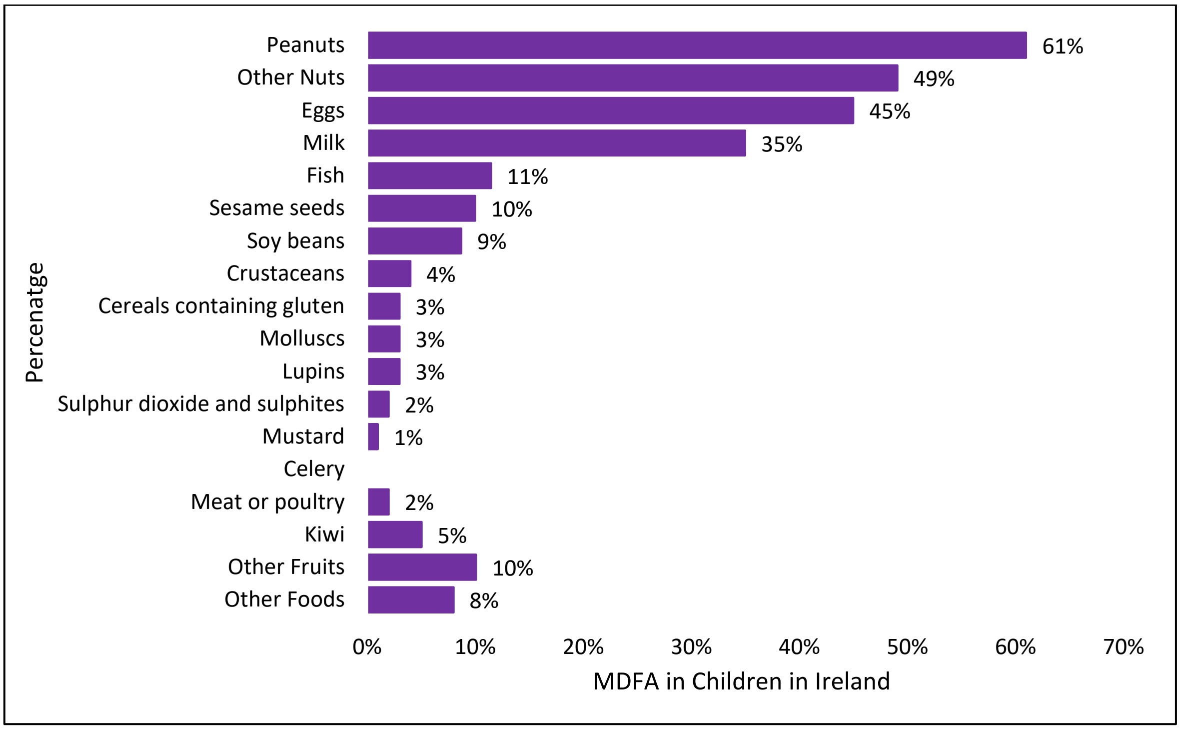
The data collected on the most common MDFA reported by all adults (Ireland and Northern Ireland, n=318) (Table 3.2.3c) were like that collected on MDFA in children and adolescents. The most common MDFA for adults were peanuts (39%), other nuts (31%), milk (29%) and eggs (17%). This trend was previously documented in other studies in Ireland (FSAI, 2011; ***safe*****food**, 2013a) and Northern Ireland (***safe*****food**, 2013b). However, fruits (including 8% kiwi) ranked as the fourth most prevalent food allergy among adults. These were followed by eggs (17%) in fifth place and crustaceans (13%) in sixth place. A lower percentage of milk (29%) and egg (17%) allergy was noted in adults (Figure 3.2.2) compared to children (45% and 42%, respectively), and these differences were statistically significant ($p < 0.05$).

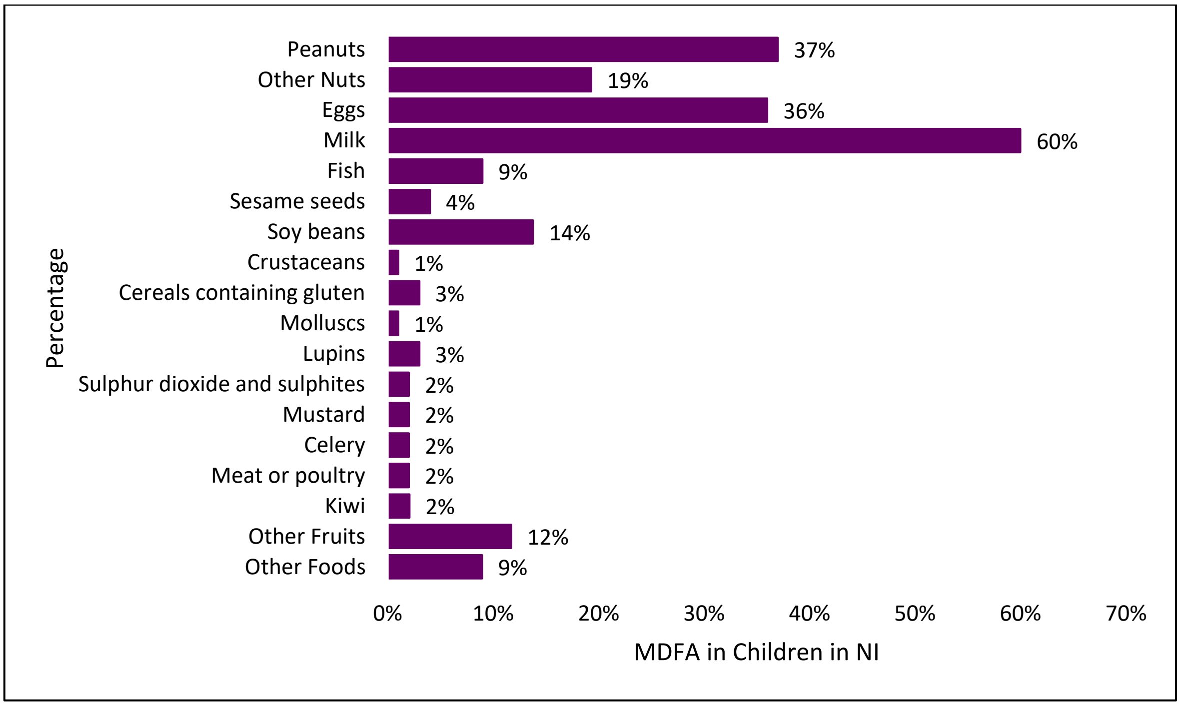
An increase in prevalence was noted for several foods in adults (in particular, cereals containing gluten, fruits, crustaceans and molluscs) when compared to those reported for children and adolescents. For example, in this study MDFA to cereals containing gluten was reported as 3% in children, 6% in adolescents and 7% for adults, while MDFA to fruit (kiwi and other fruits) was 15% (4% kiwi) in children, 14% (6% kiwi) in adolescents and 23% (8% kiwi) in adults. MDFA to crustaceans was at 3%, 5% and 13% in children, adolescents and adults, respectively, and MDFA to molluscs was at 2%, 5% and 9%, respectively. The prevalence of peanuts, other nuts, eggs and milk allergy were (independently) significantly lower ($p < 0.05$) among the adult groups (n=318) compared to children (n=363). The only significant ($p < 0.05$) increase in allergy prevalence compared to adolescents was recorded for cereals containing gluten. These findings suggest a relationship between age and prevalence of MDFA to these foods in the susceptible populations of Ireland and Northern Ireland, an observation previously documented in the literature (Ben-Shoshan *et al.* 2010; Burney *et al.* 2010; McGowan and Keet, 2013; Kamdar *et al.* 2015; and Moonesinghe *et al.* 2016).

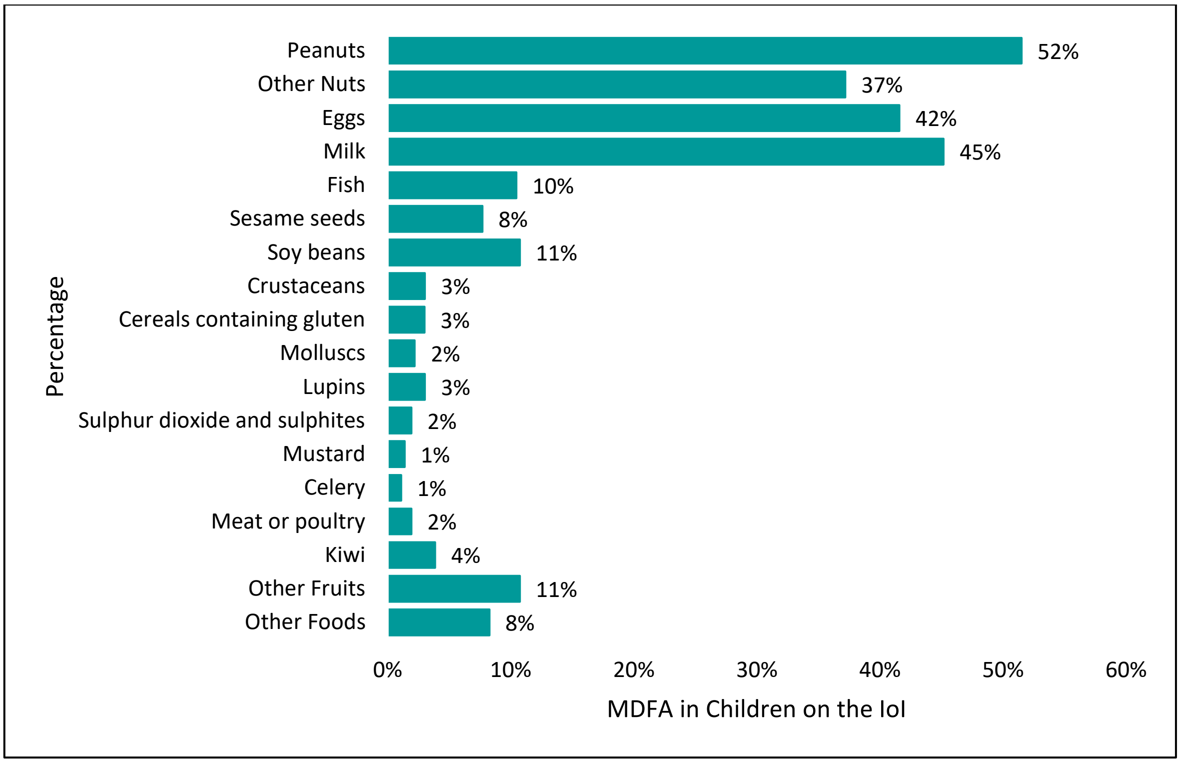
The prevalence of MDFA to kiwi was found to be higher in adults (8%) than in children (4%) (not statistically significantly). While kiwi is not one of the 14 allergens currently listed in Regulation EU No. 1169/2011, the reported percentage of MDFA to kiwi was found to be higher among MDFA children, adolescents and adults than for many of the foods causing allergies or intolerances on that list (Figure 3.2.1 and 3.2.2). For example, if we examine all adults in this study with MDFA (Ireland and Northern Ireland, n=318), kiwi allergy (8%) was reported to be equally as common as fish allergy (8%) and frequently more common than that for soybeans (5%), sesame seeds (5%), celery (4%), mustard (3%), sulphites and SO_2 (3%), and lupin (2%). That said, the difference in the reported prevalence of MDFA to kiwi was only found to be statistically significant (at the 5% level) when compared to lupin (2%). However, the overall observation regarding the high incidence of kiwi allergy noted in this study agrees with two previous ***safe*food** reports (***safe*food**, 2013a; ***safe*food**, 2013b) which describe kiwi hypersensitivity (as opposed to self-reported MDFA in this study) to be 10% in Ireland (n=259) and 10% in Northern Ireland (n=123). Both the previous ***safe*food** studies (2013a; 2013b) reported kiwi food hypersensitivity to be more prevalent than hypersensitivity to soybeans (6% Ireland, 9% Northern Ireland), celery (0% Ireland, 4% Northern Ireland), mustard (3% Ireland, 1% Northern Ireland), lupin (2% Ireland, 2% Northern Ireland), sulphites and SO_2 (1% Ireland, 4% Northern Ireland), and higher than fish (8%), crustaceans (5%) and molluscs (4%) in Northern Ireland only.

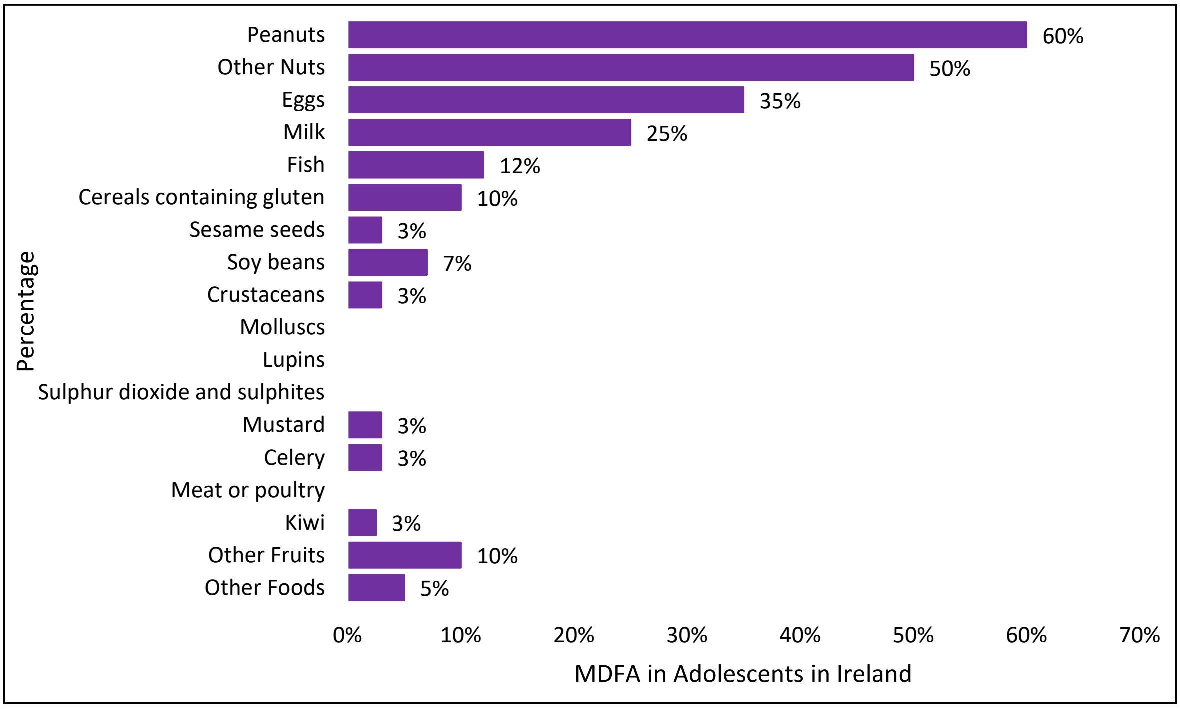
Taking a broader perspective, food hypersensitivity to kiwi is commonly reported in the EU (Mattila *et al.* 2003; Lucas *et al.* 2004; Bublin *et al.* 2010; Bublin *et al.* 2011; Le *et al.* 2013; Burney *et al.* 2014). A higher prevalence of kiwi allergy compared to allergies to foods on the EU list of 14 has been reported in other European studies (Rancé *et al.* 2005; Lyons *et al.* 2020). They reviewed food hypersensitivity in six European cities and reported higher rates of probable food allergy to kiwi than to fish (except for Athens), soybeans, sesame seed, celery (except for Lodz) and mustard seed. The incidence of probable food allergy to kiwi was also reported to be higher than for wheat in all but one city (Reykjavik), where the incidence was reported as equal. This study highlights the importance of this food allergen among sensitive populations in Europe.

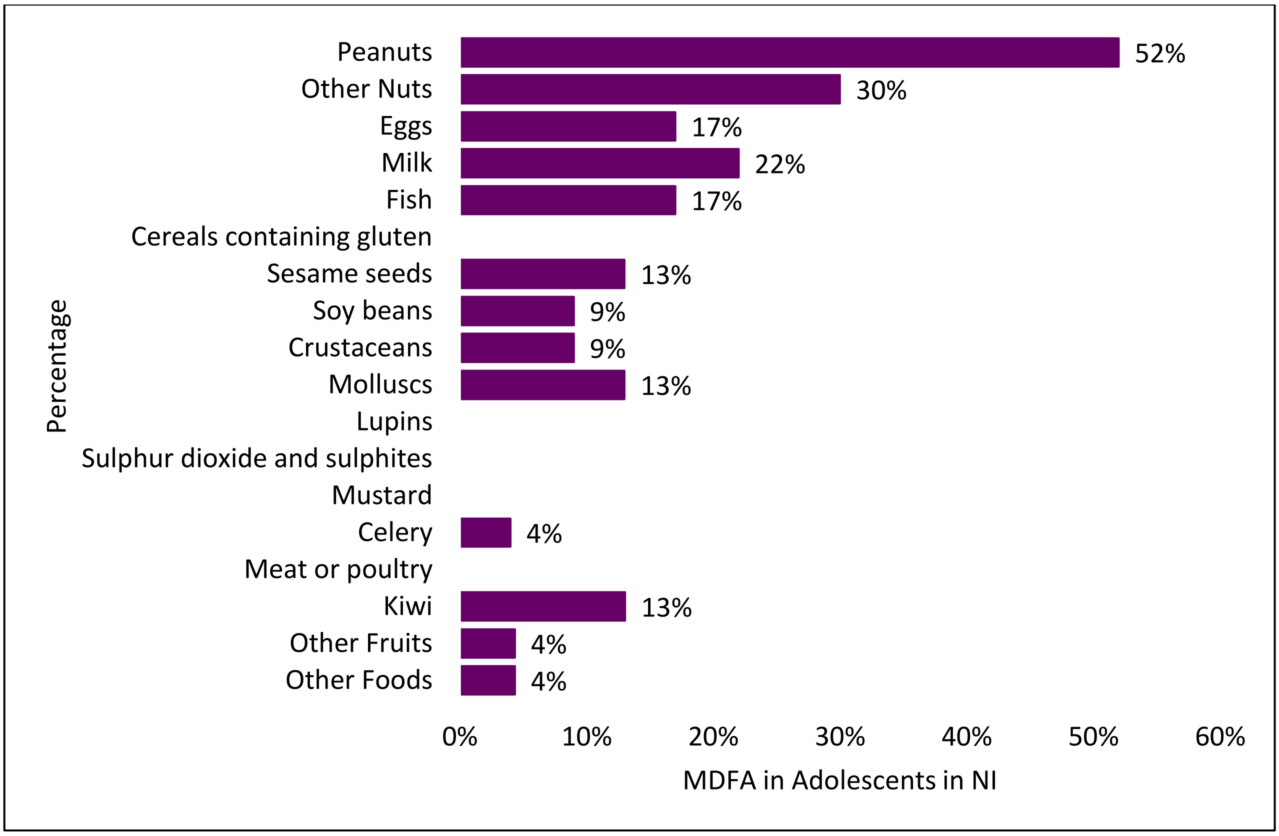
Figure 3.2.1. Breakdown of medically diagnosed food allergies (MDFA) in a food hypersensitivity survey carried out between November 2019 and October 2020: Children in Ireland (n=218), Northern Ireland (n=145), IoI (n=363); Adolescents in Ireland (n=40), Northern Ireland (n=23), IoI (n=63)






Percentage
Peanuts 52%
Other Nuts 37%
Eggs 42%
Milk 45%
Fish 10%
Sesame seeds 8%
Soy beans 11%
Crustaceans 3%
Cereals containing gluten 3%
Molluscs 2%
Lupins 3%
Sulphur dioxide and sulphites 2%
Mustard 1%
Celery 1%
Meat or poultry 2%
Kiwi 4%
Other Fruits 11%
Other Foods 8%
0%
10%
20%
30%
40%
50%
60%
MDFA in Children on the IoI


Percentage
Peanuts 60%
Other Nuts 50%
Eggs 35%
Milk 25%
Fish 12%
Cereals containing gluten 10%
Sesame seeds 3%
Soy beans 7%
Crustaceans 3%
Molluscs
Lupins
Sulphur dioxide and sulphites
Mustard 3%
Celery 3%
Meat or poultry
Kiwi 3%
Other Fruits 10%
Other Foods 5%
0%
10%
20%
30%
40%
50%
60%
70%
MDFA in Adolescents in Ireland


Percentage
Peanuts
Other Nuts
Eggs
Milk
Fish
Cereals containing gluten
Sesame seeds
Soy beans
Crustaceans
Molluscs
Lupins
Sulphur dioxide and sulphites
Mustard
Celery
Meat or poultry
Kiwi
Other Fruits
Other Foods
52%
30%
17%
22%
17%
13%
9%
9%
13%
4%
13%
4%
4%
0%
10%
20%
30%
40%
50%
60%
MDFA in Adolescents in NI

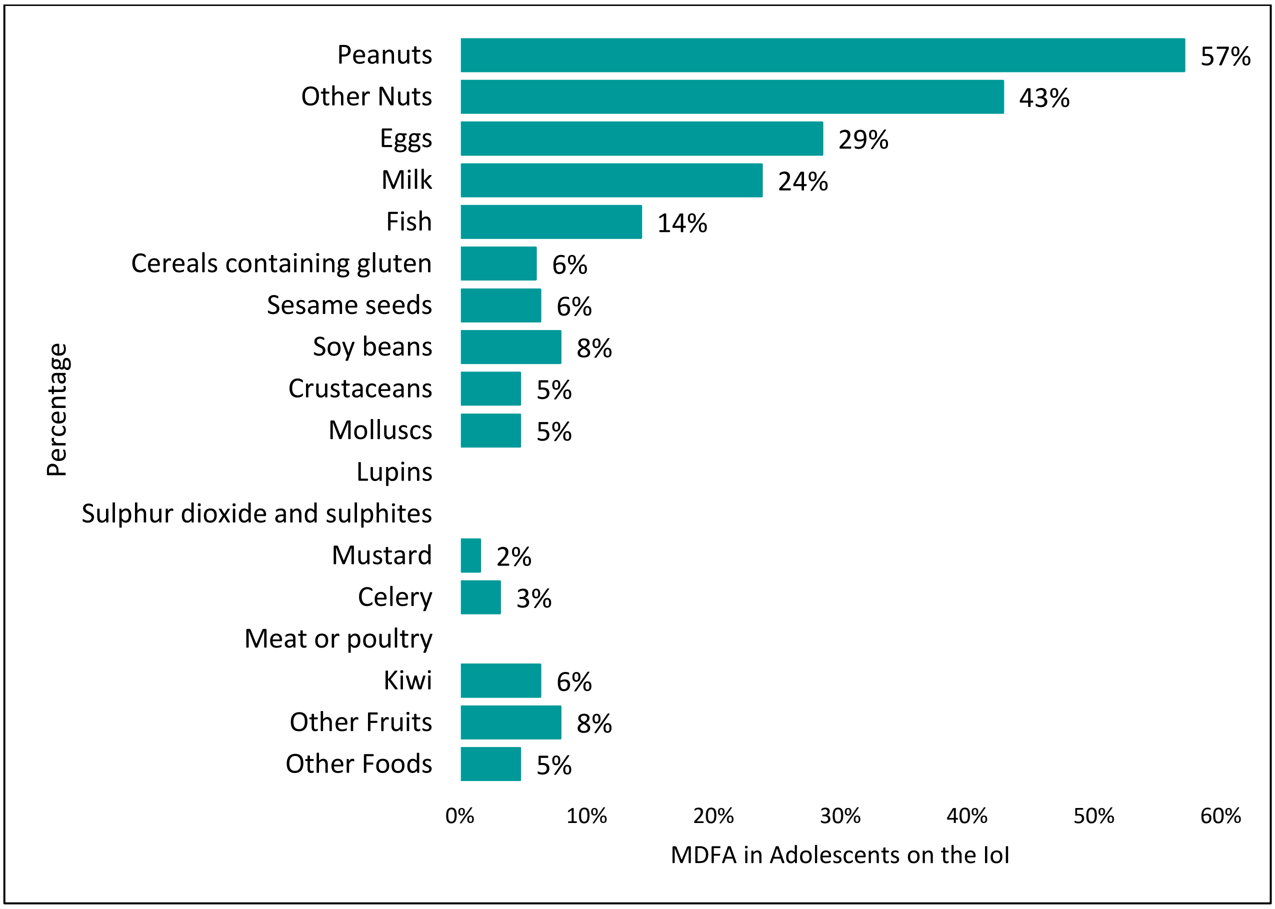
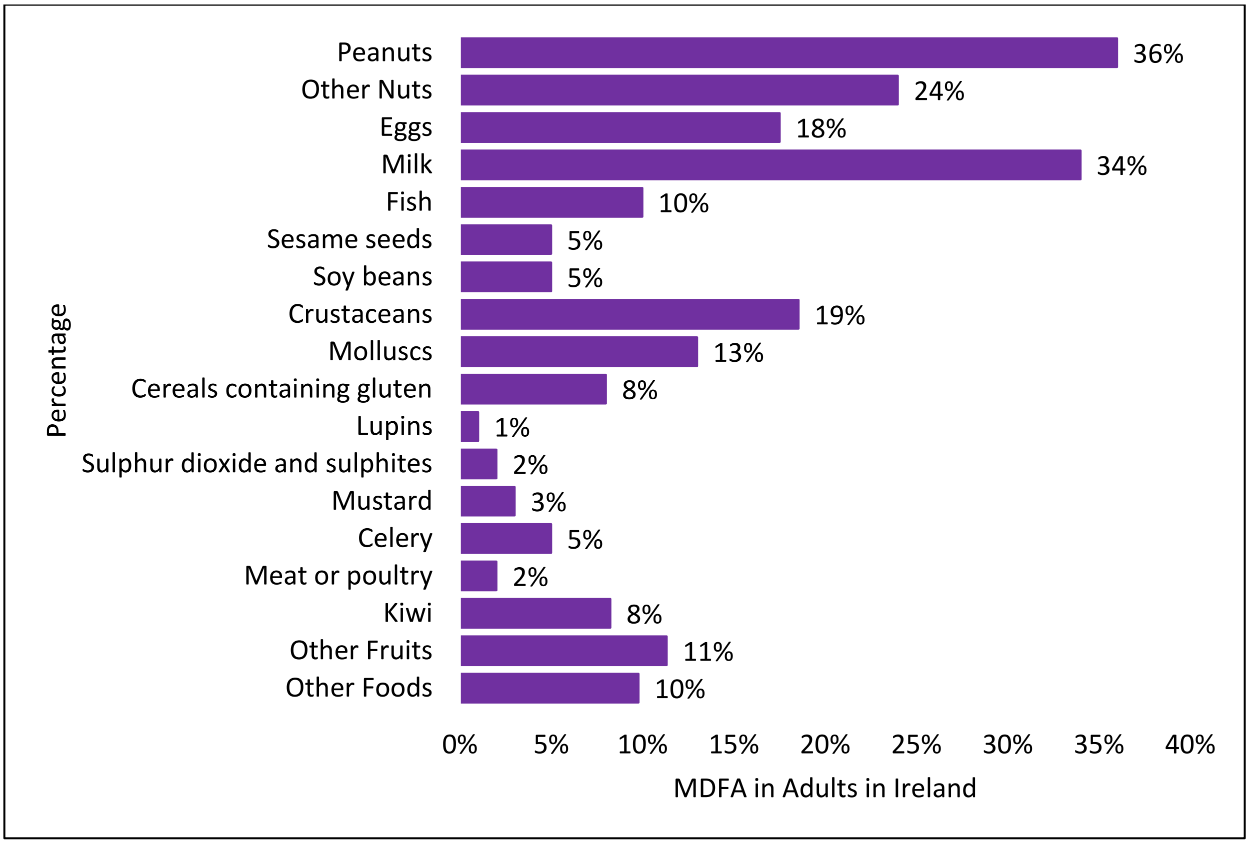
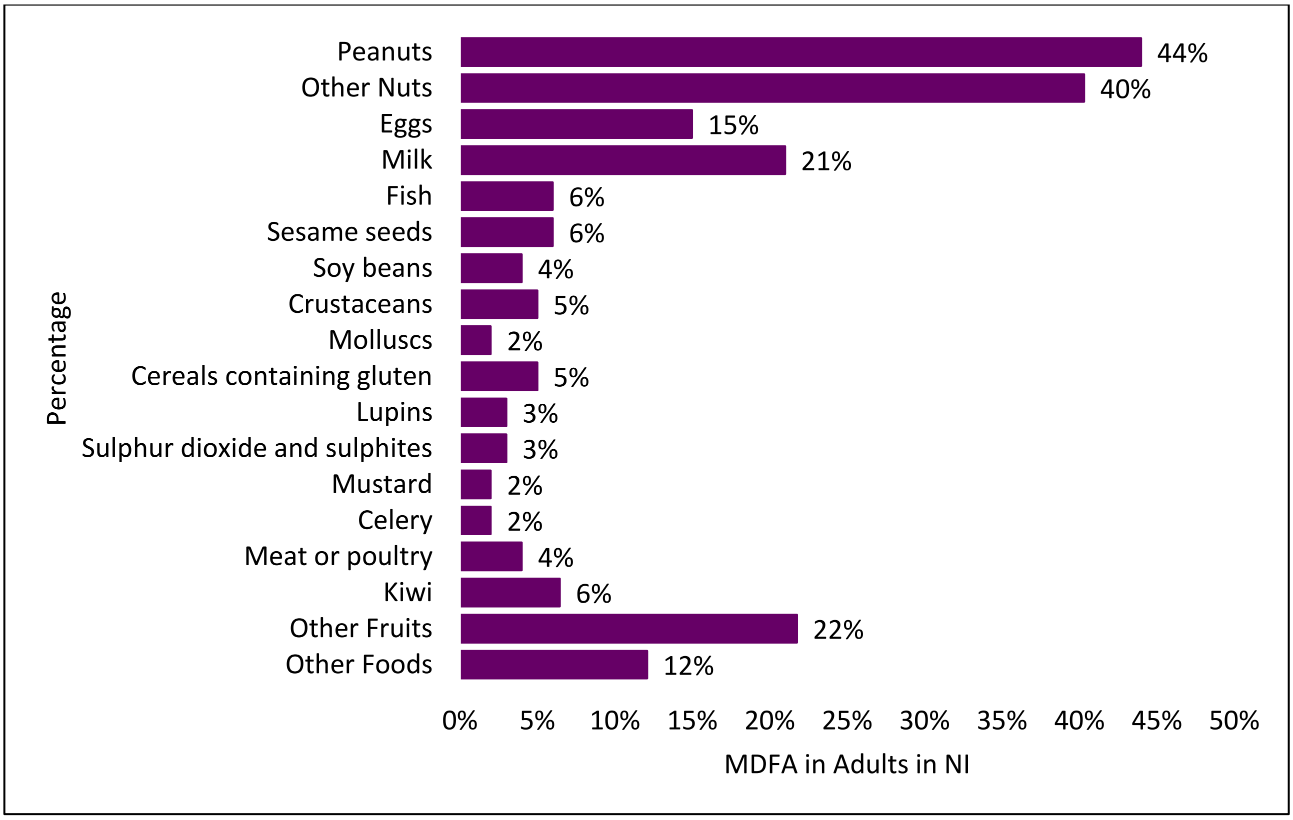
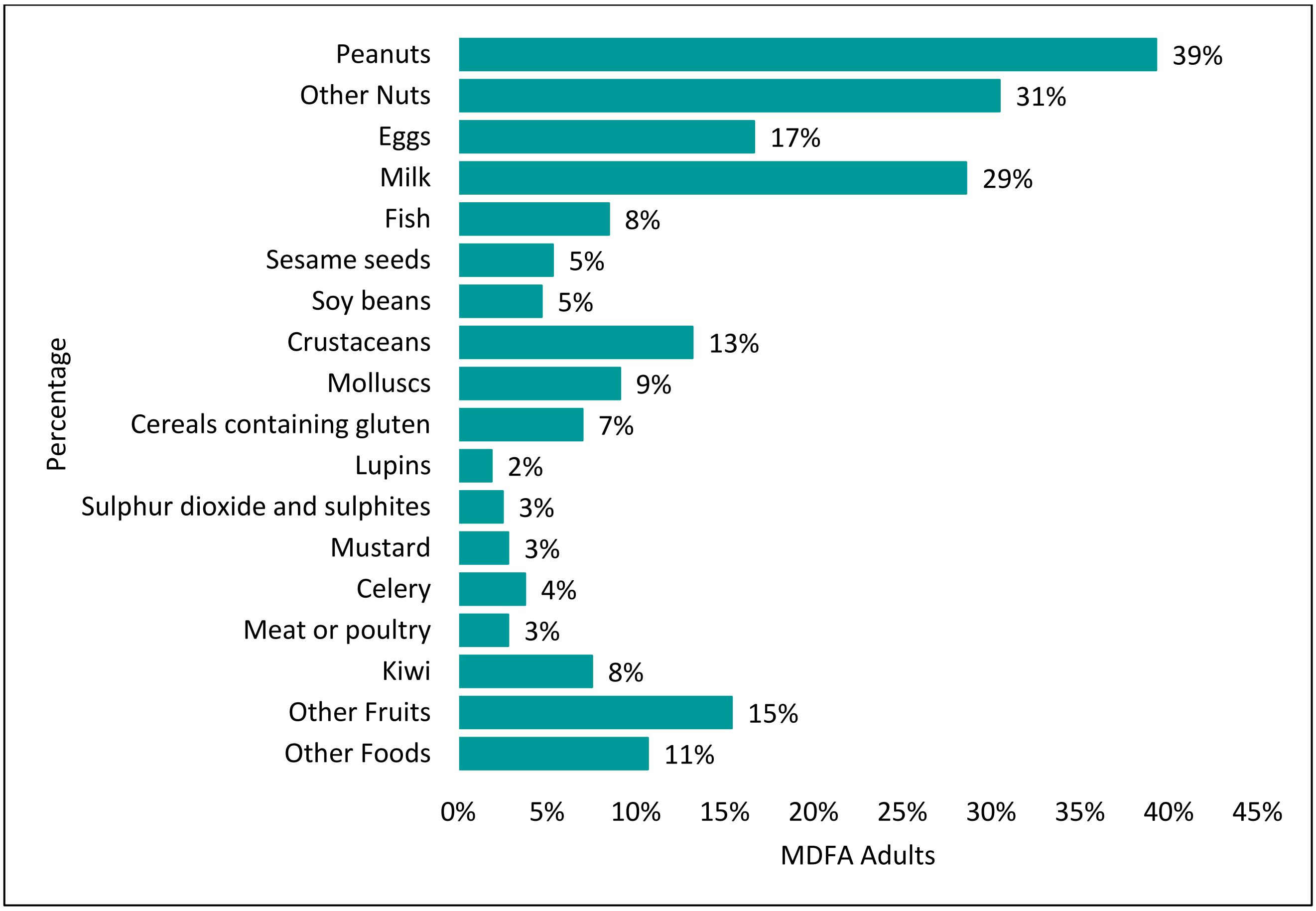

Percentage
Peanuts
Other Nuts
Eggs
Milk
Fish
Cereals containing gluten
Sesame seeds
Soy beans
Crustaceans
Molluscs
Lupins
Sulphur dioxide and sulphites
Mustard
Celery
Meat or poultry
Kiwi
Other Fruits
Other Foods
57%
43%
29%
24%
14%
6%
6%
8%
5%
5%
2%
3%
6%
8%
5%
0%
10%
20%
30%
40%
50%
60%
MDFA in Adolescents on the IoI

Figure 3.2.2. Breakdown of MDFA in adults in a survey carried out between November 2019 and October 2020. Ireland (n=194), Northern Ireland (n=124), IoI (n=318)







3.2.3 Gender breakdown of reported Medically Diagnosed Food Allergy (MDFA) in children, adolescents and adults (n=744) from the Food Hypersensitivity Survey Data

When the parental MDFA surveys were examined in this study, a slightly higher, statistically insignificant, percentage of male children (57% in Ireland, 58% in Northern Ireland) were reported with this condition. Food allergy has previously been documented as more common in male children (Ford *et al.* 2003; Ben-Shoshan *et al.* 2012), possibly because of differences in immune response regulation between the genders (DunnGalvin *et al.* 2006). A review of hospital admissions for severe allergic reactions in children between 1998 and 2000 in the UK and Ireland suggested that 65% of these admissions were male (Clover, 2005).

Interestingly, there was consistency between the genders regarding the trigger foods reported by the parents (Figure 3.2.3a). A prevalence ranking of trigger foods in male and female MDFA children can be seen in Table 3.2.3a.

Table 3.2.3a: The five most reported MDFA among children (n=363) by gender (parent-reported) in a food hypersensitivity survey carried out between November 2019 and October 2020 in Ireland and Northern Ireland

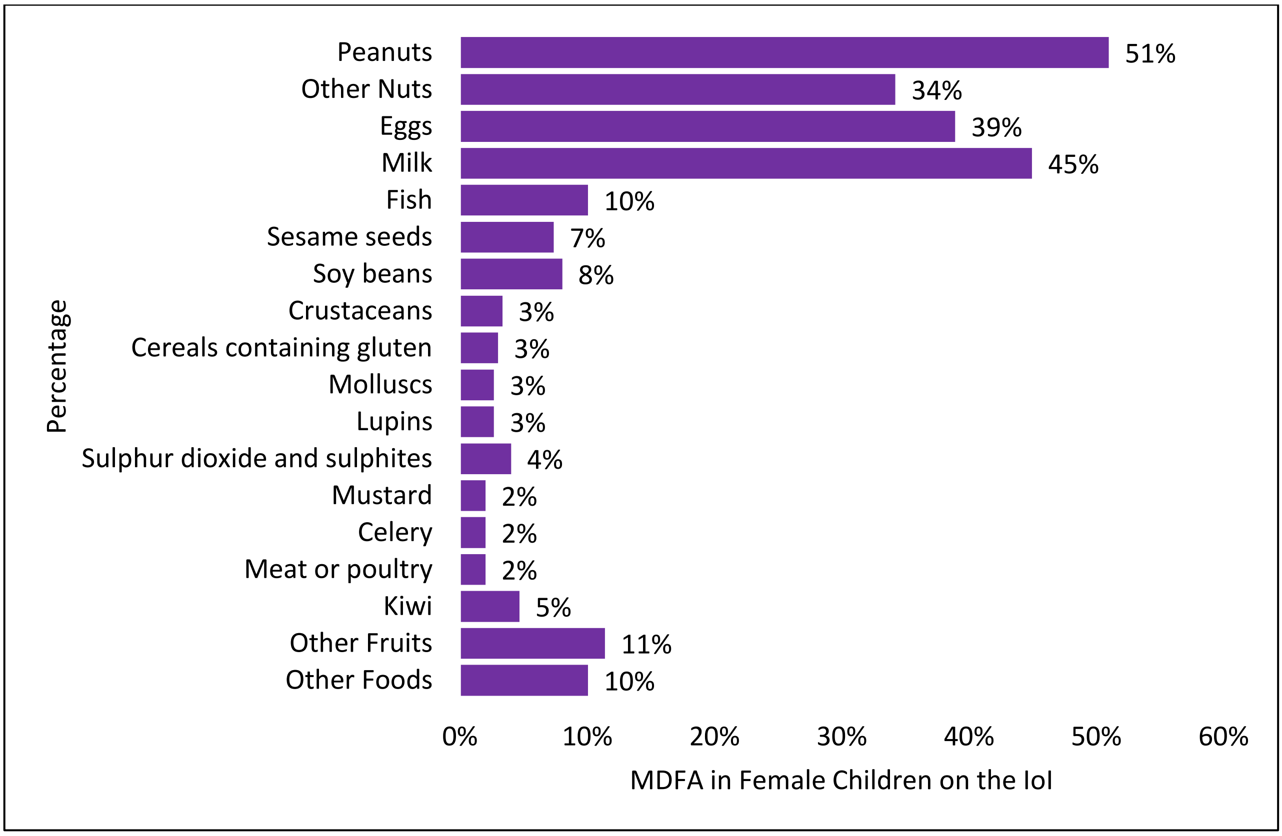
Prevalence Ranking	**Female children with MDFA (n=149)**	**Male children with MDFA (n=214)**	**Children with MDFA (Males and Females) (n=363)**
1st	Peanuts (51%)	Peanuts (52%)	Peanuts (52%)
2nd	Milk (45%)	Milk (45%)	Milk (45%)
3rd	Eggs (39%)	Eggs (43%)	Eggs (42%)
4th	Other nuts** (34%)	Other nuts** (39%)	Other nuts** (37%)
5th	Fruit* (16%)	Fruit* (13%)	Fruit* (15%)

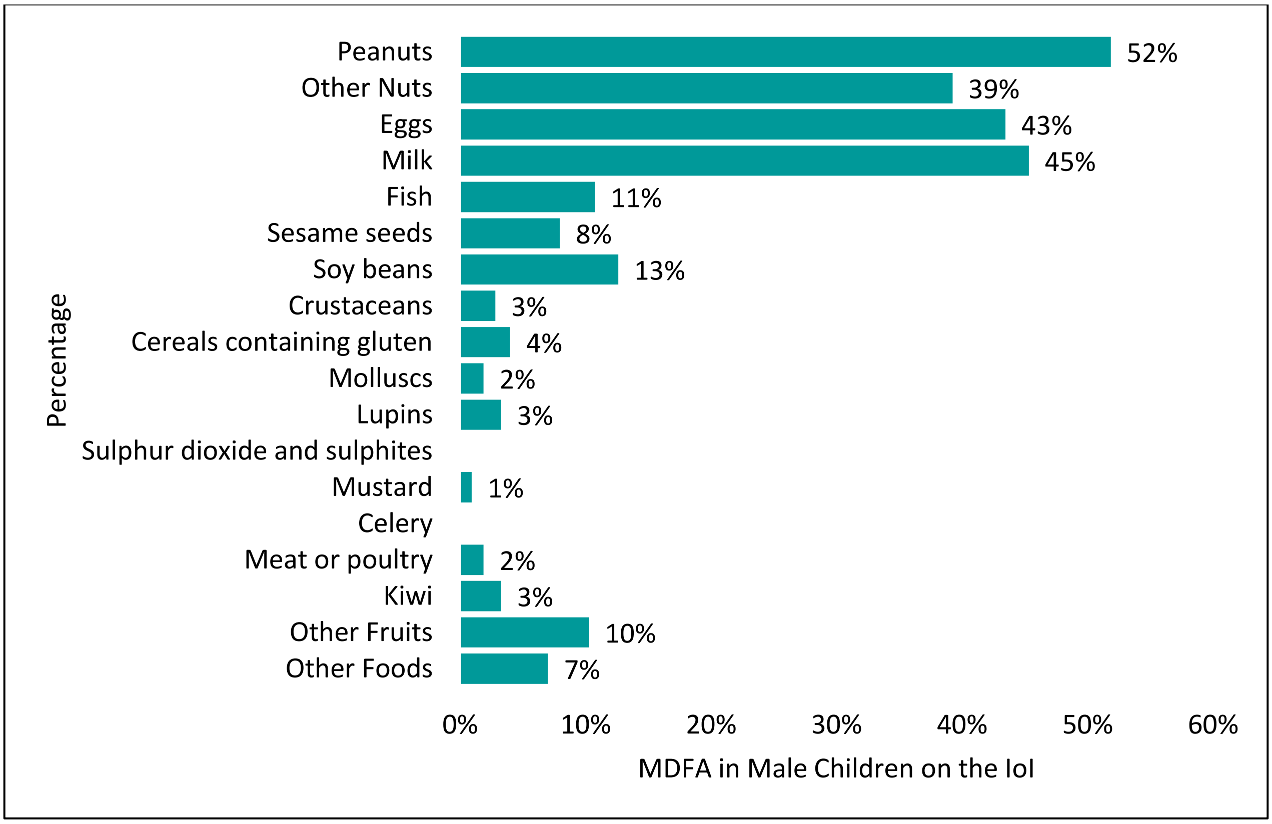
*Fruit: consists of kiwi and other fruits (Female Children: 5% kiwi and 11% other fruits; Male Children: 3% kiwi and 10% other fruits; All MDFA Children (Female and Male): 4% kiwi and 11% other fruits).

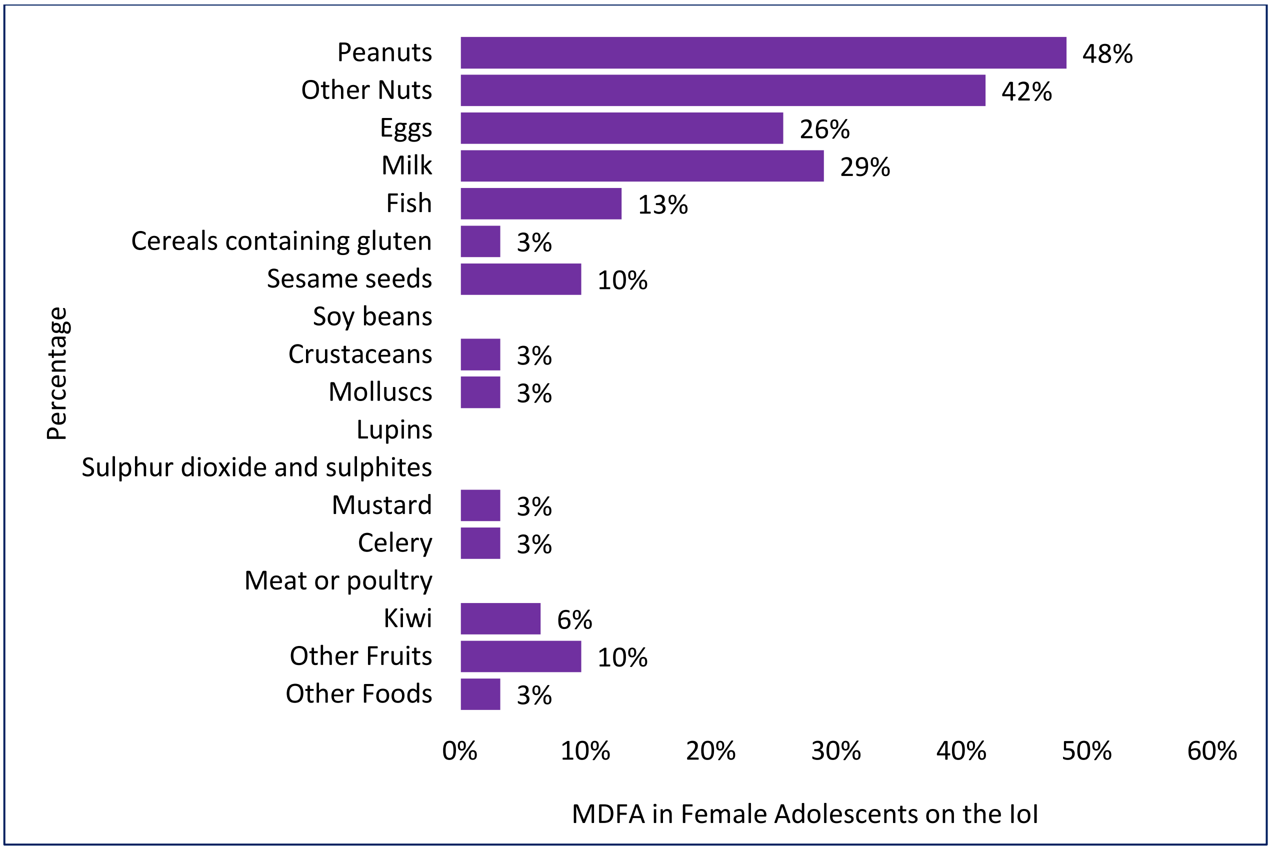
** Other nuts: see Annex 1 for a detailed breakdown.

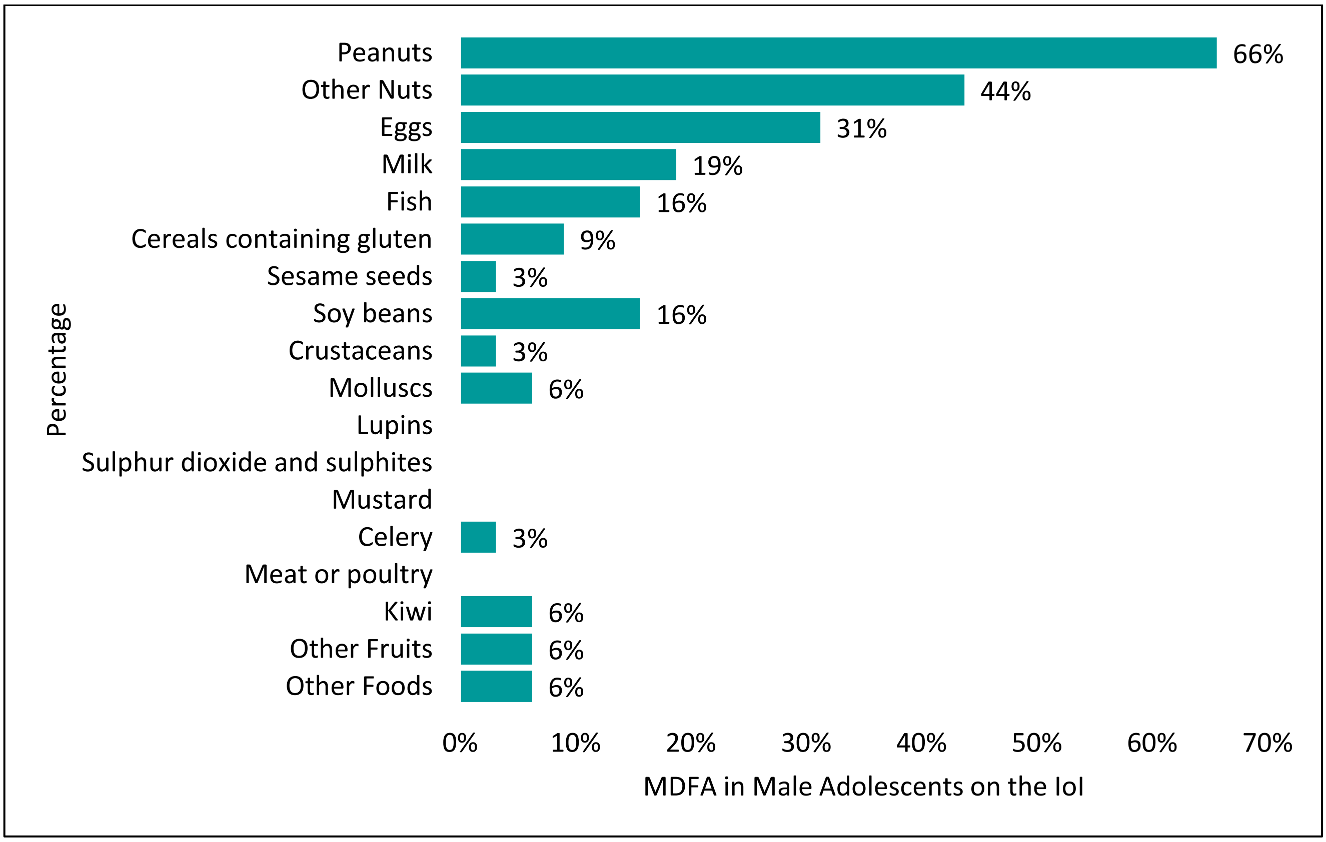
Similar prevalences emerged when data for all children (n=363) was examined for each of the 14 regulated food allergens, the largest difference for any MDFA between the genders in this age group being just 5% (Figure 3.2.3a). MDFA to sulphur dioxide and sulphites, and celery, were absent in male children and present at very low levels in female children (4% sulphur dioxide and sulphites, and 2% celery).

Figure 3.2.3a. Gender breakdown of medically diagnosed food allergy (MDFA) in IoI children (females=149, males=214) and adolescents (females=31, males=32) (parent-reported)






Percentage
Peanuts 48%
Other Nuts 42%
Eggs 26%
Milk 29%
Fish 13%
Cereals containing gluten 3%
Sesame seeds 10%
Soy beans
Crustaceans 3%
Molluscs 3%
Lupins
Sulphur dioxide and sulphites
Mustard 3%
Celery 3%
Meat or poultry
Kiwi 6%
Other Fruits 10%
Other Foods 3%
0%
10%
20%
30%
40%
50%
60%
MDFA in Female Adolescents on the IoI


Percentage
Peanuts 66%
Other Nuts 44%
Eggs 31%
Milk 19%
Fish 16%
Cereals containing gluten 9%
Sesame seeds 3%
Soy beans 16%
Crustaceans 3%
Molluscs 6%
Lupins
Sulphur dioxide and sulphites
Mustard
Celery 3%
Meat or poultry
Kiwi 6%
Other Fruits 6%
Other Foods 6%
0%
10%
20%
30%
40%
50%
60%
70%
MDFA in Male Adolescents on the IoI

A similar ranking order in prevalence was also noted in the reported percentages of MDFA to specific foods in female and male adolescents, i.e., peanuts, other nuts, eggs and milk, respectively (Table 3.2.3b). However, the sample size for adolescents (n=63) is not as large as that for children (n=363), and the similarities in percentages between the genders were not as evident in this age category. This adolescent sample size was smaller probably because it spanned just five years (13-17 years) compared to 12 years for the child groups (0-12 years).

Table 3.2.3b: The five most reported MDFA among adolescents (n=63) by gender (parent-reported) in a food hypersensitivity survey carried out between November 2019 and October 2020 in Ireland and Northern Ireland

Prevalence Ranking	Female adolescents with MDFA (n=31)	Male adolescents with MDFA (n=32)	Adolescents with MDFA (Males and Females) (n=63)
1st	Peanuts (48%)	Peanuts (66%)	Peanuts (57%)
2nd	Other nuts** (42%)	Other nuts** (44%)	Other nuts** (43%)
3rd	Milk (29%)	Eggs (31%)	Eggs (29%)
4th	Eggs (26%)	Milk (19%)	Milk (24%)
5th	Fruit* (16%)	Fish/Soybeans (16%)	Fish/Fruit* (14%)

*Fruit: consists of kiwi and other fruits (Female Adolescents: 6% kiwi and 10% other fruits; Male Adolescents: 6% kiwi and 6% other fruits; All MDFA Adolescents (Female and Male): 6% kiwi and 8% other fruits).

**Other nuts: see Annex 1 for a breakdown of other nuts.

When reported MDFA in adults is reviewed, peanuts were once again the most reported MDFA (average 39 %; Table 3.2.3c). While a large sample size was obtained for female adults (n=292), challenges in acquiring a representative adult male MDFA group in this study (n=26) made comparisons between genders in this age category difficult. However, the emergence of crustaceans is notable in the top five most reported MDFA in females (13%) and males (46%) (Figure 3.2.3c).

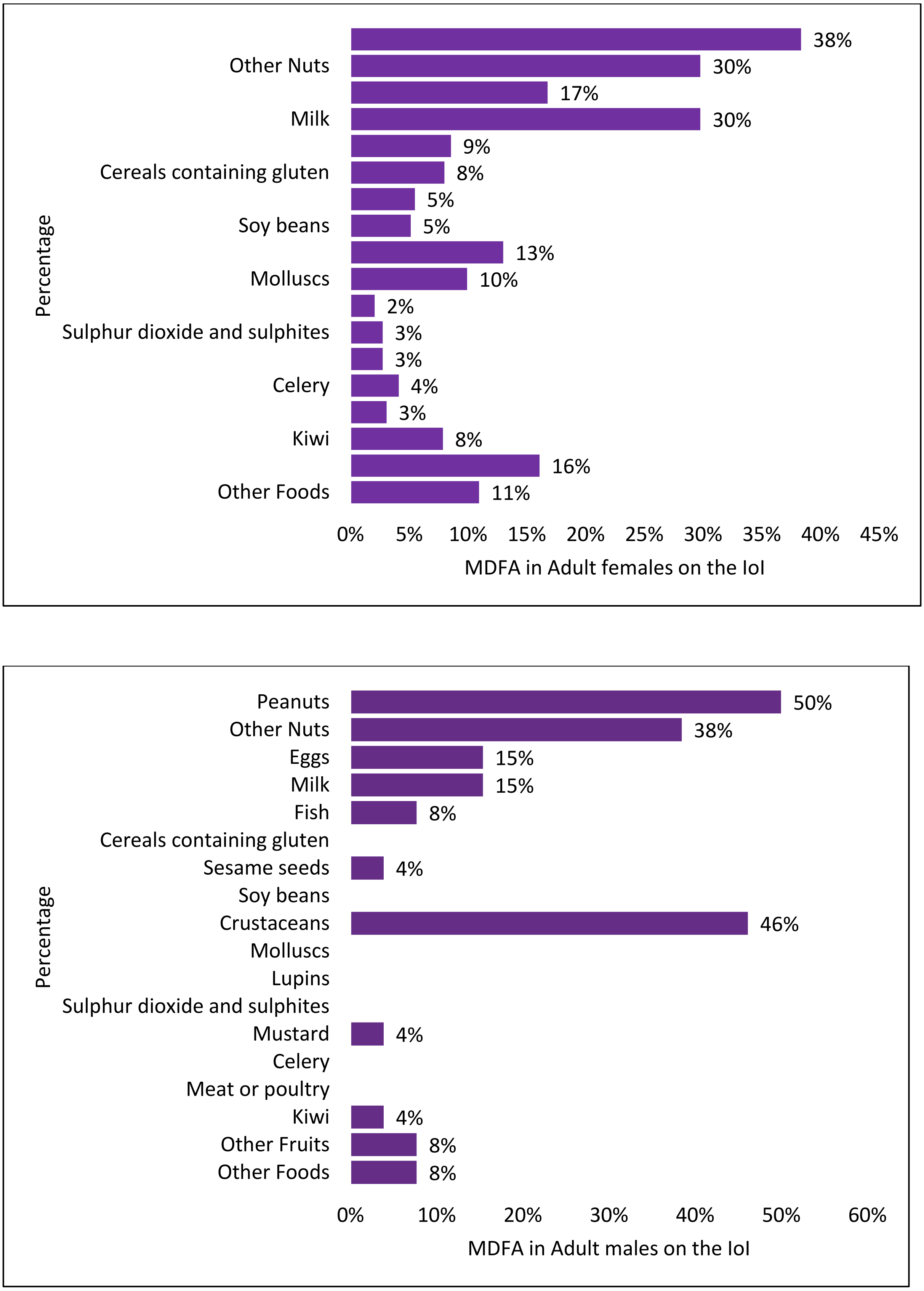
Table 3.2.3c: The five most self-reported MDFA among adults (n=318) in a food hypersensitivity survey carried out between November 2019 and October 2020 in Ireland and Northern Ireland

Prevalence Ranking	**Female Adults with MDFA (n=292)**	**Male Adults with MDFA (n=26)**	**Male and Female Adults with MDFA (n=318)**
1st	Peanuts (38%)	Peanuts (50%)	Peanuts (39%)
2nd	Other nuts** (30%)/ Milk (30%)	Crustaceans (46%)	Other nuts** (31%)
3rd	Fruit* (24%)	Other nuts** (38%)	Milk (29%)
4th	Eggs (17%)	Eggs (15%)/ Milk (15%)	Fruit* (23%)
5th	Crustaceans (13%)	Fruit* (12%)	Eggs (17%)

*Fruit: consists of kiwi and other fruits (Female Adults: 8% kiwi and 16% other fruits; Male Adults: 4% kiwi and 8% other fruits; All MDFA Adults (Female and Male): 8% kiwi and 15% other fruits).

**Other nuts: see Annex 2 for a breakdown of other nuts.

Figure 3.2.3b. Gender breakdown of MDFA in IoI adults (females=292, males=26) in a food hypersensitivity survey carried out between November 2019 and October 2020



3.2.4 Overall study findings on medically diagnosed food allergy (mdfa) from the food hypersensitivity surveys

When all of the adult and parent-reported MDFA were examined, the main trigger foods were found to be peanuts (47%), milk (36%), other nuts (35%) and eggs (30%) (Table 3.2.4). This agrees with reports from previous studies in Ireland and UK (FSAI, 2011; ***safe*food**, 2013a; ***safe*food**, 2013b; Colver, 2005; McClain et al. 2014; Kelleher et al. (2016); MacGiobuin, 2017). In addition, when the percentage of foods reported to be associated with anaphylactic episodes were examined, the same four foods were once again noted. The order of these four allergens was different, however, with peanuts (7%) and other nuts (6%) being the most reported trigger foods. Interestingly, our data indicates that kiwi-associated anaphylaxis was reported to occur in 1% of respondents (n=744). This dataset suggests that the percentage rate of anaphylaxis for kiwi (1%) is comparable to that of crustaceans (1%), sesame seeds (1%), molluscs (1%) and lupins (1%). However, unlike these foods, kiwi is currently regulated under EU Regulation EU No. 1169/2011.

Table 3.2.4: The ten most reported MDFA for all respondents (n=744) in Ireland and Northern Ireland based on adult self-reported and parent-reported data from a survey carried out between November 2019 and October 2020

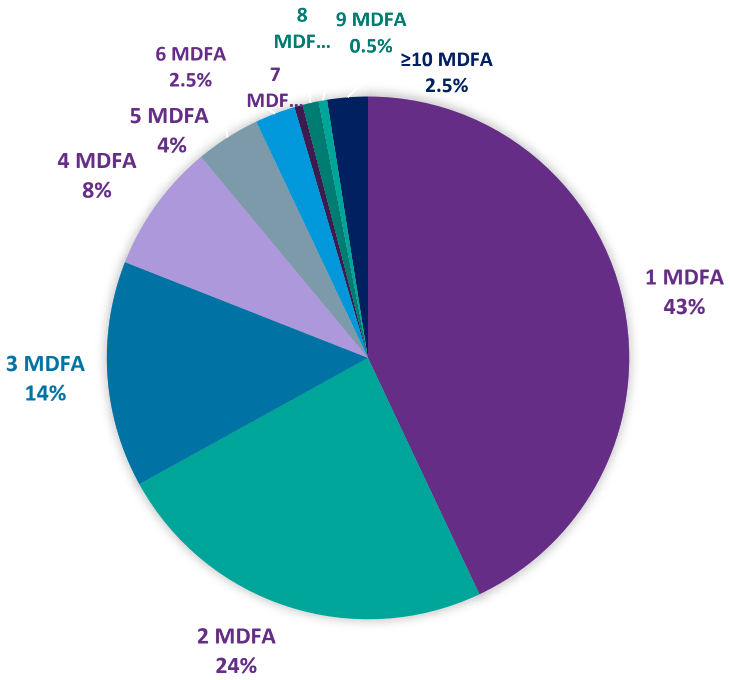
Most Reported (Rank)	**% Reported MDFA to various food from all respondents** (n=744)**	**% Reported food allergens associated with anaphylactic reactions in all respondents** (n=744)**
1st	Peanuts 47%	Peanuts 7%
2nd	Milk 36%	Other nuts* 6%
3rd	Other nuts* 35%	Eggs 4%
4th	Eggs 30%	Milk 3%
5th	Fruit* 19% (6% of which kiwi)	Fruit* 2% (1% of which kiwi)
6th	Fish 10%	Fish 2%
7th	Crustaceans 8%	Crustaceans 1%
8th	Soybeans 8%	Sesame seeds 1%
9th	Sesame seeds 7%	Molluscs 1%
10th	Cereals containing gluten 5%	Lupins 1%

* The full breakdown of 'Other nuts' and 'Fruit' is available in Annex 1 and Annex 2.

** All Respondents (n=744) with MDFA included the parental surveys of Children (n=363), Adolescents (n=63), and Adults (n=318).

Finally, when all respondents (n=744) were queried regarding the number of foods to which they (or their child/adolescent) have been medically diagnosed as allergic, 43% reported one food, 24% reported two foods and 14% indicated three foods (Figure 3.2.4). Most respondents (n=318, 43%) reported having an MDFA to just one food and just 19 respondents (2.5%) reported having an MDFA to >10 foods. Notably, 25% (n=188) of 744 respondents with MDFA also indicated that they had additional FIs, with 24% (n=175) reporting other FIs, 0.5% (n=4) reporting MDCD, and 1% (n=9) reporting both FI and MDCD. More data on these groups is available in Annexes 1 and 2 of this report.

Figure 3.2.4: Average number of MDFA to different foods per respondent, reported as a percentage of 'All Respondents' (n=744) with this condition in Ireland and Northern Ireland, based on adult self-reported and parent-reported data from a survey run between November 2019 and October 2020



318 respondents reported having one MDFA; 177 reported having two; 103 reported having three; 62 reported having four; 26 reported having five; 19 reported having six; eight reported having seven; seven reported having eight; four reported having nine, and 19 respondents reported having ≥10 MDFA.

3.3 A review of gender and age category associated with medically diagnosed coeliac disease (MDCD) in the food hypersensitivity surveys

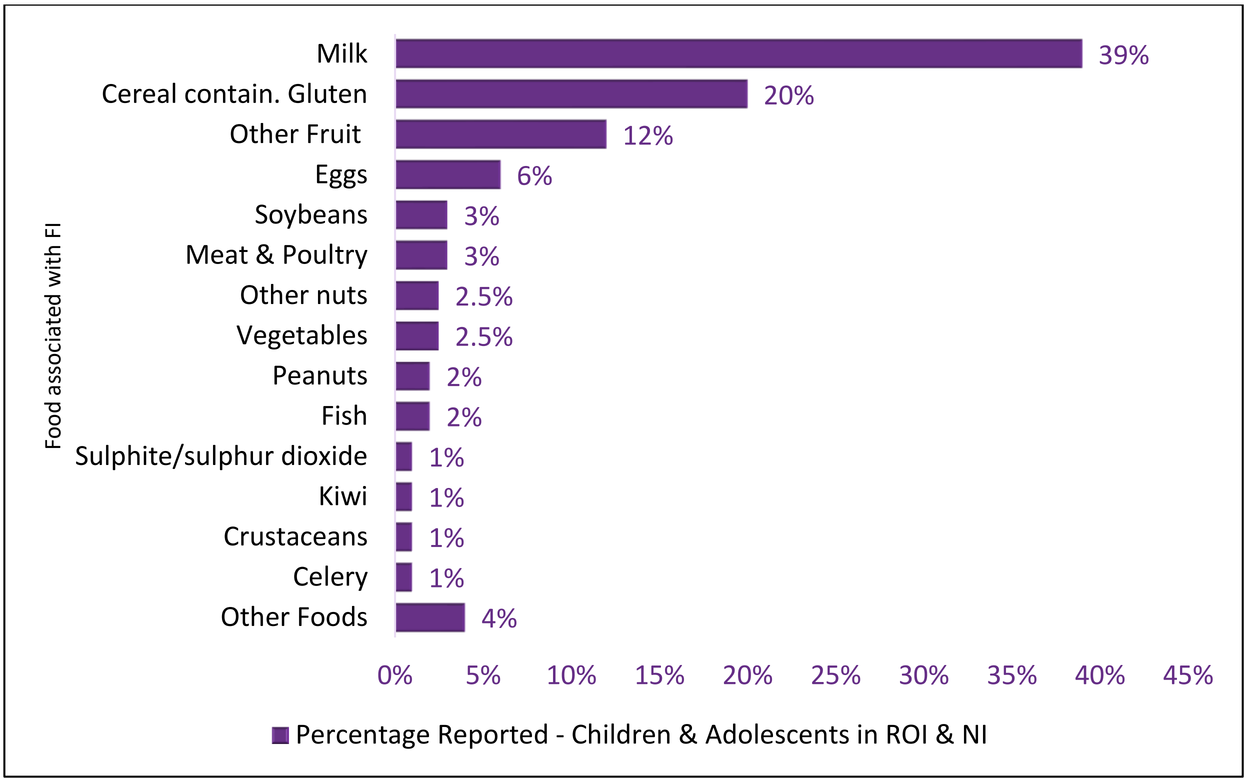
Coeliac disease is an autoimmune condition characterised by a specific serological and histological profile triggered by gluten ingestion in genetically predisposed individuals (Fasano & Catassi, 2012). Gluten is the general term for alcohol-soluble proteins present in various cereals, including wheat, rye, barley, spelt and kamut. This disease has been previously reported as predominant in females (Caio *et al.* 2019; Volta *et al.* 2014; Fasano and Catassi, 2012), with actual serological screening reporting a 60:40 or 1.5:1 ratio between female and male coeliacs (Choung *et al.* 2015). The predominant gender reported in the parental MDCD survey groups in Ireland and Northern Ireland was female (64%). This resulted in a 64:36 or 1.6:1 ratio of females to males in the children and adolescents studied. Similarly, the majority of MDCD adult survey completions (83%) were female. However, these high percentages are most likely a reflection of a greater willingness to engage in online surveys among the female adult population, as noted in other survey groups in this study.

A large dataset of adult MDCD respondents were examined in this study in Ireland (n=623) and Northern Ireland (n=195). However, the project team found it challenging to find parents of children/adolescents with MDCD to complete the parental MDCD surveys (IoI n=217). This suggests an overall lower prevalence (or more likely a lower level of diagnosis) of this disease in younger populations (Volta *et al.* 2014; Fassano and Catassi, 2005). Coeliac disease is reported to occur at any age from early childhood to old age with two suggested peaks of onset: one shortly after weaning with gluten in the first two years of life, and the other in the second or third decades of life (Fassano, 2003). The diagnosis of coeliac disease can be challenging since symptoms may vary significantly from patient to patient. Moreover, 5% (n=11) of the parental participants and 9% of the surveyed adults reported additional food intolerances in combination with MDCD. More details on these groups are available in Annexes 3 and 4 of this report.

3.4 A review of trigger foods and age category associated with food intolerance and/or suspected or undiagnosed food allergy (FI) in the food hypersensitivity surveys

A total of 1,222 participants in Ireland and Northern Ireland who completed the food hypersensitivity survey reported that they or their child had a food intolerance and/or a suspected or undiagnosed food allergy (FI). This total consisted of 120 parents and 1,102 adults. The parental group was smaller due to a lower uptake of the surveys. The reported associated FI trigger foods for Ireland (n=59) and Northern Ireland (n=60) are presented together here (Figure 3.4.a). The most reported trigger foods associated with FI were milk (59%), cereals containing gluten (20%), fruits (kiwi 1% and other fruits 12%) and eggs (6%).

Figure 3.4a: Food Intolerances and/or undiagnosed/suspected food allergy (FI) in children/adolescents as reported by their parents in a survey carried out between November 2019 and June 2020 in Ireland and Northern Ireland (n=120)



*Associated number of children and adolescents who suffer from food intolerances to these foodstuffs: Milk=81 individuals; Cereals containing gluten=42; Fruits=27 (of which two are kiwi); Eggs=12; Soybeans=6; Meat and poultry=6; Other nuts=5; Vegetables=5; Peanuts=4; Fish=4; Sulphur dioxide and sulphites=2; Honey=2; Crustaceans=1; Celery =1; other foods=15.

Breakdown of foods in unspecified groups as reported by respondents:

- Fruits (n=27): Citrus fruits (Oranges, n=7; Lemon, n=1); Strawberries (n=3); Tomatoes (n=3); Kiwi (n=2); Fruits (unspecified, n=2); Berries (n=1); Banana (n=1); Coconut (n=1); Grapes (n=1); Melon (n=1); Pineapple (n=1); Apples (n=1); Apricot (n=1); Watermelon (n =1)

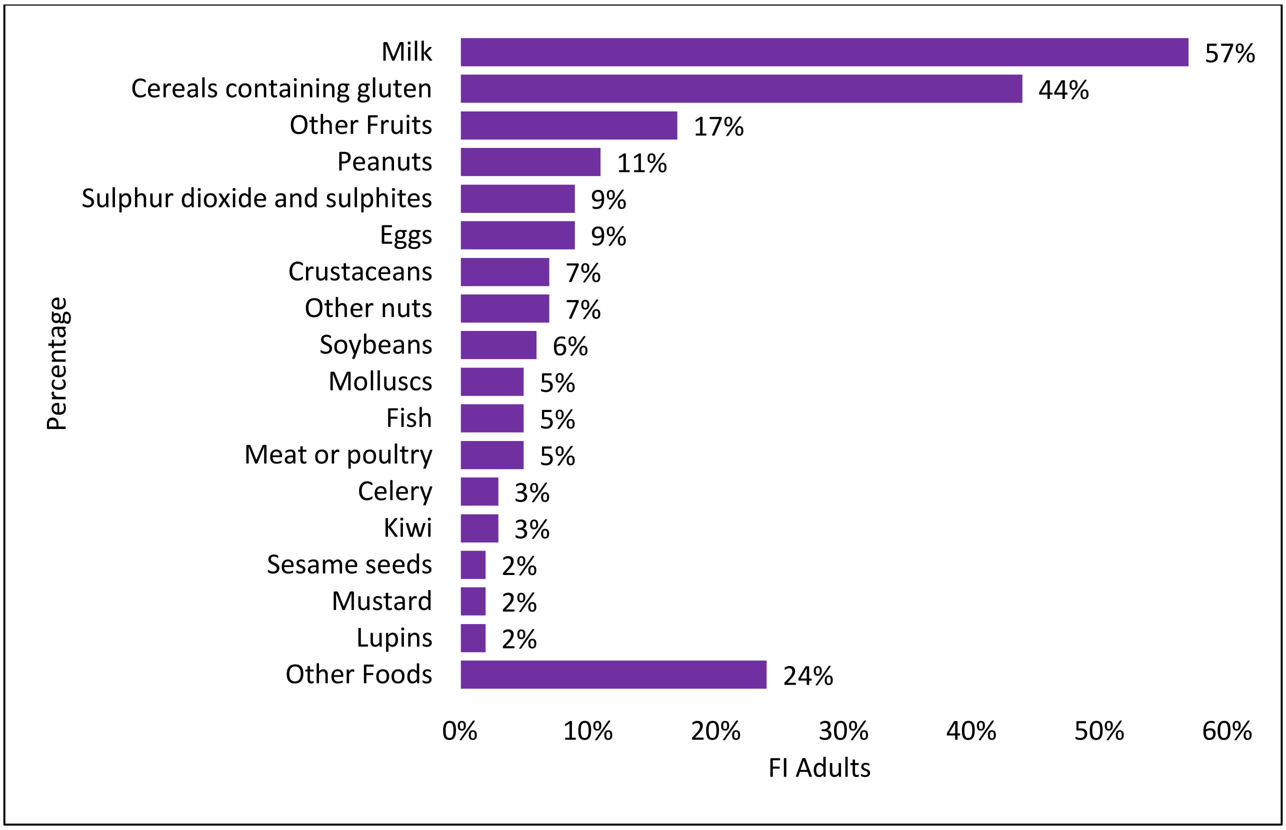
- Other nuts (n=5): Nuts (unspecified, n=4); Almonds (n=1)

- Vegetables (n=5): Green pepper (n=1); Potatoes (n=1); Peas (n=1); Carrot (n=1); Garlic (n=1)

- Other foods (n=15)=Sulphites/Sulphur dioxide (n=2); Honey (n=2); Sweets (n=2); Sugar (n=2); Crustaceans (n=1); Coffee (n=1); Buckwheat (n=1); Chia seeds (n=1); Yeast (n=1); Food colouring (n=1)

A large dataset of trigger foods associated with FI was collected for adults (n=1,102) in Ireland and Northern Ireland, so the data is presented separately in Figure 3.4b and 3.4c. The top four most reported foods in Ireland and Northern Ireland were the same as those reported for children previously (Figure 3.4a), except for the inclusion of peanuts in joint fourth place with eggs. Milk was the most reported trigger food (58%) for FI in adults, followed by cereals containing gluten (46%), fruit (3% kiwi and 17% other fruit), eggs (10%) and peanuts (9%).

Figure 3.4b: Food intolerances and/or undiagnosed/suspected food allergy (FI) in adults as reported in a survey carried out between November 2019 and June 2020 in Ireland (n=587)



*Associated number of individuals who suffer from food intolerance to these foodstuffs: Milk=333 individuals; Cereals containing gluten=259; Other foods=142; Other fruits=99; Peanuts=63; Sulphur dioxide and sulphites=54; Eggs=53; Crustaceans=40; Other nuts=41; Soybeans =38; Molluscs=28; Fish=28; Meat and poultry=30; Celery=17 individuals; Kiwi=15; Sesame seeds=14; Mustard=10; Lupins=9.

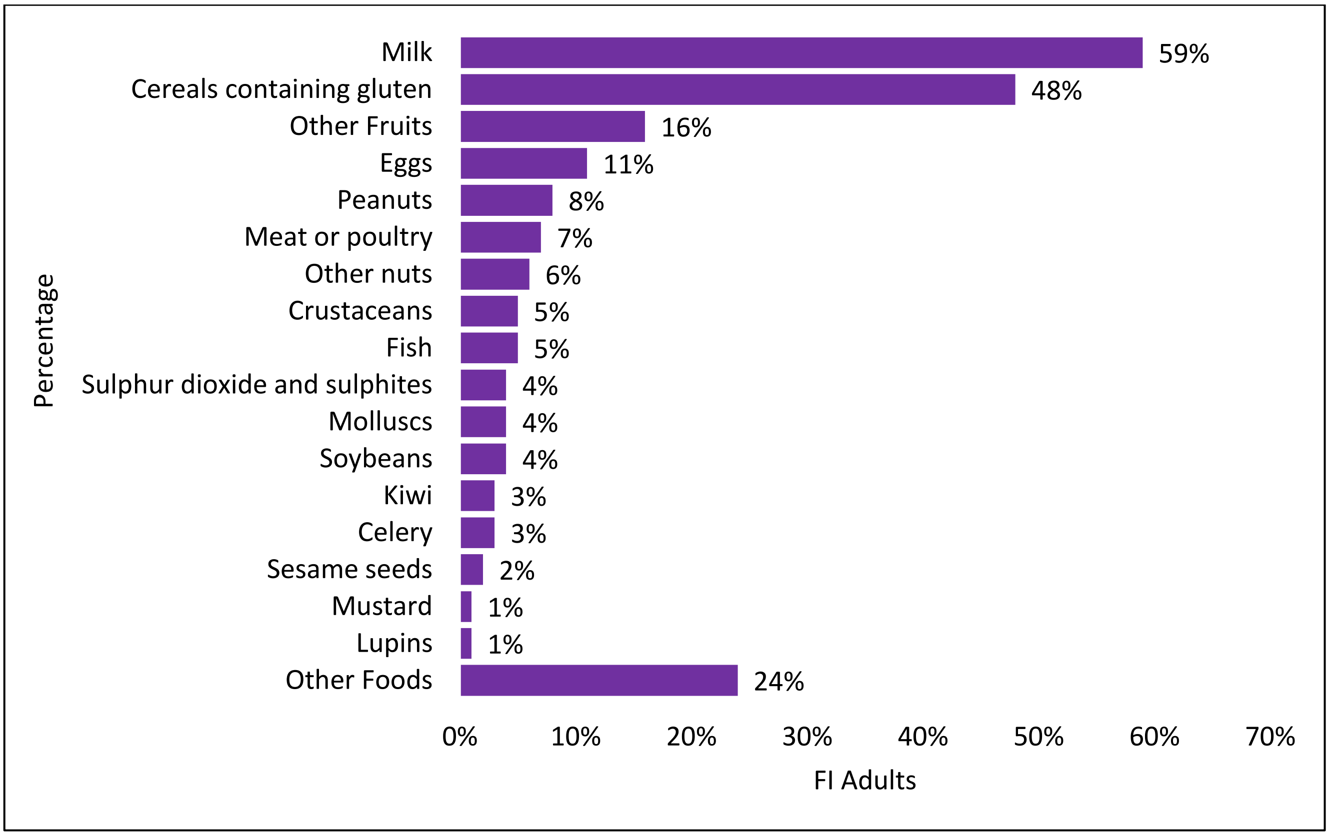
Breakdown of foods in unspecified groups as reported by respondents:

Other nuts (n=51) =Nuts, unspecified (n=13); All tree nuts (n=7); Almonds (n=7); Cashew nuts (n=7); Hazelnuts (n=7); Walnuts (n=4); Pine nuts (n=3); Pistachio (n=3).

Other fruits (n=99)=Fruits, unspecified (n=18); Citrus fruit, unspecified (n=4; Orange, n=15; Grapefruit, n=2; Lemon, n=1; Nectarine, n=1); Apple (n=18); Berries, unspecified (n=1; Strawberry, n=11; Cranberry, n=2; Blackcurrant, n=1; Pomegranate, n=1; Raspberry, n=1); Tomato (n=15); Banana (n=14); Pineapple (n=6); Pear (n=4); Avocado (n=2); Cherry (n=2); Coconut (n=2); Plum (n=2); Grape (n=1); Mango (n=1); Passion fruit (n=1); Passion fruit (n=1); Peach (n=1).

Other foods (n=142). For further details see Annex 6.

Figure 3.4c: Food intolerances and/or undiagnosed/suspected food allergy (FI) in adults as reported in a survey carried out between November 2019 and June 2020 in Northern Ireland (n=515)



Associated number of individuals who suffer from food intolerance to these foodstuffs: Milk=306; Cereals containing gluten=245; Other foods=125; Other fruits=84; Eggs=58; Peanuts=40; Meat and poultry=36; Other nuts=33; Crustaceans=26; Fish=25; Sulphur dioxide and sulphites=22; Molluscs=23; Soybeans=21; Kiwi=17; Celery=18; Sesame seeds=11; Mustard=6; Lupins=4.

Breakdown of foods in unspecified groups as reported by respondents:

Other nuts (n=36)=Nuts, unspecified (n=12); All tree nuts (n=5); Almonds (n=8); Hazelnuts (n=4); Brazil nuts (n=2); Cashew nuts (n=2); Walnuts (n=2); Pine nuts (n=1)

Other fruits (n=99)=Fruit, unspecified (n=7); Citrus fruits, unspecified (n=9); Orange (n=15); Lime (n=1); Banana (n=16); Berries, unspecified (n=3); Strawberry (n=7); Raspberry (n=4); Blackcurrant (n=1); Cranberry (n=1); Tomatoes (n=15); Apple (n=9); Grapes (n=5); Melon (n=3); Coconut (n=2); Mango (n=2); Peach (n=2); Pineapple (n=2); Avocado (n=1); Dragon fruit (n=1); Passionfruit (n=1); Pear (n=1)

Other foods (n=125). For further details see Annex 6.

3.4.1 Overview of Trigger Foods on Food Intolerance and/or Suspected, Undiagnosed Food Allergy (FI) from the Food Hypersensitivity Surveys

The top 10 most reported food intolerances for all FI survey participants (adult and parental) are presented in Table 3.4.1. This table contains eight foods that were also in the top 10 most reported foods associated with MDFA, with sulphites/SO2 and meat and poultry unique to FI, and fish and sesame seeds unique to MDFA. One of the most notable differences in the top 10 FI and MDFA trigger foods is that peanut FI (9%) and other nut FI (6%) ranked fifth and sixth, respectively (Table 3.4.1), compared to first (peanuts, 47%) and third (35% other nuts) in the case of MDFA (Table 3.2.4). In fact, the two most reported trigger foods associated with FI were milk and cereals containing gluten. Milk was associated with 59% of FI in 1,222 respondents, and it was also the second most reported MDFA (36%, Table 3.2.4). Cereals containing gluten ranked second place FI (46%) and sixth for MDFA (14%). The percentage of fruit FI was approximately the same as that reported for fruit MDFA (20% and 19%, respectively). However, kiwi FI was 3%, while kiwi MDFA was 6%. Similarly, egg FI was 10%, while egg MDFA was 30%. Overall, a large overlap in specific trigger foods associated with FI and MDFA was observed. In fact, all of the FI trigger foods mentioned in Tables 3.4.1 are regarded as food allergens under EU food law, with the exception of meat and poultry and kiwi (as part of 'fruit').

Table 3.4.1: The 10 most reported FI for all respondents (n=1,222*) in Ireland and Northern Ireland based on adult self-reported and parent-reported data from a survey run between November 2019 and October 2020

Most reported	**% reported FI to various food from all respondents****
(Rank)	(n=1,222)
1st	Milk 59%
2nd	Cereals containing gluten 45%
3rd	Fruit* 20% (3% of which kiwi)
4th	Eggs 10%
5th	Peanuts 9%
6th	Other nuts** 6%
7th	Sulphur dioxide and sulphites 6%
8th	Meat or poultry 6%
9th	Crustaceans 5%
10th	Soybeans 5%

* All respondents (n=1,222) with FI included in the parental surveys of children and adolescents (n=120); adult surveys (n=1,102).

** The full breakdown of 'Other nuts' and 'Fruit' is available in Annex 5 and Annex 6.

4 Calculation of the Socio-economic cost of food hypersensitivity in Ireland and Northern Ireland

As described in the literature review in Chapter 1, many studies have been carried out around the world to try to determine the socio-economic costs associated with food allergy and other food hypersensitivities. These studies have been carried out individually for some countries or across whole regions (multi-country). Published reports have included costing data (either collectively or singly) for the following countries: the UK, Sweden, Greece, Iceland, Poland, the Czech Republic, France, Italy, Finland, the Netherlands and the USA. This study is the first to examine the direct and indirect costs associated with MDFA, MDCD and FI in Ireland and Northern Ireland. In addition, this chapter will review intangible costs (non-monetary costs) and their impact on QoL associated with these conditions; but unlike direct and indirect costs, these will not be examined in terms of their monetary impacts.

In this study, the age groups examined were adults aged ≥18 years, children aged 0 to 12 years, and adolescents aged 13 to 17 years. Costs were reported for adults and combined for children and adolescents due to small number of respondents for the adolescents' group.

The incremental cost is the estimated excess cost for a food hypersensitive group relative to the costs observed for a similar non-food hypersensitive group (i.e., the reweighted controls). All costs reported were incremental costs associated with each of the conditions examined. Incremental costs were reported as mean individual costs for adults or households with a child/adolescent with a food hypersensitivity. No statistical comparison was made for the incremental costs calculated for each condition based on jurisdiction as these were two separate data sets and could not readily be compared given the reweighting of the associated controls.

Total costs are the sum of direct and indirect costs. These costs were self-reported data for individual food hypersensitive adults or parent-reported for households with a food hypersensitive child or adolescent. Intangible costs were non-monetary costs. Direct costs to the health services associated with health care utilizations (e.g., visits to medical practitioners, hospital stays) as well as costs incurred by the individual (e.g., travel costs,

costs for alternative therapies and medication costs) are detailed in Table 2.2.1a. Indirect costs include loss of earnings associated with health care utilization, absences from work/education and increases in the time spent food shopping. In addition, data on healthcare and out-of-pocket costs incurred by individuals and their families because of their food hypersensitivity are detailed in Table 2.2.1b, Table 4.1.2c and Table 4.2.2c.

4.1 Results for the Calculation of Socio-Economic Costs Associated with Food Hypersensitivity on the Island of Ireland: Adults

4.1.1 Overview of the adult food hypersensitivity (self-reported) dataset for Ireland and Northern Ireland

In section 4.1, we compare the responses from adults in Ireland and Northern Ireland who have MDFA (n=178/111), MDCD (n=609/173), and FI (n=536/459), with non-food hypersensitive case-matched controls (n=531/204). All costs presented are the mean values calculated from self-reported survey data and are the additional or extra (incremental) costs per annum (p.a.) associated with each condition for individual adults. No statistically significant difference was found between gender in the groups examined. Tables 4.1.2a and 4.1.2b show a summary of the breakdown of direct, indirect and total (direct plus indirect) costs under selected headings in Ireland and Northern Ireland. Statistical analysis was carried out by comparing costs reported for each of the six adult food hypersensitive groups with those of their comparative (non-food hypersensitive) control groups. The control groups have been reweighted so that they are in turn like each of the groups of interest, as described in the methodology (Chapter 2, section 2.2). A more detailed breakdown of adult costs is available in Annex 7. Figure 4.1.2a provides a visual comparison of the incremental (additional) direct, indirect, and total costs p.a. for each food hypersensitive adult group (MDFA, MDCD and FI) relative to the corresponding reweighted controls in Ireland (€) and Northern Ireland (£). All of the cost values presented are mean (average) costs.

4.1.2 Examination of additional (incremental) monetary costs associated with food hypersensitivity in adults in Ireland and Northern Ireland: direct and indirect costs

4.1.2a Medically diagnosed food allergy (MDFA) in adults

Direct costs calculated in this study included medical visits, travel to appointments, hospital stays, cost of medication, private health insurance and food costs. Higher direct costs were associated with adult MDFA in Ireland (€1,325 p.a., $p<0.01$) and Northern Ireland (£847 p.a.), compared to controls (Tables 4.1.2a and 4.1.2b). The direct costs were significant ($p<0.01$) for this group in Ireland. The range of direct costs were similar to those reported in other studies in which the direct costs of food allergy for individuals were calculated. These include a mean cost of €1,088 p.a. for the UK and the Netherlands (average of adult and child costs; n=126) by Voordouw et al. 2010, and a mean cost of €1,740 p.a. for a food allergic adult (n=81) living in Sweden (Jansson et al. 2014). When the MDFA adult group (n=178) was compared with the corresponding control group (n=531) in Ireland, medical visits (€178 p.a., p<0.05), and especially GP visits (€71 p.a., p<0.01), were found to be significantly higher than controls (Table 4.1.2a and Table 7.A.1; Annex 7). The total cost of travel to medical appointments (€71 p.a., p<0.01), and travel to GP surgeries (€58 p.a., p<0.01), were also found to be significantly higher (p<0.01) than controls. A similar trend was observed in Northern Ireland regarding significantly higher costs compared to controls, including medical visits (£281 p.a., p<0.05; Table 4.1.2b), GP visits (£48 p.a., p<0.01), travel to GP surgeries (£121 p.a., p<0.05), and travel to hospital day units (£108 p.a., p<0.01) (Table 7.A.1; Annex 7). All of these costs were found to be significantly higher for those with MDFA (n=111) compared to controls (n=204). Regarding medications (prescription and over the counter), costs were found to be significantly higher in Ireland and Northern Ireland (€52 and £16 p.a., respectively, p<0.01) than for controls, with visits to pharmacists being significantly higher in Ireland only (€15 p.a., p<0.05) (Table 7.A.1; Annex 7). The total cost of hospital stays and visits was higher for MDFA adults in Ireland (€291 p.a.), and Northern Ireland (£430 p.a.) than for controls, although neither increase was statistically significant. Similarly, a higher cost was associated with attending the emergency department with subsequent admission to a ward for Irish adults with MDFA (€371 p.a.) and Northern Ireland (£115 p.a.) compared to controls, although not statistically significantly (p<0.05). These overall findings agree with previously published studies, which report higher costs in other EU countries associated with medication, healthcare, and travel to see medical professionals because of having a food allergy (Voordouw et al. 2010; Fox et al. 2013; Jansson et al. 2014; Cerecedo et al. 2014; Protudjer et al. 2015), and in other parts of the world (Gupta et al. 2013; Bilaver et al. 2019).

Total food costs were significantly higher for MDFA adults in Ireland (€724 p.a., p<0.01), but not significantly higher in Northern Ireland (£22 p.a.). Indirect costs such as time lost, days missed, loss of earnings, etc., were all higher for the MDFA adult groups in Northern Ireland (£412 p.a., p<0.01), but not in Ireland (€277 p.a.), compared to controls. Notably, higher indirect costs (approx. €2,500 to €6,500 p.a.) associated with MDFA have been reported for some other child and adult groups (Voordouw et al. 2010; Jansson et al. 2014; Protudjer et al. 2015) from other countries (Sweden, the UK and the Netherlands combined), than were reported in this study.

Overall, a slightly higher figure (+9%) was calculated for total costs associated with adult MDFA in Ireland (€1,602 p.a., $p<0.01$) compared to Northern Ireland (£1,259 (€1,461) p.a., $p<0.05$). Both figures were statistically higher than controls, highlighting the additional costs associated with this condition in both jurisdictions. These total costs were also broken down into 'out-of-pocket' (mainly non-health) or healthcare costs (Table 2.2.1b). Out-of-pocket costs made up 71% of the total cost in Ireland (€1,141 p.a.) and 43% in Northern Ireland (£542 p.a.) (Table 4.1.2c) and were borne by MDFA adults alone. Healthcare costs made up the remaining 29% of the total cost in Ireland (€461 p.a.) and 57% (€834 p.a.) in Northern Ireland (Table 4.1.2c). These additional healthcare costs (although shared with the health service in each jurisdiction) would also have increased the yearly condition-related expenditure of MDFA adults.

4.1.2b Medically diagnosed coeliac disease in adults

Direct costs for adults with MDCD were €444 (€501 p.a. before a tax rebate for gluten-free food) in Ireland and £737 p.a. in Northern Ireland (Tables 4.1.2a and 4.1.2b). The direct costs were significantly higher ($p<0.01$) for the MDCD adult group in Northern Ireland ($n=173$) when compared to controls ($n=204$); this was not the case in Ireland (MDCD group $n=609$, control group $n=531$). In Ireland, visits to GPs, pharmacists, dieticians, alternative therapists, prescribed medicines, travel to GP and medical appointments were all significantly higher ($p<0.05$) than controls, but the associated costs were reasonably low (€31, €9, €14, €8, €36, and €44 p.a., respectively; Table 7.A.1; Annex 7). Private health insurance was a factor for Irish adults with MDCD (€95 p.a., $p<0.01$), but not in Northern Ireland. Visits to GP surgeries, dieticians and prescribed medicine were all found to be significantly higher ($p<0.01$) for those with MDCD in Northern Ireland (£43, £22, and £5 p.a., respectively). However, the data suggests that costs associated with medical visits (£255 p.a., $p<0.01$) and the total cost of hospital visits and stays (£142 p.a.) were the main drivers in the overall higher costs for MDCD adults in Northern Ireland. In addition, food costs were a factor in the overall direct costs, with reported costs of €164 p.a. (€221 p.a. before a tax rebate for gluten-free food) in Ireland, and £318 p.a. in Northern Ireland. Notably, food costs were only found to be significantly higher ($p<0.05$) in Northern Ireland.

Indirect costs were negligible in Ireland, whereas in Northern Ireland total indirect costs were £628 p.a. ($p<0.01$). A higher cost associated with preparing food (£175 p.a.), and days missed from work, school, or college, (£418 p.a.) was reported in Northern Ireland (Table 7.A.1), with an average of 6.7 missed days p.a. in Northern Ireland (compared to 0 days in Ireland). The higher direct and indirect costs reported in Northern Ireland resulted in a significant total cost of

£1,365 p.a. ($p<0.01$), which is of the same magnitude as the total cost reported for MDFA adults in Northern Ireland (£1,259 p.a. $p<0.05$). By contrast, the total cost for MDCD adults in Ireland was found to be €438 p.a. (or €495 p.a. before a tax rebate for gluten-free food).

These total costs were also broken down into 'out-of-pocket' (mainly non-health) or healthcare costs. In fact, 71% (£965 p.a.) of the total cost was reported to be borne alone, in the form of 'out-of-pocket' costs, by MDCD adults in Northern Ireland and 66% (€290) in Ireland (Table 4.1.2c). The remaining 29% and 34%, respectively, were calculated as health care costs associated with MDCD. While the latter costs are shared with the health service in each jurisdiction, they would still have increased the yearly expenditure of MDCD adults because of their condition.

4.1.2c Food intolerance / suspected food allergy in adults

The mean direct costs reported for adult FI in Ireland (n=536) and Northern Ireland (n=459) were €350 p.a. and £377 p.a., respectively (Tables 4.1.2a and 4.1.2b). Neither increase was found to be statistically significant. In Ireland, the total cost of medical appointments, hospital stays, food and travel to appointments were found to be higher for FI adults with only the cost of travel to appointments being statistically significant (€71 p.a., $p<0.01$). The total costs of medical appointments and travel to appointments were found to be significantly higher ($p<0.01$) for FI adults in Northern Ireland (£163 and £154 p.a., respectively). Food costs were not reported as an additional expense for FI adults in Northern Ireland when compared to controls. Indirect adult costs for Ireland (€154 p.a.) and Northern Ireland (£188 p.a.), and total costs (€504 and £565 p.a., respectively) were not statistically significant ($p<0.05$). When the breakdown of these total costs was examined with regard to 'out-of-pocket' (mainly non-health) and healthcare costs, FI adults in Ireland were found to incur 69% (€349 p.a.) of the total cost alone as 'out-of-pocket' costs, while their Northern Ireland counterparts bore 60% (£341 p.a.) of the total cost alone as 'out-of-pocket' costs. The remaining 31 and 40%, respectively, were healthcare costs shared by respondents and the health service in each jurisdiction. A bar chart of total additional costs (direct plus indirect) by condition in Ireland and Northern Ireland for adults is presented in Figure 4.1.2b for ease of comparison.

Table 4.1.2a: Additional mean direct and indirect Euro costs per annum associated with adult food hypersensitivity: MDFA (n=178), MDCD (n=609) and FI (n=536) compared to non-food hypersensitive controls (n=531) in Ireland (Nov 2019 – Oct 2020)

	Ireland MDFA Adults (n=178)	**Ireland MDCD Adults (n=609)**	**Ireland FI Adults (n=536)**
Components of direct costs	**Cost in € per annum**	**Cost in € per annum**	**Cost in € per annum**
Total cost of medical visits	178*	78	79
Total cost of travel to medical visits	71**	44**	71**
Total cost of hospital visits and stays	291	76	95
Total cost of medication	52**	No difference	1
Private health insurance	9	95**	22
Total food cost	724**	164/221▾	82
Total direct costs	**1,325****	**444/501**▾	**350**
Components of indirect costs	**Cost in € per annum**	**Cost in € per annum**	**Cost in € per annum**
Time spent food shopping	57	No difference	No difference
Time spent preparing food	No difference	6	71
Days missed from work/school/college	222	0	104
Lost earnings associated with healthcare visits	3	11	No difference
Total indirect costs	**277**	**No difference**	**154**
Total (direct + indirect) costs	**1,602****	**438/495**▾	**504**

*p <0.05 and ** p <0.01 are statistically significant

'No difference' indicates negative cost values that were not statistically significant but are included in the calculation of the total cost figures.

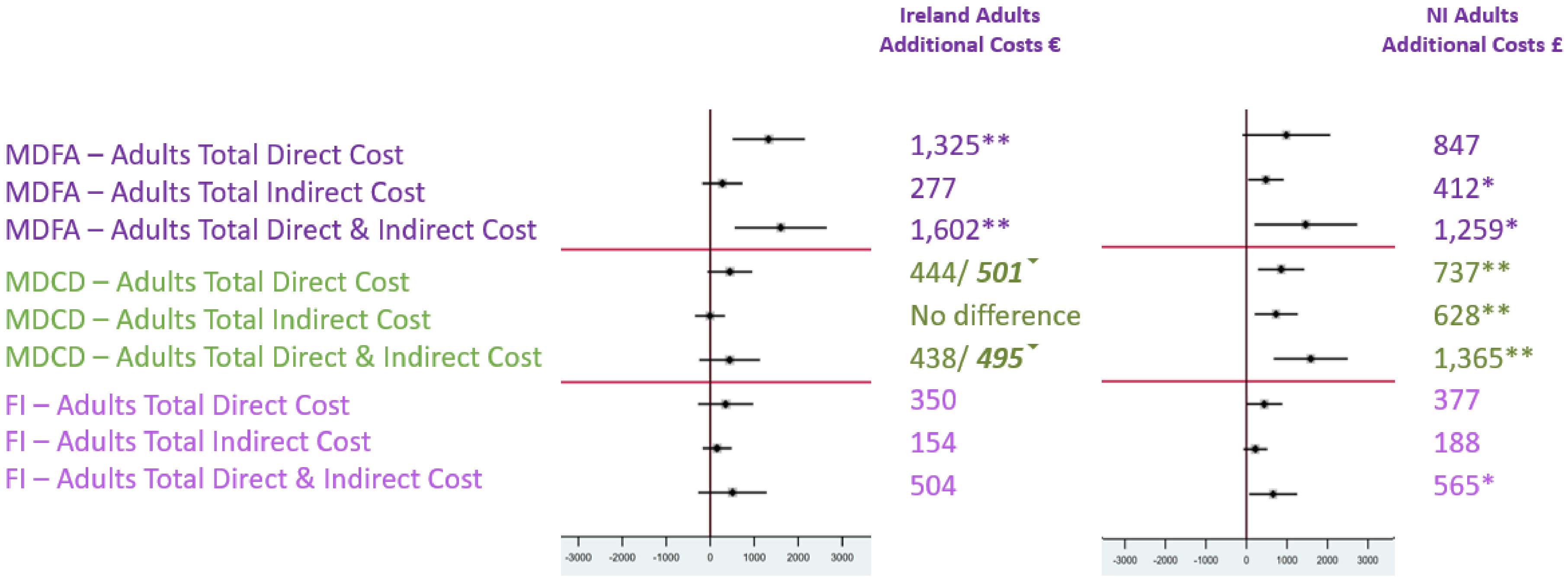
▾ Costs excluding/including a tax rebate on gluten-free foods as claimed by 29% of MDCD adults in Ireland

Table 4.1.2b: Additional mean direct and indirect Sterling costs per annum associated with adult food hypersensitivity (self-reported): MDFA (n=111), MDCD (n=173) and FI (n=459) compared to non-food hypersensitive controls (n=204) in Northern Ireland (Nov 2019 – Oct 2020)

	Northern Ireland **MDFA Adults (n=111)**	**Northern Ireland** **MDCD Adults (n=173)**	**Northern Ireland** **FI Adults (n=459)**
Components of direct costs	**Cost in £ per annum**	**Cost in £ per annum**	**Cost in £ per annum**
Total cost of medical visits	281*	255**	163**
Total cost of travel to medical visits	97	38	154**
Total cost of hospital visits and stays	430	142	77
Total cost of medication	16**	5	9**
Private health insurance	1	No difference	No difference
Total food cost	22	318*	No difference
Total direct costs	**847**	**737****	**377**
Components of indirect costs	**Cost in £ per annum**	**Cost in £ per annum**	**Cost in £ per annum**
Time spent food shopping	31	13	No difference
Time spent preparing food	51	175	No difference
Days missed from work/school/college	330	418*	230**
Lost earnings associated with healthcare visits	0	22*	20*
Total indirect costs	**412***	**628****	**188**
Total (direct + indirect) costs	**1,259***	**1,365****	**565**

*p <0.05 and ** p <0.01 are statistically significant
‘No difference’ indicates negative cost values that were not statistically significant but are included in the calculation of the total cost figures.

Figure 4.1.2a: Additional mean direct and indirect Euro/Sterling costs per annum for adults with food hypersensitivity (self-reported) based on data collected from an online survey carried out between November 2019 to October 2020 in Ireland (n=1,323) and Northern Ireland (n=743)

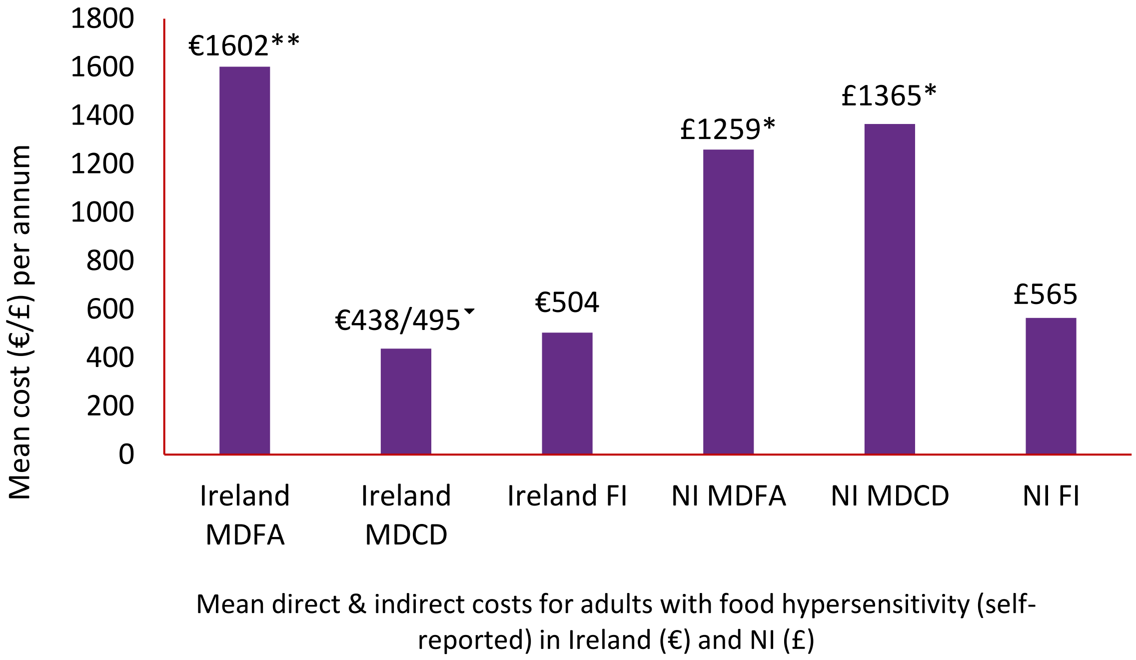


-*p <0.05 and **p <0.01 are statistically significant

▾ Costs excluding/including a tax rebate on gluten-free foods as claimed by 29% of MDCD adults in Ireland

See Tables 7.A.1 and 7.A.2 in Annex 7 for the 95% Confidence limits associated with each mean value.

Figure 4.1.2b. Additional mean total (direct + indirect) costs (Euro/Sterling per annum) for adults with food hypersensitivity (self-reported) based on data collected from an online survey carried out between November 2019 and October 2020 in Ireland (n=1,323) and Northern Ireland (n=743)



* p <0.05 and **p <0.01 are statistically significant

˚ Costs excluding/including a tax rebate on gluten-free foods as claimed by 29% of MDCD adults of Ireland

Table 4.1.2c Additional (incremental) healthcare and out-of-pocket costs (mainly non-healthcare) in Euro associated with adult food hypersensitivity (self-reported) in Ireland and Northern Ireland (November 2019 – October 2020)

	Ireland (€)			**Northern Ireland (£)**		
	MDFA adult	**MDCD adult**	**FI adult**	**MDFA adult**	**MDCD adult**	**FI adult**
Healthcare costs (borne by respondents and the health service)	461 (29%)	148 (34%)	155 (31%)	717 (57%)	400 (29%)	224 (40%)
Out-of-pocket costs (typically borne by respondents alone)	1,141(71%)	290 (66%)	349 (69%)	542 (43%)	965 (71%)	341 (60%)
Total cost	**1,602**	**438**	**504**	**1,259**	**1365**	**565**
Number in group	178	609	536	111	173	459
Number in comparison group	531	531	531	204	204	204

Table 2.2.1b lists the components of (a) healthcare costs and (b) out-of-pocket costs for each food hypersensitivity. These are described in depth in Tables 7.A.1 (euro) and 7.A.2 (sterling) in Annex 7. MDCD figures for Ireland are reported after the tax rebate on gluten-free food had been subtracted.

4.2 Results for the calculation of socio-economic costs associated with food hypersensitivity on the island of Ireland: children and adolescents

4.2.1 Overview of the parental food hypersensitivity dataset for Ireland and Northern Ireland

In section 4.2. we compared 173 and 147 responses (Ireland and Northern Ireland, respectively) from the parental surveys for children/adolescents with MDFA, 148 and 60 responses (Ireland and Northern Ireland, respectively) for MDCD, and 56 and 51 responses (Ireland and Northern Ireland, respectively) for FI with 130 and 165 controls in Ireland and Northern Ireland, respectively. The controls have been reweighted so that they match the food hypersensitivity groups. Given the small number of adolescents for many groups (Table 2.2.2a), we do not include the figures for this group separately, and instead present children and adolescents together. Costs were calculated for a family with just one food hypersensitive child or adolescent in this study, although many families have more than one food hypersensitive child/adolescent. No statistically significant difference was found between gender in the groups examined. Tables 4.2.2a and 4.2.2b show a summary of the breakdown of direct and indirect costs, and total costs under selected headings in Ireland and Northern Ireland. Statistical analysis was carried out by comparing costs reported for each of the six parental test groups with their comparative (non-food hypersensitive) control groups. More detailed tables of these costs for children and adolescents in euro and pounds sterling are available in Annex 7 (Table 7.A.3 in Euro and 7.A.4 in pounds Sterling).

As a visual guide, Figure 4.2.2a displays the mean and confidence intervals for the direct, indirect and total incremental costs for each food hypersensitive group (FI, MDCD, MDFA) for the parental surveys in Ireland and Northern Ireland. In addition, and for ease of comparison, a bar chart of total additional costs (direct and indirect) by condition and jurisdiction for the parents of children/adolescents with MDFA is presented in Figure 4.2.2b.

4.2.2 Examination of additional (incremental) monetary costs associated with food hypersensitivity in children and adolescents reported by parents in Ireland and Northern Ireland: direct and indirect costs

4.2.2a Medically diagnosed food allergy in children/adolescents

Direct costs associated with MDFA children and adolescents were reported as a mean cost of €1,115 p.a. in Ireland (n=173) and £1,208 p.a. in Northern Ireland (n=147) (Tables 4.2.2a and 4.2.2b). Both costs were significantly higher ($p < 0.01$) than that of their corresponding controls (Ireland n=130, Northern Ireland n=165). These figures are lower than the direct costs reported for food allergic children (n=84) and adolescents (n=60) in a study in Sweden (€2,085 and 2,892 p.a., respectively). However, they are similar to those reported by Fox et al. (2013) for mean healthcare costs for food allergic children (n=270) (approximately €1,334 p.a., or I$1,134) in Greece, Iceland, Poland and Spain, and those reported by Voordouw et al. 2010 for food allergic individuals in the UK and the Netherlands (mean of €1,088 p.a., average of adult and children).

The cost of medical appointments reported by parents of children/adolescents with MDFA was found to be significantly higher for families affected by MDFA in Ireland (€386, p <0.01) and Northern Ireland (£338 p.a., p <0.01) (Tables 4.2.2a and 4.2.2b). In Ireland, this was comprised of increased costs associated with visits to GP surgeries, consultants/specialists, pharmacists and dieticians (€76, €131, €148 and €17, respectively), all of which were found to be significantly higher (p <0.01) than the control group (Table 7.A.3; Annex 7). Increased costs associated with visits to GPs, consultants/specialists, pharmacists, dieticians and travel costs (£73, £101, £88, £51 and £246 p.a. respectively; p <0.01) were noted for families of MDFA children/adolescents (parent-reported) living in Northern Ireland. Comparable costs for hospital visits were reported in Ireland (€542 p.a.) and Northern Ireland (£512 p.a.), both of which were significant (p <0.01 and <0.05, respectively; Tables 4.2.2a and 4.2.2b). These costs were mainly comprised of outpatient, day unit and emergency department attendance (without and with subsequent admission to hospital in Ireland: €82, €175, €130 (p <0.05) and €150, respectively). This was the same as in Northern Ireland, where the mean costs were £110, £1685, £57 (p <0.05), and £166, respectively (Table 7.A.3; Annex 7). Other increased costs for children/adolescents affected by MDFA were the total cost of medication and private health insurance in both Ireland (€93, p <0.01 and €85, respectively) and Northern Ireland (£29 and £28, respectively; p <0.01). Food costs associated with children/adolescents with MDFA were not found to be significantly higher compared to controls in Ireland (€14 p.a.) or Northern Ireland (£55 p.a.).

Regarding indirect costs, children/adolescents with MDFA incurred additional comparable costs in Ireland (€324 p.a.) and Northern Ireland (£2069 p.a.). However, neither were found to be significantly higher compared to controls (Tables 4.2.2a and 4.2.2b). That said, 'days missed' and 'lost earnings' were significant (p <0.01) when examined independently for Ireland (€302 and €170 p.a., respectively). The cost of 'days missed' was also significant in Northern Ireland (£122p.a., p <0.05), but not the cost of 'lost earnings' (£48 p.a.). Like indirect costs calculated for MDFA adults, these figures are lower than those reported for children/adolescents in Sweden (€1,876 p.a. and €1,900 p.a., respectively). The total mean additional cost (direct and indirect costs) incurred by parents of MDFA children/adolescents in this study was calculated at €1,439 p.a. in Ireland and £1,414 p.a. in Northern Ireland (Tables 4.2.2a and 4.2.2b). Both figures were significantly higher ($p < 0.1$) than controls highlighting the cumulative additional costs associated with this condition.

Total costs were also examined as 'out-of-pocket' (mainly non-health) and healthcare costs. Notably, 35% (€499 p.a.) of the out-of-pocket costs were reported to be borne alone by households of MDFA children/adolescents in Ireland, and 39% (£550 p.a.) in Northern Ireland (Table 4.2.2c). The remaining 65% and 61% (respectively) were deemed as healthcare costs. While these latter costs are shared with the health service in each jurisdiction, they still add to the financial burden on families with a MDFA child/adolescent.

4.2.2b Medically diagnosed coeliac disease in children/adolescents

Regarding food hypersensitivity-related expenses reported by parents with MDCD children/adolescents, significant direct costs were calculated in Ireland (€903; $p < 0.01$; n=148) and Northern Ireland (£1,608 p.a.; $p < 0.01$; n=60) when compared with the corresponding control groups (Ireland: n=130; Northern Ireland: n=165) (Tables 4.2.2a and 4.2.2b). The direct cost associated with having a MDCD child in Ireland was €993 p.a. before a tax rebate for gluten-free food. For Ireland, the cost of medical visits was found to be a statistically significant expense for families (€253 p.a.; $p < 0.01$), particularly consultant/specialist appointments (€117 p.a.; $p < 0.01$). The cost of medical visits reported by parents of MDCD children/adolescents in Northern Ireland was £433 ($p < 0.01$) (Table 7.A.3.; Annex 7). This was driven by visits to GP surgeries (£39 p.a.), consultant/specialist appointments (£126 p.a.), and visits to pharmacists (£177 p.a.) in Northern Ireland, all of which were found to be statistically significant ($p < 0.01$) for these families when compared to controls.

The mean costs of ravel to medical appointments and hospital stays reported by parents of MDCD children/adolescents in Northern Ireland were £355 and £257, respectively ($p < 0.05$) The equivalent costs in Ireland were €14 and 167 p.a., respectively, and were not statistically significant. Costs associated with private health insurance were higher in Ireland (€189 p.a.; $p < 0.01$) than in Northern Ireland (£41; $p < 0.05$), while the costs of medication were comparable were lower in Ireland (Ireland €23 p.a.; $p < 0.05$; Northern Ireland £50 p.a.; $p < 0.01$). Food costs for MDCD children/adolescents were significantly higher in both Ireland at a cost €257 p.a. ($p < 0.01$, or €347 p.a. before a tax rebate for gluten-free food), and Northern Ireland at £472 p.a. ($p < 0.01$) (Tables 4.2.2a and 4.2.2b). Food costs for MDCD children/adolescents in Ireland and Northern Ireland were a significant household cost, but not for their MDFA or FI counterparts.

Indirect costs were higher for the MDCD groups in Ireland (€130 p.a.) and Northern Ireland (£82 p.a.) when compared to controls, but not significantly so. The main driver was 'days missed from work/school/college', particularly in Northern Ireland where it was a significant cost (£349 p.a.; p <0.05). In fact, an average of 5.6 missed days p.a. was reported by the parents of children/adolescents with MDCD in Northern Ireland compared to 1.5 days in Ireland. The overall total additional cost was however significant in both Ireland at €1,033 (p <0.01, or €1,123 p.a. before a tax rebate for gluten-free food) and Northern Ireland (£1,690 p.a.; p <0.01), highlighting the additional expenses incurred by this condition.

Total costs were also examined as 'out-of-pocket' (mainly non-health) and healthcare costs. Notably, 59%, or €607 p.a. (or €697 p.a. before a tax rebate for gluten-free food) of the total cost was reported to be borne alone by households of MDCD children/adolescents in Ireland in the form of 'out-of-pocket' costs, and 60%, or £1,011 p.a. in the Northern Ireland (Table 4.2.2c). The remaining 41% and 40%, respectively, were healthcare costs incurred by the respondents and health service in each jurisdiction. These additional 'out-of-pocket' healthcare costs increase the yearly expenditure of families of MDCD children/adolescents, and particularly in Northern Ireland.

4.2.2c Food intolerance / suspected food allergy

Of all the surveys carried out this study, and despite several online promotion attempts during this project, the FI questionnaire for children/adolescents had the lowest number of respondents, with 56 surveys in Ireland and 51 in Northern Ireland. Direct costs were not statistically significant for children/adolescents with FI (Ireland: €-128, Northern Ireland: £292 p.a.). The higher cost for Northern Ireland was mainly driven by medical visits, including travel to medical appointments (£179 p.a.; p <0.01; £66 p.a.; p <0.05). In Ireland, these costs were statistically insignificant at €73 and €9 p.a., respectively. Total indirect costs in Ireland and Northern Ireland were statistically insignificant, as were the overall total costs. This contrasts with their MDFA and MDCD counterparts in Ireland and Northern Ireland, where the cost of having a child/adolescent with either condition was found to be a significant additional financial burden on their households.

Table 4.2.2a: Additional direct and indirect Euro costs per annum associated with children/adolescents with food hypersensitivity (parent-reported): MDFA (n=173), MDCD (n=148) and FI (n=56) compared to non-food hypersensitive controls (n=130) in Ireland (November 2019 – October 2020)

	Ireland MDFA Child and Adolescent (n=173)	**Ireland MDCD Child and Adolescent (n=148)**	**Ireland FI Child and Adolescent (n=56)**
COMPONENTS OF DIRECT COSTS	**Cost in € per annum**	**Cost in € per annum**	**Cost in € per annum**
Total cost of medical visits	386**	253**	73
Total cost of travel to medical visits	23	14	9
Total cost of hospital visits and stays	542**	167	No difference
Total cost of medication	93**	23*	24**
Private health insurance	85	189**	32
Total food cost	No difference	257**/347▾	No difference
TOTAL DIRECT COSTS	**1,115****	**903**/993▾**	**No difference**
COMPONENTS OF INDIRECT COSTS	**Cost in € per annum**	**Cost in € per annum**	**Cost in € per annum**
Time spent food shopping	No difference	64	59
Time spent preparing food	No difference	No difference	18
Days missed from work/school/college	302**	115	98
Lost earnings associated with healthcare visits	170**	34	23
TOTAL INDIRECT COSTS	**324**	**130**	**198**
TOTAL (DIRECT + INDIRECT) COST	**1,439****	**1,033**/1,123▾**	**70**

*p <0.05 and ** p <0.01 are statistically significant

'No difference' indicates negative cost values that were not statistically significant but are included in the calculation of the total cost figures.

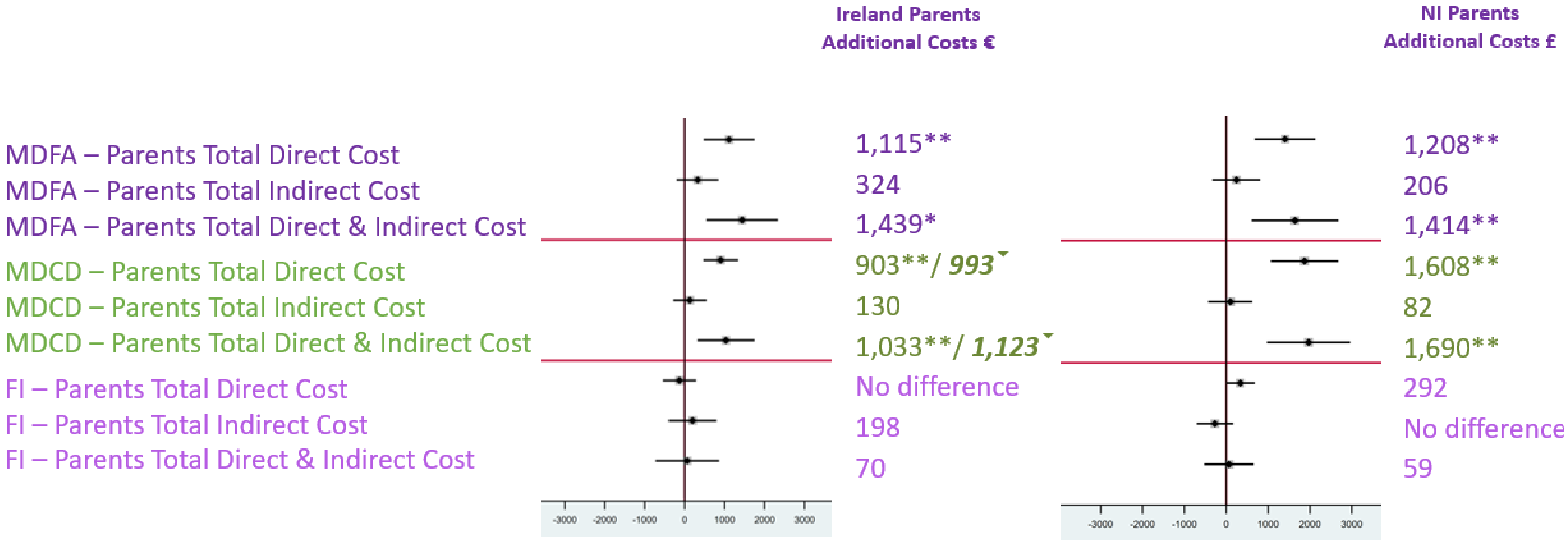
▾Costs excluding/including a tax rebate on gluten-free foods claimed by 30% of parents of MDCD children/adolescents in Ireland

Table 4.2.2b: Additional direct and indirect Sterling costs per annum associated with children/adolescents with food hypersensitivity (parent-reported): MDFA (n=147), MDCD (n=60) and FI (n=51) compared to non-food hypersensitive controls (n=165) in Northern Ireland (November 2019 – October 2020)

	Northern Ireland MDFA Child and Adolescent (n=147)	**Northern Ireland MDCD Child and Adolescent (n=60)**	**Northern Ireland FI Child and Adolescent (n=51)**
COMPONENTS OF DIRECT COSTS	**Cost in £ per annum**	**Cost in £ per annum**	**Cost in £ per annum**
Total cost of medical visits	338**	433**	179**
Total cost of travel to medical visits	246**	355*	66*
Total cost of hospital visits and stays	512*	257*	No difference
Total cost of medication	29**	50**	9
Private health insurance	28**	41*	14
Total Food Cost	55	472**	40
TOTAL DIRECT COSTS	**1,208****	**1,608****	**292**
COMPONENTS OF INDIRECT COSTS	**Cost in £ per annum**	**Cost in £ per annum**	**Cost in £ per annum**
Time spent food shopping	No difference	7	No difference
Time spent preparing food	88	-280*	-329**
Days missed from work/school/college	122*	349*	144
Lost earnings associated with healthcare visits	48	6	13
TOTAL INDIRECT COSTS	**206**	**82**	**No difference**
TOTAL (DIRECT + INDIRECT) COST	**1,414****	**1,690****	**59**

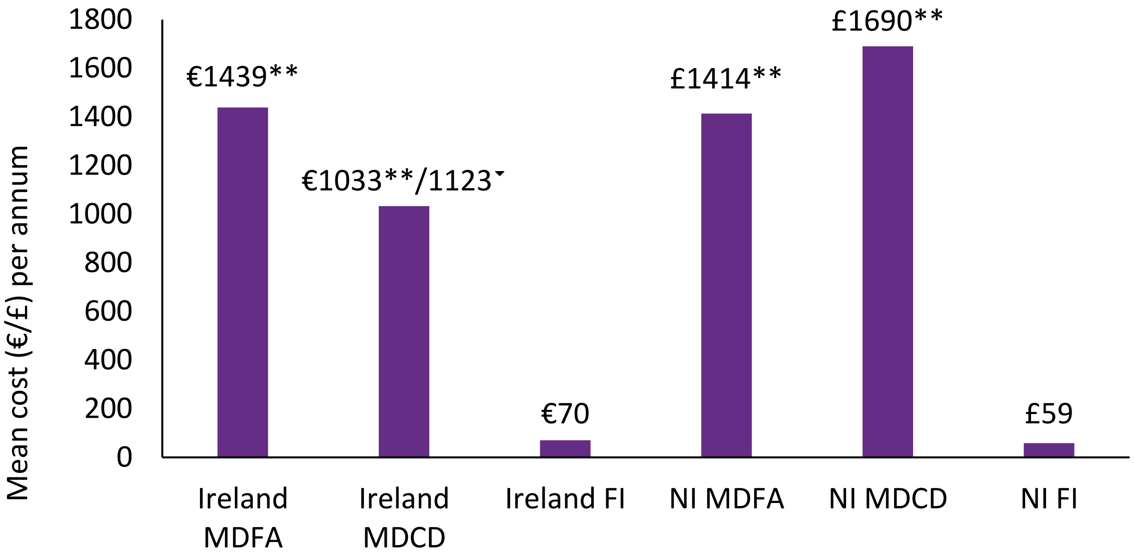
*p <0.05 and ** p <0.01 are statistically significant
'No difference' indicates negative cost values that were not statistically significant but are included in the calculation of the total cost figures.

Figure 4.2.2a: Additional direct and indirect Euro/Sterling costs per annum for food hypersensitive children/adolescents (parent-reported) based on data collected from an online survey carried out between November 2019 and October 2020 in Ireland (n=377) and Northern Ireland (n=258)



*p <0.05 and **p <0.01 are statistically significant
Costs excluding/including a tax rebate on gluten-free foods claimed by 30% of parents of MDCD children/adolescents in Ireland
See Tables 7.A.1 and 7.A.2 in Annex 7 for the 95% Confidence limits associated with each mean value.

Figure 4.2.2b: Additional mean total (direct + indirect) costs (Euro/Sterling per annum) for families with a food hypersensitive child or adolescent (parent-reported) based on data collected from an online survey carried out between November 2019 to October in Ireland (n=377) and Northern Ireland (n=258)



Mean direct & indirect costs for adults with food hypersensitivity (self-reported) in Ireland (€) and NI (£)

* p <0.05 and **p <0.01 are statistically significant

˅ Costs excluding/including a tax rebate on gluten-free foods claimed by 30% of parents of MDCD children/adolescents in Ireland

Children/adolescent sample sizes: MDFA Ireland=173, MDFA Northern Ireland=147, MDCD Ireland=148, MDCD Northern Ireland=60, FI Ireland=56, FI Northern Ireland =51; control groups Ireland=130 and Northern Ireland =165

Table 4.2.2c: Additional (incremental) healthcare and out-of-pocket costs associated with children/adolescents with food hypersensitivity (parent-reported) in Ireland (€) and Northern Ireland (£) (November 2019 – October 2020)

	MDFA Parental (IRL €)	MDCD Parental (IRL €)	FI Parental (IRL€)	MDFA Parental (NI £)	MDCD Parental (NI £)	FI Parental (NI £)
Healthcare Costs (borne by respondents and the health service)	940 (65%)	426 (41%)	-39 (26%)	864 (61%)	679 (40%)	151 (62%)
Out-of-Pocket Costs (typically borne by respondents alone)	499 (35%)	607 (59%)	109 (74%)	550 (39%)	1,011 (60%)	No difference
Total Cost	**1,439**	**1,033**	**70**	**1,414**	**1,690**	**59**
Number in group	173	148	56	147	60	51
Number in comparison group	130	130	130	165	165	165

Table 2.2.1b lists the components of (a) healthcare costs and (b) out-of-pocket costs for each food hypersensitivity. These are described in depth in Tables 7.A.3 (euro) and 7.A.4 (pounds sterling) in Annex 7. MDCD figures for Ireland are reported after the tax rebate on gluten-free food had been subtracted

4.3 Examination of the Factors Contributing to Additional Costs for Individuals with Food Hypersensitivity

This study examined data provided by 2,066 adults with food hypersensitivity (self-reported) against information collected from a separate control survey of non-food hypersensitive adults (n=735) in Ireland and Northern Ireland. Similarly, reported costs associated with having a food hypersensitive child or adolescent from 635 parental surveys were examined in comparison to data from parents of non-food hypersensitive child/adolescent (n=295). A total of 12 test groups were studied, consisting of three food hypersensitivities (MDFA, MDCD and FI) in the adult groups and parents of child/adolescent groups in Ireland and Northern Ireland. Higher total costs of additional condition-related expenses up to €1,602 and £1,690 p.a. were calculated for the 12 food hypersensitive groups examined. The yearly out-of-pocket costs (mainly non-healthcare) borne by individuals and households alone ranged from no difference to up to €1,141 and £1,011 p.a. (Table 4.1.2c & 4.2.2c), depending on the condition examined, while healthcare costs (shared by the respondents and health service) were reported as high as €940 p.a. in Ireland and £864 p.a. in Northern Ireland. Notably, healthcare costs were consistently the main driver of food hypersensitivity-related expenses for individuals and households in this study (sections 4.1. and 4.2; Table 7.A.1 and 7.A.3; Annex 7).

4.3.1 Additional healthcare costs for food hypersensitive consumers on the island of Ireland

If all the healthcare elements examined (medical visits, hospital visits/stays, associated travel, medication and insurance) are combined into one figure per test group, certain trends are observed (Figure 4.3a and Figure 4.3b). Individuals with MDFA (child/adolescent and adult) had higher healthcare-related outgoings in Ireland (€601 to €1,129 p.a.) and Northern Ireland (£825 to £1,153 p.a.) than other food hypersensitive groups. This was followed by MDCD, which reported the next highest healthcare-related costs for Ireland (€280 to €646 p.a.) and Northern Ireland (£419 to £1,136 p.a.). FI had the lowest set of healthcare-related costs for Ireland (€32 to €268 p.a.) and also for Northern Ireland (£252 to £394 p.a.).

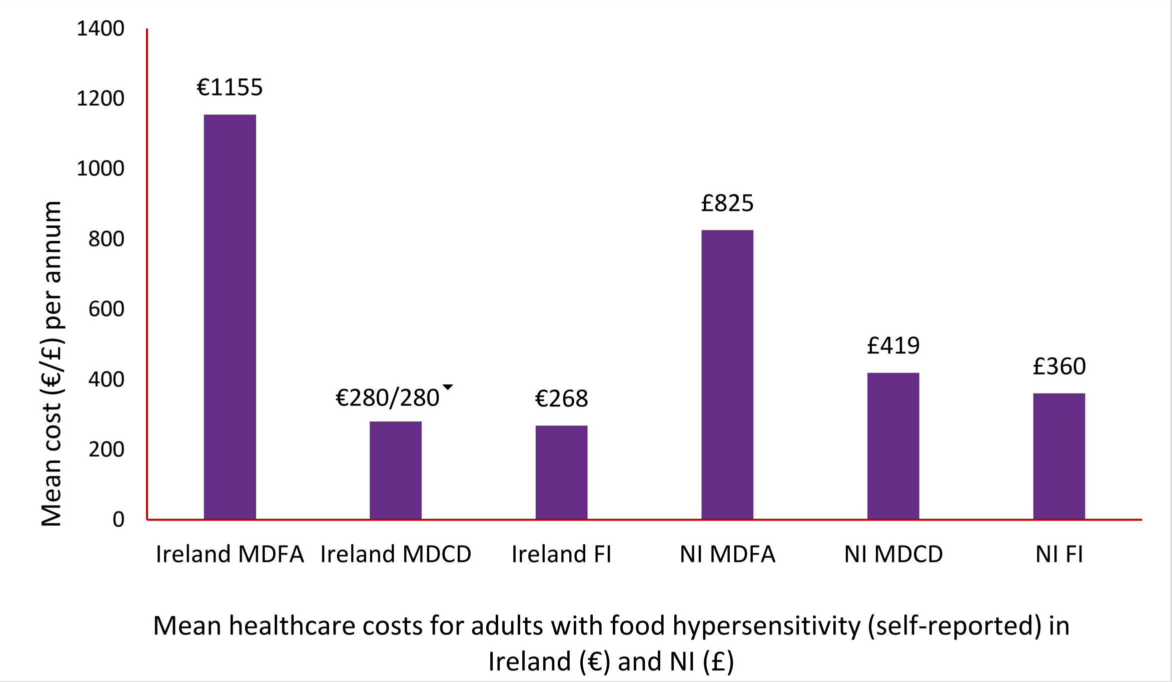
The second observation to be noted is that healthcare costs were higher for all of the Northern Ireland test groups in comparison to their Ireland counterparts (Figure 4.3a and Figure 4.3b). In fact, healthcare costs were reported to be approximately 40% higher in Northern Ireland for all of the food hypersensitive adult groups. Similarly, healthcare costs were reported to be approximately 39% higher by all parental groups of food hypersensitive children/adolescents. This difference was found to range from costs of €190 p.a. (adult, FI) up to €676 p.a. (children and adolescent, MDCD) when the two jurisdictions were compared. The result in many instances was higher healthcare costs for MDCD individuals/households in Northern Ireland (although shared with the health service) compared to Ireland (Table 4.1.2c & 4.2.2c).

One additional finding regarding private healthcare can be seen in Tables 7.A.1 and 7.A.3 in Annex 7. Higher additional private health insurance-related costs were noted for the families of food hypersensitive children/adolescents in Ireland (€32 to €189 p.a.) compared to the same group in Northern Ireland (£13 to £41 p.a.). A similar observation was made regarding private health insurance costs for food hypersensitive adult respondents in Ireland (€9 to €95 p.a.) compared to Northern Ireland (no difference to £1 p.a.) (sections 4.1 and 4.2).

4.3.2 Additional food costs for food hypersensitive consumers on the island of Ireland

Regarding food-related expenses (shopping, eating out, take-aways, etc.), all of the adult respondents in both jurisdictions were found to have higher mean total food costs than their control counterparts (up to €724 p.a. and £318 p.a. in Ireland and Northern Ireland, respectively), with the exception of FI in Northern Ireland (no difference). Similarly, the mean additional food costs were up to €257 p.a. in Ireland and £472 p.a. in Northern Ireland for the parental groups, except for MDFA and FI in Ireland which returned no difference compared to controls. If we examine food costs by condition, additional food costs were consistently high (and often as significantly as $p < 0.05$) for MDCD respondents on the island of Ireland. However, MDCD food costs were higher for individuals/households in Northern Ireland, at £318 to £472 p.a., than in Ireland at €164 to €257 p.a. (or €221 to €347 p.a. before a tax rebate for gluten-free food). Tax relief on gluten-free foods is available in Ireland and was considered, when reported, in the final calculated figure by survey respondents (30% of parental and 29% adult of MDCD survey respondents reported claiming tax-relief). It is worth noting that certain gluten-free food products are currently free-of-charge for coeliac individuals in Northern Ireland on prescription but would not have been included in the final food costs for Northern Ireland. These aspects are discussed in more detail in Chapter 5. Finally, food costs were also reported to be high for the MDFA adult group in Ireland (€724 p.a., $p < 0.01$), but not for the other test groups examined.

Figure 4.3a Additional mean healthcare costs (Euro/Sterling per annum) for adults with food hypersensitivity based on cost data collected from an online survey carried out between November 2019 and October 2020 in Ireland (n=1,323) and Northern Ireland (n=743)

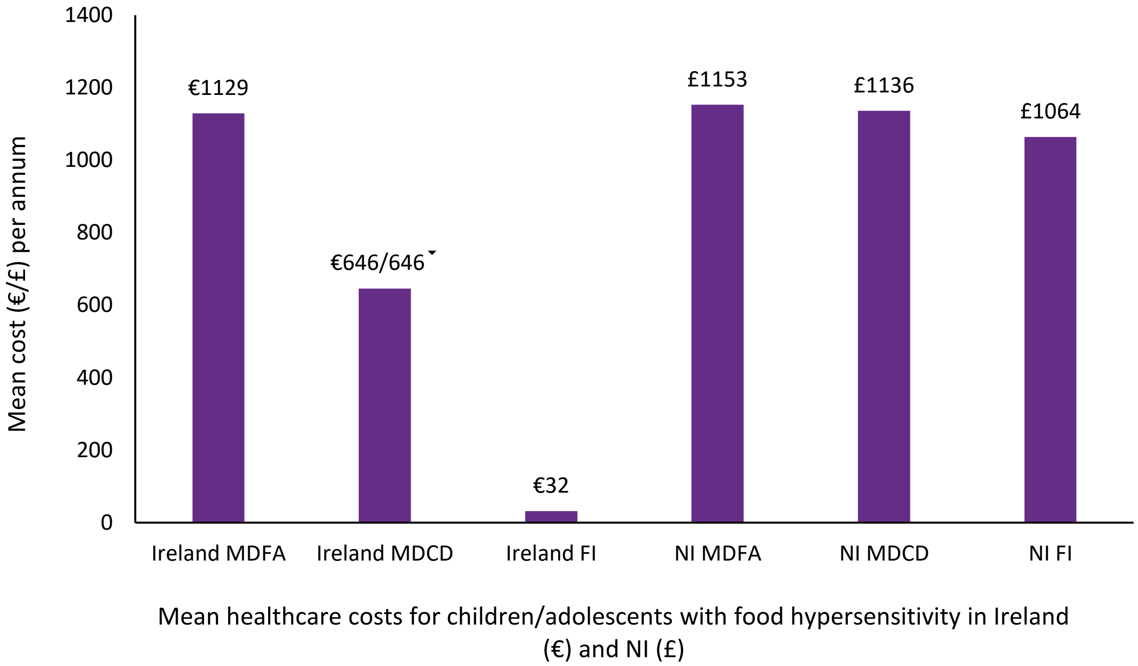


Adult sample sizes: MDFA Ireland=178, MDFA Northern Ireland =111, MDCD Ireland=609, MDCD Northern Ireland =173, FI Ireland=536, FI Northern Ireland =459, control groups Ireland=531 and Northern Ireland =204.

A statistical analysis for incremental costs for each condition between Ireland and Northern Ireland was not carried out as these data sets are separate and cannot readily be compared given the reweighting of controls.

▾Costs excluding/including a tax rebate on gluten-free foods claimed by 29% of MDCD adults in Ireland.

Figure 4.3b: Additional mean healthcare costs (Euro/Sterling per annum) for children/adolescents with food hypersensitivity (parent-reported) based on data collected from an online survey carried out between November 2019 and October 2020 in Ireland (n=377) and Northern Ireland (n=258)



Children/adolescent sample sizes: MDFA Ireland=173, MDFA Northern Ireland =147, MDCD Ireland=148, MDCD Northern Ireland =60, FI Ireland=56, FI Northern Ireland =51, control groups Ireland=130 and Northern Ireland =165.
A statistical analysis for incremental costs for each condition between Ireland and Northern Ireland was not carried out as these data sets are separate and cannot readily be compared given the reweighting of controls.
˅ Costs excluding/including a tax rebate on gluten-free foods claimed by 30% of parents of MDCD children/adolescents in Ireland.

4.3.3 Additional indirect costs for food hypersensitive consumers on the island of Ireland

A large amount of variation was reported in indirect costs across the test groups, where they were in some cases negligible and in others a significant cost. This variation was often associated with responses for ‘time spent preparing food’. The main driver of indirect cost was associated with ‘days missed from work/school/college’. These costs tended to be higher in responses from Northern Ireland (£122 to £418 p.a.) than in Ireland (€0 to €302). Indirect costs (up to €324 p.a. in Ireland and £628 p.a. in Northern Ireland) contributed to the overall total cost of food hypersensitivity for all groups, except for adult MDCD in Ireland and child/adolescents FI in Northern Ireland (sections 4.1. and 4.2). While a higher overall cost was attributed to indirect costs in most instances, they were only found to be a statistically significant for MDFA and MDCD adults in Northern Ireland (£412 p.a. $p < 0.05$, and £628 p.a. $p < 0.01$).

4.3.4 Additional out-of-pocket costs for food hypersensitive consumers on the island of Ireland

All the parameters examined in this study were found to contribute to increases in the overall cost of food hypersensitivity in Ireland and Northern Ireland. Most notable was the contribution of health care-related expenses (Figures 4.3a and 4.3b), although total food costs, lost earnings and lost days of work/college/schools (among other aspects) were significant in some of the groups studied. Out-of-pocket costs (as opposed to healthcare costs) borne alone by individuals and households (parental survey), were found to range from €499 to €1,141 p.a. for MDFA in Ireland, and £542 to £550 p.a. in Northern Ireland (Table 4.1.2c & 4.2.2c). The equivalent costs for MDCD were found to range from €290 to €607 p.a. in Ireland (€347 to €697 p.a. before a tax rebate for gluten-free food), and £965 to £1,011 p.a. in Northern Ireland.

In addition, respondents shared healthcare costs with their health service provider (€461 to €940 p.a. for MDFA in Ireland, and £717 p.a. to £864 p.a. in Northern Ireland, and €148 to €426 p.a. for MDCD in Ireland, and to £400 to £679 p.a. in Northern Ireland), adding to their annual burden of expense. These figures highlight the high additional costs associated with diagnosis of either condition for individuals and families. Condition-associated out-of-pocket costs were also noted for three of the FI groups, albeit to a lesser degree (up to £341 p.a.) than other groups examined in this study. Out-of-pocket costs were not reported for the FI parental Northern Ireland group.

4.4 Examination of Intangible Costs associated with Food Hypersensitivity in Ireland and Northern Ireland

Intangible costs were examined for adults and children/adolescents. Intangible costs are defined as a loss of value or utility. This can be difficult to measure in monetary terms but can be examined through self-reported health status. This includes aspects such as loss of welfare and well-being, pain/suffering, inconvenience, or effects on QoL due to having a food hypersensitivity in this instance (Miles et al. 2005; Voordouw et al. 2016). Intangible costs are typically examined via a health-related quality of life (HRQoL) assessment (Miles et al. 2005) which focuses on an individual's perception of the overall effects of the associated illness and its treatment. This includes aspects of physical, psychological and social well-being and functioning. For the purposes of this study, the EQ-5D questionnaire (sections 4.4.1 - 4.4.3) and a specific food hypersensitivity intangible question (section 4.4.4.), which was included in all surveys, is presented here.

4.4.1 EQ-5D Questionnaire: Examination of the five dimensions

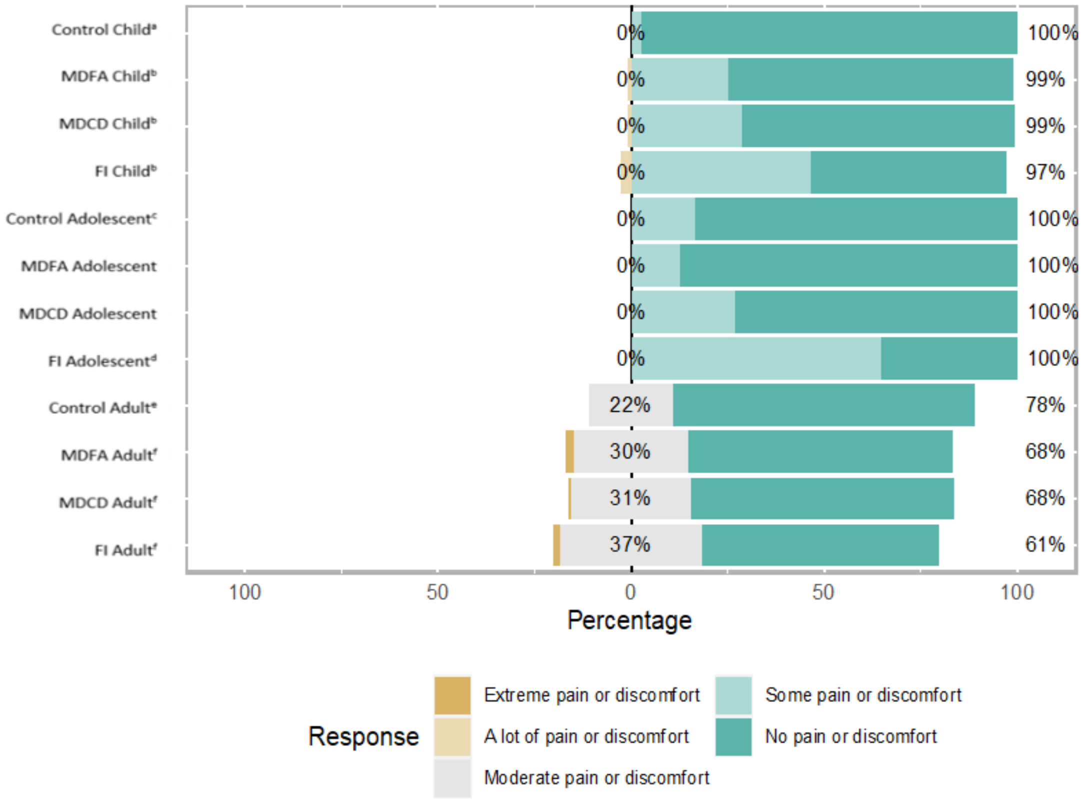
EQ-5D is a standardised health-related quality of life questionnaire. The five dimensions examined in EQ-5D relate to various aspects of health and have been widely used to assess health states and health-related quality of life for different conditions in many countries, including Ireland (e.g., 0.60 for patients on hemodialysis, 0.59 for individuals with multiple sclerosis, and 0.49 for rheumatoid arthritis etc., (Adams et al. (2010); Lowney et al. (2015); MSS (2015)). It should be noted that the EQ-5D questions have not been designed specifically to examine food hypersensitivity but are instead a mechanism to assist in measuring the overall impact of a disease or illness on an individual's QoL.

From this perspective, dimensions such as 'mobility' and the ability of a food hypersensitive person to complete their 'usual activities' unhindered or 'look after him or herself', while included as part of the EQ-5D questionnaire, were unlikely to be affected by food hypersensitivity. Pearson chi-squared was used to compare differences between the control and food hypersensitive groups, because of which no patterns or significant differences were noted between groups regarding the three aforementioned dimensions. However, significant differences were noted between the food hypersensitive groups and the control group regarding the dimensions 'having pain or discomfort' and 'having anxiety and depression' (Figures 4.4.1a and 4.4.1b).

From data reported in the parental study, children belonging to all three groups (MDFA, MDCD, and FI) on the IoI (n=223, n=116, n=73, respectively) were found to have significantly higher levels of pain and discomfort ($p<0.05$) compared to controls (n=212) (Figure 4.4.1a). Similarly, adults belonging to all three food hypersensitive groups (MDFA, MDCD, and FI) on the IoI (n=194, n=528, n=767, respectively) were found to have a significantly higher level (p-value <0.05) of pain and discomfort compared to controls (n=669). With regard to adolescents, a significant difference was only found for the FI group (and not MDFA and MDCD) for this dimension. However, it should be noted that the sample size of this groups (n=14) was smaller than others examined which may have had a bearing on this result. These findings strongly suggest a relationship between food hypersensitivity and higher levels of pain and discomfort in the daily lives of those affected.

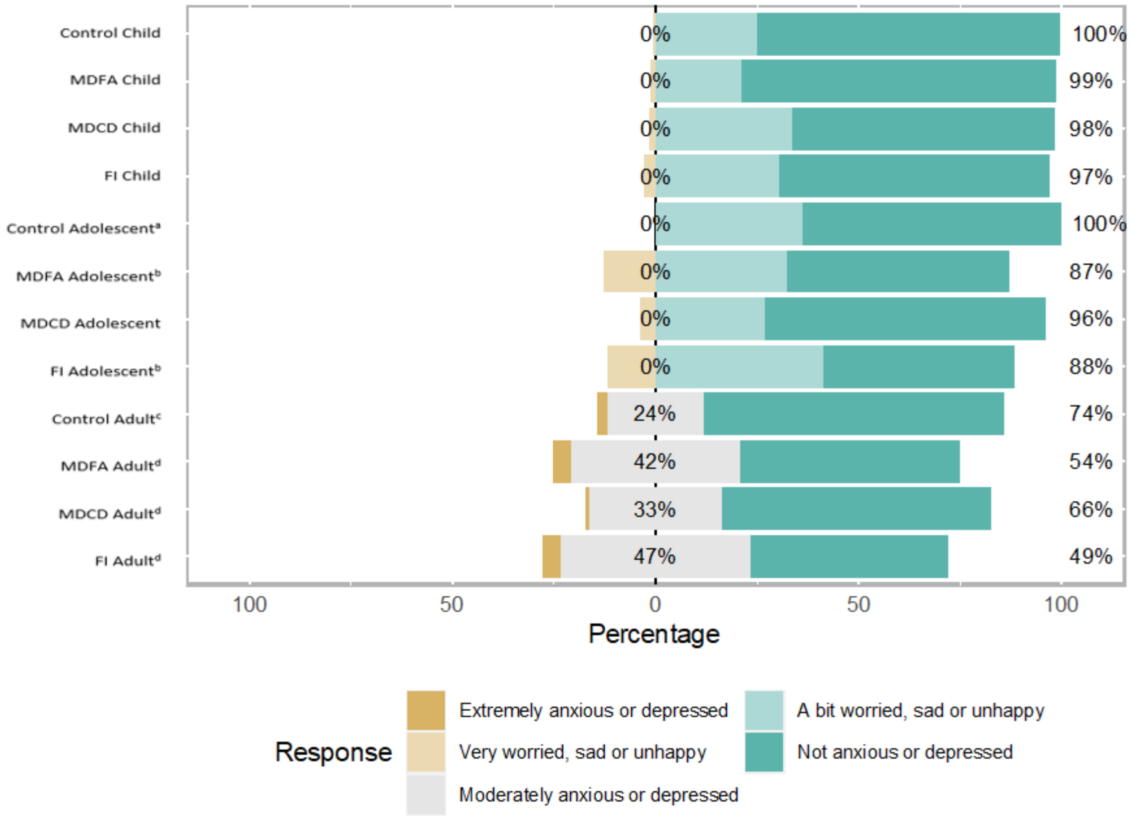
Regarding the last dimension, ‘feeling worried or sad’ (Figure 4.4.1b), no significant difference was found between child MDFA, MDCD and FI and their corresponding controls (n=223, n=116, n=73, and n=212, respectively). In contrast, MDFA and FI adolescents were found to have significantly higher levels of anxiety and depression (<0.05) than their controls. While adolescent’s with MDCD did have a higher level of sadness and anxiety when compared to their corresponding control group, this was not found to be statistically significant. Notably, a significantly higher level of anxiety and depression (p<0.05) was found for adults in all three of the food hypersensitive groups compared to controls (n=194, n=528, n=767, and n=669, respectively). These findings suggest an increased level of anxiety and depression associated with having a food hypersensitivity in the adult and adolescent groups examined. However, it was noted that the levels of anxiety and depression were higher for MDFA and FI. This finding may be underpinned by a greater ability of those with MDCD to manage and control their condition, compared to those with MDFA or FI.

Figure 4.4.1a: Self-reported and parent-reported health status associated with food hypersensitivity in children (n=412), adolescents (n=98), adults (n=1,489) and non-food hypersensitive controls (n=962) on the island of Ireland under the EQ-5D dimension of ‘Pain and Discomfort’.



* a versus b, c versus d, and e versus f are significantly different (p <0.05)

Figure 4.4.1b: Self-reported and parent-reported health status associated with food hypersensitivity in children (n=412), adolescents (n=98), adults (n=1.489) and non-food hypersensitive controls (n=962) on the island of Ireland under the EQ-5D dimension of 'Feeling worried, sad or unhappy'.



*a versus b, and c versus d are significantly different (p <0.05)

4.4.2 EQ-5D Questionnaire: Examination EQ-5D Single Index Value

A single index value of the health status of each food hypersensitive and control group was calculated by averaging values for each of the five dimensions of the EQ-5D reported for children/adolescents (parental survey) and adults. These figures are presented and statistically analysed using a two-sample t-test in Table 4.4.2. It is noteworthy that these data are unweighted and are therefore not comparable with the costing data previously reported in Section 4.1 and 4.2.

When the Irish parental surveys were examined, the mean value for the control group was found to be 0.90, while the three food hypersensitive groups were all found to be lower (0.79 to 0.83) but not significantly so (Table 4.4.2). These values were significantly lower for MDFA (0.83) and FI (0.79), suggesting an overall lower reported health status among these groups.

With regard to the parental surveys in Northern Ireland, the control group for children/adolescents was found to be 0.89, while the three food hypersensitive groups were found to be 0.76 to 0.84. As with the Irish groups, the index values reported for MDFA (0.80) and FI (0.76) were also significantly lower ($p < 0.05$) than controls in Northern Ireland. The same trend was also observed for the IoI with index values for MDFA (0.82) and FI (0.78) being significantly lower ($p < 0.05$) than controls (0.90). On all three occasions (Ireland, Northern Ireland and IoI), MDCD was found to have a lower index value than the control group, but not significantly so ($p < 0.05$).

When Irish adult groups were examined (Table 4.4.2), a significantly lower health status was reported for MDFA (0.78) and FI (0.77) compared to controls (0.89). In contrast, no statistically significant difference was found between the control group (0.79) and MDFA adults in Northern Ireland (0.75) while the index value reported for FI adults in Northern Ireland (0.74) was significantly lower than controls (0.79) ($p < 0.05$). The overall IoI index figure for the three adult food hypersensitive groups (0.76 to 0.82) was significantly lower (p 0.05) than the control group (0.84). These results highlight the significant impact of food hypersensitivity on the reported health status of susceptible adults on the IoI.

Table 4.4.2: EQ-5D utility index of parent-reported health status of children/adolescents and self-reported health status of adults in a survey carried out between November 2019 and June 2020 in Ireland (n=2,361) and Northern Ireland (n=1,370)

Health Status	**Control Children/ Adolescents Ireland**	**MDFA Children/ Adolescents Ireland**	**MDCD Children/ Adolescents Ireland**	**FI Children/ Adolescents Ireland**	**Control Adults Ireland**	**MDFA Adults Ireland**	**MDCD Adults Ireland**	**FI Adults Ireland**
Sample size	130	173	148	56	531	178	609	536
Mean value	**0.90**	**0.83**	**0.86**	**0.79**	**0.89**[a]	**0.78**[b]	**0.84**	**0.77**[b]
Standard deviation	0.19	0.25	0.21	0.22	0.17	0.25	0.19	0.24
Health Status	**Control Children/ Adolescents Northern Ireland**	**MDFA Children/ Adolescents Northern Ireland**	**MDCD Children/ Adolescents Northern Ireland**	**FI Children/ Adolescents Northern Ireland**	**Control Adults Northern Ireland**	**MDFA Adults Northern Ireland**	**MDCD Adults Northern Ireland**	**FI Adults Northern Ireland**
Sample size	165	148	60	52	204	111	173	459
Mean value	**0.89**[c]	**0.80**[d]	**0.84**	**0.76**[d]	**0.79**[c]	**0.75**	**0.79**	**0.74**[f]
Standard deviation	0.18	0.25	0.19	0.24	0.26	0.29	0.25	0.27
Health Status	**Control Children/ Adolescents IoI**	**MDFA Children/ Adolescents IoI**	**MDCD Children/ Adolescents IoI**	**FI Children/ Adolescents IoI**	**Control Adults IoI**	**MDFA Adults IoI**	**MDCD Adults IoI**	**FI Adults IoI**
Sample size	295	320	208	107	735	289	782	995
Mean value	**0.90**[g]	**0.82**[h]	**0.85**	**0.78**[h]	**0.84**[i]	**0.77**[j]	**0.82**[j]	**0.76**[j]
Standard deviation	0.19	0.25	0.20	0.23	0.23	0.27	0.22	0.25

* The following relationships are statistically significant ($p < 0.05$); a versus b, c versus d, e versus f, g versus h, i versus j.

4.4.3 EQ-5D Questionnaire: Examination Mean Overall Health Status score (EQ VAS)

A second mechanism of measuring overall health status (other than the calculation of a single index value based on five dimensions described in section 4.4.2) is asking respondents and parents of food hypersensitive children to rate their own perceived status. The mean overall health status score (or EQ VAS) records the respondents' self-rated health on a vertical 20 cm visual analogue scale, where the endpoints are labelled 'Best imaginable health state' and 'Worst imaginable health state' (Figure 2.3b). This information can be used as a quantitative measure of health outcome as judged by individual respondents.

The mean overall health status score of children/adolescents with MDFA, MDCD, and FI in surveys completed by their parents, was significantly lower ($p<0.05$) for all food hypersensitive groups in Ireland (score 79 – 84, control group score 89), Northern Ireland (score 81 - 87, control group score 91) and for the IoI (score 80 - 84, control group score 90) (Table 4.4.3). In other words, parents reported a significantly lower overall health status for their food hypersensitive child/ adolescent (p-value <0.05) than those recorded by parents of non-hypersensitive children/adolescents (control group). This finding is in agreement with observations regarding lower health status noted in section 4.4.2 (EQ-5D single index value). However, on this occasion children/adolescents with MDCD also had a significantly lower health status than their control counterparts, like the MDFA and FI groups.

Interestingly, while a significantly lower health status was reported for all the food hypersensitive groups in Ireland regarding their calculated EQ-5D single index value (section 4.4.2), only FI (score 75) was found to be significantly lower ($p <0.05$) than the control group (score 80) with regard to the Irish EQ-VAS. Figures for MDFA (score 77) and MDCD (score 79) were lower than the control group but not significantly so. Similarly, the three food hypersensitive groups (score 77) were found to have lower EQ-VAS scores than the control group for Northern Ireland (score 80), but not significantly so. However, when an average of these figures was taken for the overall IoI, both MDFA (score 77) and FI (score 76) were found to have a significantly lower EQ-VAS score than the control group (score 80). These findings once again highlight the impact of MDFA and FI on the overall health status of affected adults on the IoI. The mean reported overall health status for MDCD adults (score 79) was also lower than the control group (score 80), but not significantly so.

Table 4.4.3: Parent-reported health status of children/adolescents and self-reported health status (out of 100) of adults in a survey carried out between November 2019 and June 2020 in Ireland (n=1,743) and Northern Ireland (n=1,015)

Health Status	**Control Child/ Adolescent Ireland**	**MDFA Child/ Adolescent Ireland**	**MDCD Child/ Adolescent Ireland**	**FI Child/ Adolescent Ireland**	**Control Adults Ireland**	**MDFA Adults Ireland**	**MDCD Adults Ireland**	**FI Adults Ireland**
Sample size	124	124	111	40	475	105	376	388
Mean value	**89^{a}**	**81^{b}**	**84^{b}**	**79^{b}**	**80^{g}**	**77**	**79**	**75^{h}**
Standard deviation	13.1	14.6	12.6	15.3	13.4	15.6	14.8	15.6
Health Status	**Control Child/ Adolescent Northern Ireland**	**MDFA Child/ Adolescent Northern Ireland**	**MDCD Child/ Adolescent Northern Ireland**	**FI Child/ Adolescent Northern Ireland**	**Control Adults Northern Ireland**	**MDFA Adults Northern Ireland**	**MDCD Adults Northern Ireland**	**FI Adults Northern Ireland**
Sample size	142	115	50	42	151	73	114	328
Mean value	**91^{c}**	**87^{d}**	**86^{d}**	**81^{d}**	**80**	**77**	**77**	**77**
Standard deviation	10.8	11.3	10.8	12.0	14.7	15.1	14.1	14.9
Health Status	**Control Child/ Adolescent IoI**	**MDFA Child/ Adolescent IoI**	**MDCD Child/ Adolescent IoI**	**FI Child/ Adolescent IoI**	**Control Adults IoI**	**MDFA Adults IoI**	**MDCD Adults IoI**	**FI Adults IoI**
Sample size	266	239	161	82	626	178	490	716
Mean value	**90^{e}**	**84^{f}**	**84^{f}**	**80^{f}**	**80^{i}**	**77^{j}**	**79**	**76^{j}**
Standard deviation	11.6	14.0	12.3	13.6	13.7	15.4	14.7	15.3

*The following relationships are statistically significant ($p < 0.05$); a versus b, c versus d, e versus f, g versus h, i versus j.

4.4.4 Examination of areas of life affected by food hypersensitivity

In preparation for the release of the surveys to determine the socio-economic cost of food hypersensitivity on the IoI, a specific question was prepared to help highlight key areas of life affected by having a food hypersensitivity, both for the individuals affected and their families. This question was designed with the assistance of food hypersensitive individuals and with reference to the literature. The areas of life were selected in advance and added to, following the pilot study of the questionnaires completed by 104 individuals, before the formal survey run commenced. The final amended question consisted of 25 options by which the respondent could tick the areas affected in their life, or that of their child/adolescent, because of their food hypersensitivity. The options included the following: cost, time, ability to eat out, social life, travel life, relationships, household tasks, social activities/interactions, sports, public transport, childcare, choice of job and schools, among others. The reported areas of life affected, by the 3,001 food hypersensitive survey respondents, are detailed by condition, jurisdiction and status (whether they completed the questionnaire as an adult or as a parent) in Tables 7.A.3 to 7.A.10 in Annex 7. A summary of the top five most important areas by condition and age category for the IoI are included in Table 4.4.4.

The previous examination of the EQ-5D results revealed that areas such as ‘pain and discomfort’ and ‘feeling worried, sad or unhappy’ were significantly worse for many of the food hypersensitive survey participants than the control respondents. This question regarding areas of life affected by food hypersensitivity adds additional detail to this dataset, and some interesting trends were observed. Notably, ‘the ability to eat out’ (74% to 86%) was the most recorded parameter affecting QoL of all MDFA respondents (Table 4.4.4), thereby clarifying the impact of the many challenges associated with this activity because of having a food allergy. This was also closely linked to other important concerns reported by those with MDFA and their families (top five most reported) such as the ‘assumption of being a fussy eater’, ‘difficulties regarding children’s parties’ and ‘travel’. Other important areas included the ‘cost of food shopping’ and ‘the effect on the diet of the whole family’, which highlight the impact of food hypersensitivity on family life. In addition, 75% of participants of the parental survey reported that food hypersensitivity had a notable effect on their adolescents’ emotional well-being.

Table 4.4.4: Areas of life affected for food hypersensitive adults (self-reported) and children/adolescents (parent-reported) on the IoI (n=3,001) following an online survey November 2019 to October 2020

Children with MDFA (n=363)	Ability to eat out (82%) Children's parties (78%) Affects the diet of all the family (77%) Cost of food shopping (70%) Time for food shopping (70%)
Adolescents with MDFA (n=63)	Ability to eat out (86%) Affects the diet of all the family (78%) Travel (75%) Emotions (72%) Children's parties (64%)
Adults with MDFA (n=318)	Ability to eat out (74%) Assumption of being a fussy eater (72%) Affects the diet of the family (68%) Cost of food shopping (64%) Poor treatment in restaurants (58%)
Children with MDCD (n=150)	Cost of food shopping (98%) Ability to eat out (95%) Affects the diet of all the family (81%) Children's parties (79%) Travel (73%)
Adolescents with MDCD (n=67)	Cost of food shopping (98%) Ability to eat out (91%) Time spent food shopping (81%) Affects the diet of all the family (74%) Travel (70%)
Adults with MDCD (n=818)	Cost of food shopping (96%) Ability to eat out (82%) Assumption of being a fussy eater (65%) Time spent food shopping (62%) Poor treatment in restaurants (61%)
Children with FI (n=91)	Cost of food shopping (84%) Ability to eat out (71%)

	Affects the diet of all the family (67%) Time spent food shopping (59%) Emotions (56%)
Adolescents with FI (n=29)	Cost of food shopping (88%) Affects the diet of all the family (75%) Ability to eat out (62%) Time spent food shopping (50%) Assumption of being a fussy eater (44%)
Adults with FI (n=1,102)	Cost of food shopping (68%) Assumption of being a fussy eater (62%) Ability to eat out (54%) Time spent food shopping (46%) Emotions (42%)

*MDFA: Medically Diagnosed Food Allergy; MDCD: Medically Diagnosed Coeliac Disease; FI: Food Intolerance or suspected/undiagnosed food allergy.

** A more detailed breakdown of this data is available in Annex 7 of this report.

The most reported parameter affecting QoL in those with MDCD (96-98%), FI (68-88%) and their families was the ‘cost of food shopping’, highlighting the importance of this issue for individuals living with these conditions. This was followed by ‘ability to eat out’, which was consistently the second most reported aspect for all the MDCD groups examined (82-95%), and the second/third most reported issue for the FI respondents (62-75%). Related areas such as ‘children’s parties’, ‘travel’, ‘assumption of being a fussy eater’ and ‘poor treatment in restaurants’ were also noted in the ‘top five’. In addition, ‘time spent food shopping’ (extended time associated with reading food labels, for instance) is reported in the ‘top five’ for two of the MDCD groups (62-81%), and all three of the FI groups (46-59%). Lastly, the overall impact of food hypersensitivity on emotional well-being was recorded as an important issue for children with FI (parental survey) and adults with FI.

One interesting aspect of these results is the consistency of the findings between groups with the same conditions (Table 4.4.4). Overall, these results highlight key issues which could be addressed to help improve the lives of those affected by food hypersensitivity and the lives of their families. These areas associated challenges and potential strategies to address them are explored in more detail in Chapter 5 (priority setting interviews) and in the final study recommendations.

4.5 Conclusion

Total additional condition-related costs (up to €1,602 in Ireland to and £1,690 p.a. in Northern Ireland) were calculated for the 12 food hypersensitive groups examined in Ireland and Northern Ireland, with higher and typically significant costs associated with MDFA and MDCD. Total healthcare costs were the main driver of food hypersensitivity-related expenses and were found to be 40% higher in Northern Ireland than in Ireland for adult respondents, and 39% for parental respondents. In addition, total food costs were also an important contributor to direct costs, particularly for all four MDCD groups (up to €257 p.a. in Ireland and £472 p.a. in Northern Ireland), and for the MDFA adult group in Ireland (€724 p.a.).

Direct costs were higher and significant (except for Northern Ireland adults) for most of the MDFA groups examined (up to €1,325 p.a. in Ireland and £1,208 p.a. in Northern Ireland). Similarly, direct costs were also high, and usually significant (except for adults in Ireland) for the MDCD groups (up to €903 p.a. in Ireland and £1,608 p.a. in Northern Ireland). In addition, indirect costs were also found to contribute to the total costs calculated, but not to the same degree as direct costs. More specifically, indirect costs ranged up to €324 p.a. in Ireland and £412 p.a. in Northern Ireland for the four MDFA groups, and up to €130 p.a. in Ireland and £628 p.a. in Northern Ireland for three MDCD groups, except for the MDCD adult Ireland group (no difference). The reason for the negligible indirect costs associated with the MDCD Ireland group (n=609) was due to no reported additional 'missed days from work/school/college' p.a. for this group, compared to their control group (n=531). 'Missed days' were the main driver of indirect costs of food hypersensitivity, with 6.7 additional 'missed days' p.a. reported by the equivalent MDCD adult group in Northern Ireland (n=173) when compared to their control counterparts (n=204).

Total costs incurred were calculated by adding reported direct and indirect expenses together. The high additional total costs associated with the MDFA and MDCD groups that achieved statistical significance were €1,602 p.a. in Irish adults and £1.414 p.a. in Northern Ireland parents (MFDA), and €1,033 p.a. in Irish parents and £1,690 p.a. in Northern Ireland parents (MDCD). The exception was the MDCD adult Ireland group, who were also associated with a high additional total cost p.a. (€438, or €495 without the gluten-free food tax rebate), but it was not found to be statistically significant. Regarding FI, higher additional total costs were calculated for adult respondents in Ireland and Northern Ireland (€504 and £565 p.a.) than for children/adolescents (€70 and £59 p.a. respectively). The main driver behind the adult costs for FI were higher healthcare costs (€268 and £360 p.a.) and 'missed days' (€104 and £230 p.a.).

Out-of-pocket costs typically borne alone by individuals and households (parental survey) with food hypersensitivity were found to range from €499 to €1,141 p.a. for MDFA in Ireland, and £542 to £550 p.a. in Northern Ireland, while the equivalent for MDCD was found to range from €290 to €607 p.a. in Ireland (€347 to €697 p.a. before a tax rebate for gluten-free food) and £965 to £1,011 p.a. in Northern Ireland. In addition, respondents incurred healthcare costs in conjunction with (or shared with) their healthcare provider (cumulative cost: €461 to €940 p.a. for MDFA in Ireland, and £717 p.a. to £864 p.a. in Northern Ireland, and €148 to €426 p.a. for MDCD in Ireland, and to £400 to £679 p.a. in Northern Ireland). These findings reveal the often-substantial additional expenses incurred by individuals with food hypersensitivity and their families. These costs were more pronounced for MDFA and MDCD participants than for FI participants, although all conditions were associated with additional costs.

Two mechanisms were employed to rate the overall perceived health status of adults with food hypersensitivity and parents of children/adolescents with food hypersensitivity. These were the calculation of an EQ-5D single index figure and a mean overall health status EQ-VAS score. A significantly lower ($p < 0.05$) overall EQ-VAS score was reported for children/adolescents with any food hypersensitivity. Similarly, a significantly lower EQ-5D single index figure ($p < 0.05$) was reported for children/adolescents with MDFA and FI, but not with MDCD (although the reported figure was lower than the control group). Interestingly, a significantly lower EQ-5D single index figure ($p < 0.05$) was reported for adults on the IoI who had food hypersensitivity. This was only significant ($p < 0.05$) for adults with MDFA or FI when examined by the second measure of overall mean health status (EQ-VAS). MDCD adults reported a lower EQ-VAS score than controls, but not significantly so. These findings suggest a significantly lower perceived health status (and a notable intangible cost, or effect on QoL) associated with food hypersensitivity, particularly for those with MDFA or FI. While the lowest overall total costs of the three food hypersensitivities were associated with FI, it was associated with a significantly reduced overall perceived health status for those affected (by EQ-5D single index value and EQ-VAS score), even more so than MDCD in many cases (Tables 4.4.2 and Tables 4.4.3).

In addition to reviewing the health status of respondents group, distinct areas of life affected by food hypersensitivity were examined. Regarding two dimensions of the EQ-5D – ‘having pain or discomfort’ and ‘feeling worried, sad or unhappy’ – children/adolescents and adults on the IoI with MDFA, MDCD or FI were found to have significantly higher levels of ‘pain and discomfort’ (<0.05) in their daily lives compared to controls. Regarding ‘feeling worried, unhappy, or sad’, a significant difference was found between adult MDFA, MDCD and FI groups and MDFA and FI in the adolescent groups. The MDCD adolescents had higher levels of depression and anxiety, but the difference compared to controls was not significant.

In summary, these results indicate a higher level of pain and discomfort associated with food hypersensitivity, and a higher level of anxiety and depression in adolescents and adults (not children) because of their condition. When aspects of QoL affected were investigated, the ‘ability to eat out’ and areas related to this were found to be an important issue for those with MDFA, with ‘cost’ reported as the next important. In contrast, those with MDCD and FI rated cost as the most important issue for respondents, followed by their ‘ability to eat out’ (and related areas). Addressing both challenges could potentially improve QoL. These aspects and others are reviewed in Chapter 5 (priority setting interviews) and considered in the key recommendations of this report.

5 Priority setting interviews with adults and parents of children/adolescents with MDFA or MDCD

A total of 76 phone interviews were completed in which participants discussed eight key issues which emerged from the initial survey results for this study (Chapter 3, and Annexes 1-6). These issues included perceptions of awareness (and recognition) of a condition, associated costs, available supports and specifics such as adrenaline auto-injector availability for individuals with MDFA. This report presents the findings from these interviews, including the positive and negative experiences of participants in Ireland and Northern Ireland, for each of the issues discussed. In addition, it includes potential solutions to these issues as proposed by the participants interviewed.

5.1 Priority Setting Interview Results: Priority Ranking and Interview Responses for Ireland and Northern Ireland

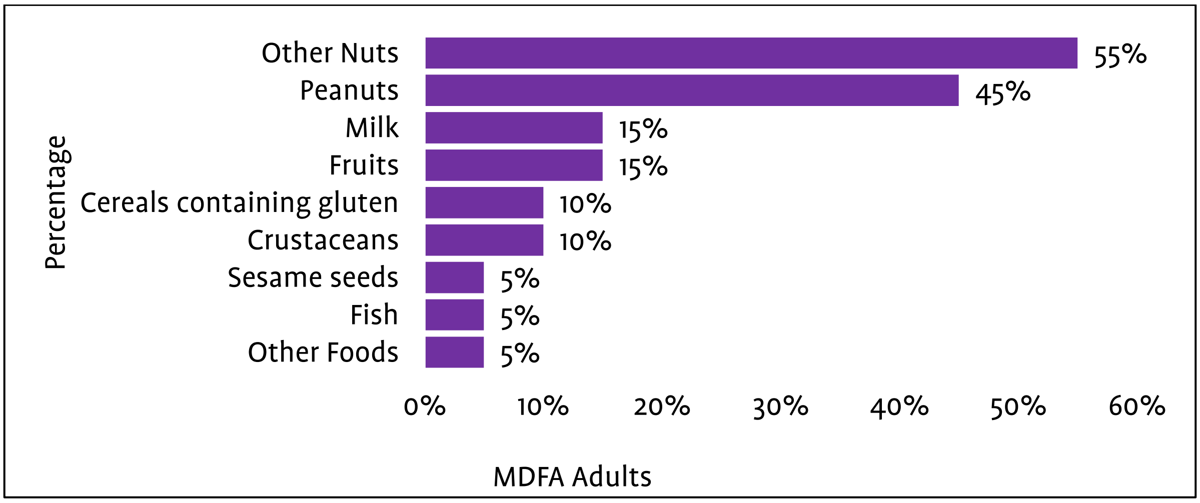
Participants openly shared their opinions and provided informative insights into their real-life experiences of the issues. Both positive and negative perspectives were proffered, and participants proposed strategies for addressing the issues. A large volume of data was gathered during this exercise and interesting observations and suggestions (often common to both MDFA and MDCD) emerged. This information is presented under each individual heading in the Tables 5.2.1 to 5.3.6. Information on the interviewees is provided in Table 2.4b and in section 5.1.1.

5.1.1 Trigger foods

Adults and parents of children/adolescents with MDFA in Ireland (n=20) and Northern Ireland (n=20) provided information on the trigger foods associated with their condition.

The top five most reported food allergies among the adults with MDFA in Ireland and Northern Ireland (n=20) were: other nuts (n=11), peanuts (n=9), milk (n=3), fruits (n=3) and cereals containing gluten (n=2) (Figure 5.1.1a). Additional FI were also reported (n=10, 50%) by the adult participants (Figure 5.1.1c).

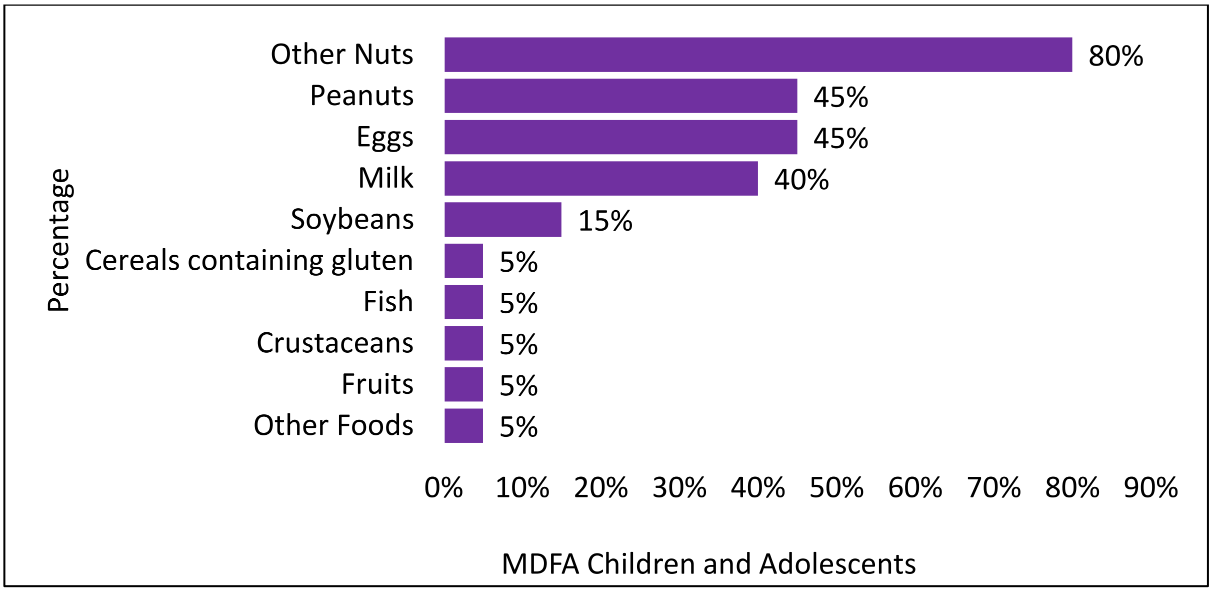
Figure 5.1.1a: Trigger foods indicated by adults with MDFA* in Ireland and Northern Ireland (n=20)



*Number of adults who reported MDFA to these foodstuffs: Other Nuts = 11 individuals; Peanuts = 9 individuals; Milk = 3 individuals; Fruits = 3 individuals; Cereals containing gluten = 2 individuals; Crustaceans = 2 individuals; Sesame seeds = 1 individual; Fish = 1 individual; Other foods = 1 individual. Breakdown of MDFA to: Other nuts= Nuts (unspecified) (n=9), Cashew nuts (n=1), Pine nuts (n=1); Fruits = Kiwi (n=2) and Strawberries (n=1); Cereals containing gluten = Wheat (n=2); Other foods = Grass seeds (n=1).

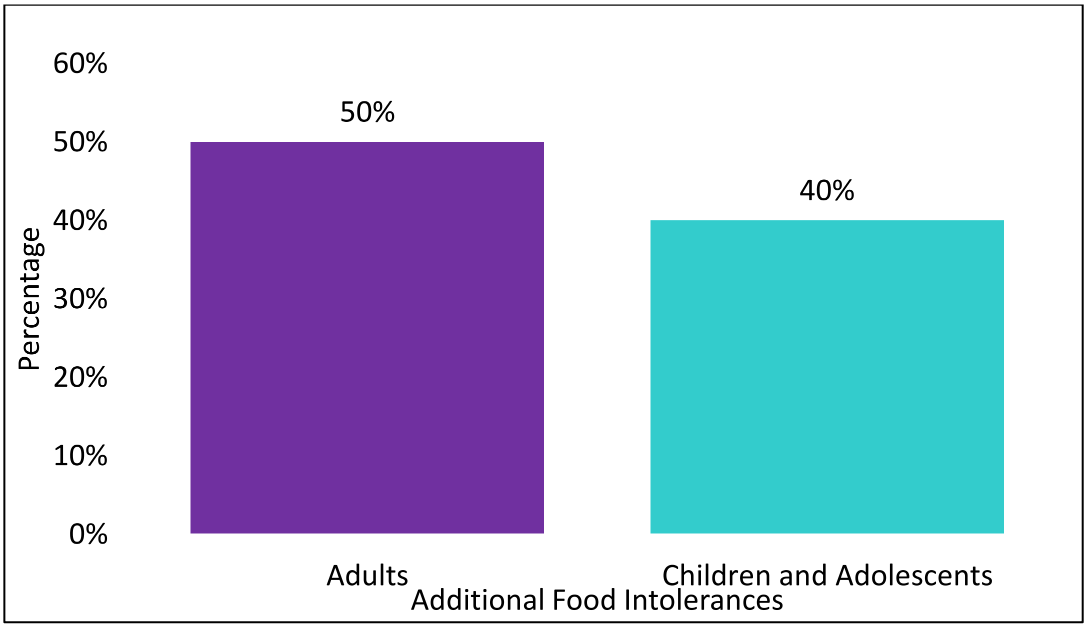
The top five most reported food allergies among the children/adolescents with MDFA in Ireland and Northern Ireland (n=20) were other nuts (n=16), peanuts (n=9), eggs (n=9), milk (n=8) and soya beans (n=3) (Figure 5.1.1b). Additional FI were reported (n=8, 40%) for children/adolescents (Figure 5.1.1c).

Figure 5.1.1b: Trigger foods indicated for children/adolescents with MDFA* in Ireland and Northern Ireland (n=20)



*Number of parents who reported their child's/adolescent's MFDA to these foodstuffs: Other nuts = 16 individuals; Peanuts = 9 individuals; Eggs = 9 individuals; Milk = 8 individuals; Soybeans = 3 individuals; Cereals containing gluten = 1 individual; Fish = 1 individual; Crustaceans = 1 individual; Fruits = 1 individual; Other foods = 1 individual. Breakdown of MDFA to: Other nuts = Nuts (unspecified) (n=11), Hazelnuts (n=2), Macadamia nuts (n=1), Walnuts (n=1), Pecan nuts (n=1); Cereals containing gluten = Wheat (n=1); Fruits = Kiwi (n=1); Other foods = Rice (n=1).

Figure 5.1.1c: Additional FI indicated by adults* (n=20) and parents of children/adolescents (n=20) with MDFA in Ireland and Northern Ireland.



* Number of adults who reported additional FI to these foodstuffs: Other nuts = 2 individuals; Milk = 1 individual; Cereals containing gluten = 2 individuals; Fish = 1 individual; Soybeans = 1 individual; Molluscs = 1 individual; Fruits = 1 individual; Other foods = 4 individuals.

**Breakdown of additional FI to: Other nuts = Nuts (unspecified) (n=2); Fruits = Lemon (n=1); Other foods = Meat (n=2); Legumes (n=1); Peas (n=1); Oats (n=1); Food additives (n=1).

[x] Number of parents who reported their child's/adolescent's additional FI to these foodstuffs: Eggs = 3 individuals; Milk = 1 individual; Fish = 1 individual; Cereals containing gluten = 1 individual; Fruits = 2 individuals; Other foods = 2 individuals. [xx]Breakdown of additional FI to: Fruits = Oranges (n=1); Apricots (n=1); Berries (n=1); Other foods = Beans (n=1); Food additives (n=2).

5.2.1 Priority setting interview ranking for adults and parents of children/adolescents with MDFA in Ireland

Adults and parents of children/adolescents with MDFA interviewed in Ireland (n=20) were requested to rank each of the issues discussed in order of priority, with 1 being the most important issue and 8 being the least important. Similarly, they were asked to rank which issues were easiest to resolve, with 1 being the easiest to resolve and 8 being the most difficult.

Table 5.2.1: Priority setting interviews ranking by adults and parents of children/adolescents with MDFA in Ireland (n=20) of issues of importance (1-8, most to least) and how easy they perceived these issues to resolve (1-8, easiest to most difficult)

Priority rank	**Eight issues considered: Adults with MDFA (n=10) in Ireland**	**Ease of resolution**
1	Public and food industry awareness and understanding of your (or your child's) condition	**3**
2	Accessing medical teams, e.g., consultants, specialist nurses etc., to treat your (or your child's) condition	**4**
3	Adrenaline auto-injector to be available in all public spaces in case of emergency (similar to automated external defibrillator, AED)	**5**
4	Cost and availability of medication and supplements to treat your (or your child's) condition	**1**
5	Awareness and training regarding your (or your child's) condition in an educational setting	**2**
6	Dietetic support for your (or your child's) condition	**7**
7	Counselling/psychological services for those affected and their families	**8**
8	Recognition of your (or your child's) condition as a 'disability'	**6**
Priority Rank	**Eight issues considered: Parents of Children/Adolescents with MDFA (n=10) in Ireland**	**Ease of resolution**
1	Public and food industry awareness and understanding of your (or your child's) condition	**2**
2	Accessing medical teams, e.g., consultants, specialist nurses etc., to treat your (or your child's) condition	**6**
3	Adrenaline auto-injector to be available in all public spaces in case of emergency (similar to automated external defibrillator, AED)	**4**
4	Awareness and training regarding your (or your child's) condition in an educational setting	**1**
5	Counselling/psychological services for those affected and their families	**8**
6	Cost and availability of medication and supplements to treat your (or your child's) condition	**5**
7	Dietetic support for your (or your child's) condition	**3**
8	Recognition of your (or your child's) condition as a 'disability'	**7**

5.2.2 Priority setting interview ranking for adults and parents of children/adolescents with MDCD in Ireland

Adults and parents of children/adolescents with MDCD interviewed in Ireland (n=20) were requested to rank each of the issues discussed in order of priority, with 1 being the most important issue and 8 being the least important. Similarly, they were asked to rank which issues were easiest to resolve, with 1 being the easiest to resolve and 8 being the most difficult.

Table 5.2.2: Priority setting interviews ranking by adults and parents of children/adolescents with MDCD in Ireland (n=20) of issues of importance (1-7, most to least) and how easy they perceived these issues to resolve (1-7, easiest to most difficult)

Priority Rank	**Seven issues considered: Adults with MDCD (n=10) in Ireland**	**Ease of resolution**
1	Public and food industry awareness and understanding of your (or your child's) condition	1
2	Accessing medical teams, e.g., consultants, specialist nurses etc., to treat your (or your child's) condition	7
3	Cost and availability of medication and supplements to treat your (or your child's) condition	3
4	Dietetic support for your (or your child's) condition	6
5	Awareness and training regarding your (or your child's) condition in an educational setting	2
6	Counselling/psychological services for those affected and their families	5
7	Recognition of your (or your child's) condition as a 'disability'	4
Priority Rank	**Seven issues considered: Parents of Children/Adolescents with MDCD (n=10) in Ireland**	**Ease of resolution**
1	Public and food industry awareness and understanding of your (or your child's) condition	6
2	Accessing medical teams, e.g., consultants, specialist nurses etc., to treat your (or your child's) condition	4
3	Dietetic support for your (or your child's) condition	2
4	Awareness and training regarding your (or your child's) condition in an educational setting	1
5	Counselling/psychological services for individuals affected and their families	3
6	Cost and availability of medication and supplements to treat your (or your child's) condition	5
7	Recognition of your (or your child's) condition as a 'disability'	7

Table 5.2.3: Summary of priority setting interview findings for Irish adults with MDFA ($n \leq 10$)

	KEY ISSUES	**PROPOSED STRATEGIES**
PRIORITY 1: **Public and food industry awareness and understanding of your condition**	**Opinions were obtained from 10 participants:** • 80% (n=8) were not confident about awareness and understanding of food allergy within the restaurant/catering sector. Although participants noted that some establishments are highly reliable (e.g., franchise restaurants were mentioned by one participant), they were concerned about the inability of staff in other establishments to answer questions on food allergens and guarantee that a meal is allergen free. Consequently, people with food allergies adopt a cautionary approach to dining out, i.e., they only consume trusted meals in trusted establishments. • 60% (n=6) of participants mentioned their concern regarding cross-contamination. Although pre-packed foods are seen by many people with food allergies as a safer option, 40% (n=4) raised issues regarding labelling (e.g., inaccurate/unclear labelling and overuse of the precautionary wording 'may contain ….'). One participant noted that it can take several hours to complete food shopping because of the time required to read labels. • 60% (n=6) suggested that awareness of food allergy is poor amongst the public.	**Strategies were proposed by 10 participants:** • 70% (n=7) proposed improved education and training (i.e., professional training, work-place training). • 60% (n=6) proposed more public awareness campaigns (using traditional and social media channels). • 20% (n=2) proposed stricter controls in food establishments (e.g., avoidance of cross contamination).

PRIORITY 2: **Accessing medical teams, e.g. consultants, specialist nurses etc., to treat your condition**	**Opinions were obtained from 10 participants:** • 80% (n=8) referred to difficulty accessing appointments with specialists/consultants. • Participants noted that GPs are not equipped to diagnose food allergies and thus referral to a specialist/consultant is required. One participant waited nine months to see a specialist/consultant. Another took part in a medical research trial in the UK, thereby avoiding the Irish waiting lists. • 20% (n=2) had a positive experience in terms of medical access.	**Strategies were proposed by nine participants (one respondent did not propose any strategies):** • 77% (n=7) proposed greater access to medical support for both initial and follow-up appointments, where possible. Additional proposals from participants included: more engagement from GP with regard to care, understanding and management of their condition, where possible. • 11% (n=1) suggested the establishment of a helpline for newly diagnosed patients.
PRIORITY 3: **Adrenaline auto-injector to be available in all public spaces in case of emergency (similar to automated external defibrillator, AED)**	**Opinions were obtained from 10 participants:** • 70% (n=7) agreed that adrenaline auto-injectors should be available in all public places. • 10% (n=1) stated that adrenaline auto-injectors should be available in schools only and not other public places.	**Strategies were proposed by nine participants (one respondent did not propose any strategies):** • 55% (n=5) stated that adrenaline auto-injectors should be in public places such as shopping centres, premises serving food and on public transport. • 11% of participants (n=1) stated that adrenaline auto-injectors should be in First Aid boxes, with their location identifiable through a service such as Google Maps. • 33% (n=3) suggested that training should be provided (to the public) on the administration of adrenaline auto-injectors.

PRIORITY 4: **Cost and availability of medication & supplements to treat your condition**	**Opinions were obtained from 10 participants:**	**Strategies were proposed by nine participants (one respondent did not propose any strategies):**
	• 60% (n=6) commented on the high cost of adrenaline auto-injectors and other medications for the treatment of food allergies. • 60% (n=6) suggested that this was compounded by the short shelf-life of adrenaline auto-injectors, which need to be replaced frequently, thereby increasing the cost. • 50% (n=5) noted that the cost of adrenaline auto-injectors and other medications such as inhalers and antihistamines are covered under the Drug Payment Scheme/Medical Card Scheme. Participants were very appreciative of these schemes. • 30% (n=3) commented on the high cost of 'free-from …' foods in supermarkets compared to conventional foods.	• 77% (n=7) proposed additional financial support to reduce the cost of medication for people with a food allergy. In particular, many felt that adrenaline auto-injectors should be available free of charge. • 22% (n=2) proposed strategies to address the short shelf-life of adrenaline auto-injectors. These included: ○ Manufacturers to consider reformulation to extend shelf-life (e.g., preservative content). ○ Medical Board to undertake market review of adrenaline auto-injector shelf-life in other countries and to utilise this information for the Irish market. ○ Pharmacies to establish an alert system to identify when an adrenaline auto-injector is approaching the end of its shelf-life (this will assist timely re-ordering). • 22% (n=2) of participants proposed price controls on 'free-from ….' foods.

PRIORITY 5: **Awareness and training regarding your condition in an educational setting**	**Responses were obtained from eight participants regarding second level schools (two respondents did not specify any issues):** • 62% (n=5) commented that food allergy awareness was poor, and that policies and procedures were not strict enough to deal with food allergens within school environments. In addition, these participants highlighted that teachers and educators are not trained in this regard, and may not even be aware of the location of an adrenaline auto-injector in a school. • 37% (n=3) advised that schools had good awareness and management of allergies. In one school, allergy forms were provided to parents at the beginning of each year to collate information on food allergies. However, this information was often not shared or reviewed by new teachers and substitute teachers within these schools. **Responses were obtained from three participants regarding third level institutes:** • 66% (n=2) advised of poor food allergy awareness (e.g., leaflets/posters for students and educators), policies or training.	**Strategies were proposed by six participants for primary level (four respondents did not propose any strategies):** • 50% (n=3) proposed greater awareness and information campaigns on food allergies (e.g., training, leaflets, posters) for inclusion in an educational setting. These should be directed at parents, students and teachers who aren't affected by food hypersensitivity. • 50% (n=3) proposed stricter policies and procedures within schools, and that ideally all staff should complete food allergen training (including training on adrenaline auto-injector administration). All new teachers and substitute teachers should be aware of children in their class with food allergies (in particular those carrying adrenaline auto-injectors). Parents should be informed of allergens which are not permitted within the school and the school menu should be shared in advance with parents. • 17% (n=1) proposed greater availability and range of allergen-free foods in school canteens.

	• 33% (n=1) highlighted the lack of an ‘allergen-free zone’ to allow students to eat in a safe environment. On a more positive note, one participant commented on a recent visit to a university where food allergen leaflets were available and a ‘nut ban’ policy in place.	**Strategies were proposed by three participants for third level institutes:** • 66% (n=2) proposed stricter policies and procedures on the prohibition of eating in lecture halls. • 33% (n=1) proposed greater awareness within the educational setting of allergen-free zones.
PRIORITY 6: **Dietetic support for your condition**	**Opinions were obtained from 10 participants:** Information, knowledge and support from dietician post-diagnosis • 60% (n=6) were not referred to a dietitian. • 20% (n=2) specifically stated that were referred to a dietitian. Mixed feedback was provided on the supports obtained. • For the remaining 20% (n=2) of participants, it was not clear if they were/were not referred to a dietitian. Support on suitable foods and brands • 30% (n=3) commented on the support provided: ○ Two participants received literature (leaflets/books) on food allergens. Another participant noted that the advice provided was not child-friendly.	**Strategies were proposed by nine participants (one respondent did not propose any strategies):** • 100% (n=9) proposed that adults with medically diagnosed food allergies should, ideally, have immediate access to a dietitian post-diagnosis. One participant noted that group sessions with a dietitian should be considered if individual appointments are not possible. • 33% (n=3) proposed improved resources. Relevant topics included information on food allergies, diet plans and recipes. Resources should also be developed specifically for children.

PRIORITY 7: **Counselling/psychological services for those affected and their families**	**Opinions were obtained from 10 participants:** - 100% (n=10) believe access to these services are important. Some participants noted that a food allergy diagnosis is a life-changing event which is stressful not only for the patient but also for their family and possibly even friends. This stress may be exacerbated by long waiting lists for appointments with allergy specialists. A number of participants noted that access to counselling/psychological services should be made available immediately after diagnosis. - 20% (n=2) commented on existing services for those with food allergies. One participant noted that many support groups exist in the community. Another participant raised concern over online support groups because they are not supported by the medical community.	**Strategies were proposed by nine participants (one respondent did not propose any strategies):** - 100% (n=9) proposed that access to counselling/psychological services should be made available as soon as possible after diagnosis. - 11% (n=1) proposed that group counselling sessions should be available if private individual sessions are not feasible. - 11% (n=1) proposed the establishment of a helpline.
PRIORITY 8: **Recognition of condition as a 'disability'?**	**Opinions were obtained from 10 participants:** - 50% (n=5) were 'unsure'. One participant stated that recognition as a disability could depend on the severity of the condition. - 30% (n=3) agree. Key points of rationale: (i) a medically diagnosed food allergy is a life-changing event; (ii) allergies, such as nut allergies, negatively impact employment prospects; and (iii) although a	**Strategies were proposed by four participants (six respondents did not propose any strategies):** - 25% (n=1) suggested recognition of food allergies as a disability (due to its life-changing nature). - 75% (n=3) suggested more education and awareness campaigns to improve understanding of food allergies in all settings, combined with greater availability

	medically diagnosed allergy is not a ‘physical disability’, it is a ‘body malfunction’. - 20% (n=2) disagree. Key points of rationale: (i) recognition of a food allergy condition as a disability would undermine conditions that are more serious; and (ii) it is a manageable condition (however, the participant acknowledged that the severity varies per individual).	of gluten-free food as an alternative to disability status.

Table 5.2.4: Summary of priority setting interview finding for Irish parents of children/adolescents with MDFA $(n \leq 10)$

	Key issues	**Proposed strategies**
PRIORITY 1: **Public and food industry awareness and understanding of your condition**	**Opinions were obtained from 10 participants:** • 100% (n=10) commented on food industry awareness of allergies ○ 60% (n=6) were not confident about awareness and understanding of food allergy within the food industry (including the restaurant/catering sector). ○ 50% (n=5) noted that awareness and understanding of food allergy within the food industry has improved over the years. ○ 30% (n=3) stated that they adopt a cautionary approach to dining out, i.e., they only consume trusted meals in certain establishments. • 60% (n=6) raised concern over the provision of allergen information on food labels and food menus. Key concerns included over-use of precautionary ‘may contain’ statements/labels on labels of pre-packed foods (this protects the manufacturer but limits consumer choice); no precautionary information on food menus (this gives a false sense of security to	**Strategies were proposed by 10 participants:** • 70% (n=7) proposed more public awareness campaigns. • 60% (n=6) proposed improved education and training for the food industry. • 10% (n=1) proposed the implementation of policies in schools to prohibit students from bringing allergens to school (i.e., to reduce the risk of cross-contamination for those with food allergy). • 10% (n=1) proposed that allergen information should be an integral part of the online shopping experience and customers should have the ability to filter products based on presence/absence of food allergens.

	consumers); and a lack of specificity for some allergens (e.g., nut species). • 50% (n=5) raised concerns over cross-contamination. Of these, 40% (n=4) stated that they only purchase pre-packed foods. • 30% (n=3) commented on public awareness of food allergies and suggested that this was sometimes poor.	
PRIORITY 2: **Accessing medical teams e.g. consultants, specialist nurses etc. to treat your condition**	**Opinions were obtained from 10 participants:** • 100% (n=10) referred to challenges accessing specialists/consultants, i.e., often lengthy waiting lists. Private appointments were noted as more rapid but were associated with additional costs.	**Strategies were proposed by 10 participants:** • 90% (n=9) focused on greater access to medical specialists and treatment. Proposals included: ○ Ideally, more expedited access to a specialist post-diagnosis. ○ From this perspective, it was suggested more specialists should be provided where possible. ○ A query regarding outsourcing of tests, if necessary (and if capacity is not available to conduct tests on-site). • 10% (n=1) proposed better education and support for parents.

PRIORITY 3: **Adrenaline auto-injector to be available in all public spaces in case of emergency (similar to automated external defibrillator, AED)**	**Opinions were obtained from 10 participants:** • 100% (n=10) supported the concept of availability of adrenaline auto-injectors in public spaces. However, 30% (n=3) provided caveats: ○ Adrenaline auto-injectors should only be available in specific locations (i.e., strategic locations, such as those not easily accessible to the ambulance services) and people with a food allergy should be made aware of these locations. ○ Another agreed but suggested that it may not be practicable to provide adrenaline auto-injectors in all public locations because stolen and expired adrenaline auto-injectors would need to be replaced. ○ It was also noted that the availability of adrenaline auto-injectors in all public locations could possibly discourage people with food allergy from carrying their own auto-injector.	**Strategies were proposed by five participants (five respondents did not propose any strategies):** • 40% (n=2) stated that adrenaline auto-injectors should be located in public spaces, premises serving food and in designated locations (i.e., within 50 meters of premises serving food). One of these participants stated that adrenaline auto-injector locations should be made available to the public. • 40% (n=2) suggested that awareness and training on the administration of adrenaline auto-injectors should increase.
PRIORITY 4:	**Opinions were obtained from 10 participants:**	**Strategies were proposed by 10 participants:** • 80% (n=8) focused on the need for greater awareness and training on food allergies for

Awareness and training regarding your condition in an educational setting	Parents of children/adolescents attending primary school advised of mixed experiences in relation to awareness of food allergies in school. • 60% (n=6) reported poor allergen management and lack of awareness of food allergies in the classroom from teachers and other students. In one case the parent reported that when the teacher brings in treats, they do not always check if they are nut-free, so the child with allergies is left out. Three participants felt that the obligation was on parents to educate teachers about food allergies and the administration of adrenaline auto-injectors. One of these participants noted that parents meet with the school annually to discuss changes to medication, allergy plans and training of staff on how to use the different types of adrenaline auto-injectors. • 30% (n=3) reported positive experiences such as good awareness, procedures and enforcement of a 'nut-free' policy in schools (e.g., one school requiring a medical form to be completed at the start of entry into the school and for school trips).	both staff and students. Topics included food allergy management, symptoms of food allergies and anaphylaxis, what to do in the case of emergency, how to administer an adrenaline auto-injector and the link between allergies and other conditions (such as asthma and eczema). One participant proposed that anaphylaxis training should be provided by the government (rather than charities or informal groups/networks). The importance of practical and engaging training was highlighted (e.g., real-life stories, colourful posters, videos etc). • 60% (n=6) focused on food allergy policies, procedures and guidelines within schools. Three participants highlighted that direction on the management of food allergies in educational settings should come from the Department of Education. Other actions were proposed by several participants. These included: distribution of the school allergy policy and canteen menus to all parents;

		clear labelling of allergens in the canteen; school to be provided with an annual update of each child's allergy medication; teachers to take greater responsibility for food allergies; and a dedicated allergy nurse to be assigned to a number of schools/region.
PRIORITY 5: Counselling/psychological services for those affected and their families	**Opinions were obtained from 10 participants:** • 100% (n=10) noted the importance of the availability of these services, particularly for older children as they become more aware of their allergy and its management. Specific comments were raised around the psychological distress caused by anaphylaxis and the use of adrenaline auto-injectors. • 60% (n=6) stated that they have not accessed or are not aware of existing counselling/psychological services for children/adolescents with medically diagnosed food allergies.	**Strategies were proposed by six participants (four respondents did not propose any strategies):** • 100% (n=6) proposed that counselling/psychological services should be available to children/adolescents with medically diagnosed food allergies. These services should be available when the child is diagnosed, when the child starts school, and after an anaphylaxis incident. • 16.6% (n=1) proposed support groups on social media or support systems from schools to help manage and get information about their condition.

PRIORITY 6: **Cost and availability of medication & supplements to treat your condition**	**Opinions were obtained from 10 participants:** • 90% (n=9) focused on the cost of products and the supports currently available via the Drug Payment Scheme/Medical Card Scheme. Whilst there was a consensus that these schemes are extremely helpful, four participants noted that certain products (e.g., liquid antihistamines, eczema creams, food supplements) are not covered under one or both of these schemes and this has a significant financial impact for the families affected. • 40% (n=4) focused on the short shelf-life of adrenaline auto-injectors. The financial impact on families was discussed (as adrenaline auto-injectors need to be replenished frequently). • 40% (n=4) focused on 'free-from' foods for those with food allergy. It was acknowledged that many foods available in the supermarket do not contain allergens; however, an additional cost is associated with foods specifically labelled as 'free-from'. It was noted that tax credits are available for coeliacs for the purchase of 'gluten-free' foods and that similar supports should be available for those with food allergies as well.	**Strategies were proposed by nine participants (one respondent did not propose any strategies):** • 88% (n=8) focused on the need for greater financial support for the purchase of medication and allergen-free foods. It was suggested that: (i) adrenaline auto-injectors should be provided free of charge (because they are a life-saving product); (ii) products such as antihistamines and skin allergy creams should be available on the DPS; (iii) tax credits should be available for the purchase of 'free-from ….' Foods; and (iv) long-term illness cards should be issued for individuals with medically diagnosed food allergies. • 33% (n=3) focused on issues relating to the availability of adrenaline auto-injectors. It was noted that: (i) similar brands should be available across all pharmacies; (ii) adrenaline auto-injectors should be available in public places in case of emergency; and (iii) efforts should be made to increase the

		shelf-life of adrenaline auto-injectors, if possible
PRIORITY 7: **Dietetic support for your condition**	**Opinions were obtained from nine participants (one respondent did not specify any issues):** Information, knowledge and support from dietician post-diagnosis: • 44% (n=4) stated that their child had no access to a dietitian. • 55% (n=5) stated that their child had access to a dietitian, but mixed views were expressed on the service provided, with two participants suggesting that the advice was minimal. Support on suitable foods and brands: • 20% (n=2) commented positively on the supports available regarding suitable foods and brands. Both participants received information; however, one participant claimed that minimal information was provided on 'living with food allergies'.	**Strategies were proposed by 10 participants.** • 70% (n=7) proposed that children/adolescents with a medically diagnosed food allergy should have improved access to a dietitian. Immediate access to a dietitian post-diagnosis and regular follow-up appointments were deemed important. • 40% (n=4) of participants specifically mentioned a need for additional information and resources. Relevant topics include food allergy management, understanding food labels (particularly regarding the listing of nuts) and information on the appropriate intake of vitamins and minerals.
PRIORITY 8: **Recognition of condition as a 'disability'?**	**Opinions were obtained from 10 participants:** • 40% (n=4) agreed. It was noted that recognition of medically diagnosed food allergies as a disability may be beneficial for advocacy purposes, i.e., to highlight	**Strategies were proposed by four participants (six respondents did not propose any strategies):** • 100% (n=4) agreed that MFDA should be considered a disability.

	the condition and influence strict protocols in public/educational/food industry settings. • 40% (n=4) disagreed. It was noted that carers are not required for this condition. However, it was also reported that financial support would be beneficial for the purchase of 'free-from' foods). • 20% (n=2) were 'unsure'. However, they noted that recognition might help to: (i) provide financial support for individuals with anaphylaxis, and (ii) remove the label of 'fussy eater' from children with medically diagnosed allergies.	• 75% (n=3) suggested that and increased focus on education and an awareness of food allergies should be also be considered.

Table 5.2.5: Summary of priority setting interview findings for **Irish adults** with **MDCD** ($n \leq 10$)

	KEY ISSUES	PROPOSED STRATEGIES
PRIORITY 1:	**Opinions were provided by 10 participants:** • 80% (n=8) commented on food industry awareness of coeliac disease. Regarding the restaurant/catering sector, establishments with poor knowledge of coeliac disease and gluten-free foods are not trusted. Participants noted that within establishments, staff vary in their understanding (i.e., waiting staff typically have a poorer understanding compared to chefs). The importance of accurate and effective communication from customers to waiting staff to chefs (and vice versa) was stressed. One participant noted that whilst some restaurants offer good and safe places to eat, others instil a feeling of embarrassment when the a coeliac requests specific information. • 70% (n=7) commented on public awareness of coeliac disease. There was a consensus that the public are aware of this disease; however, it was suggested that there was poor accuracy in their understanding. Some see it is a 'dietary fad', 'healthy option' or 'lifestyle choice'. • 60% (n=6) raised concern over cross-contamination and the majority have a preference for pre-packed foods (as the risk of cross-contamination is perceived to be lower than with loose foods).	**Strategies were proposed by 10 participants:** • 90% (n=9) proposed improved education and training for the food industry. • 40% (n=4) proposed improvements in the provision of accurate information on the gluten status of foods (i.e., on menus, clearer food labelling, in-store etc.). • 30% (n=3) proposed more public awareness campaigns. • 20% (n=2) proposed improvements in the availability of gluten-free foods. • 10% (n=1) proposed the use of technology (e.g., apps) to improve communication between waiting staff and chefs.

PRIORITY 2:	**Opinions were obtained from 10 participants:**	**Strategies were proposed by nine participants (one respondent did not propose any strategies):**
	- 40% (n=4) noted poor access to medical teams. Participants stated that public patients encounter lengthy delays in securing initial appointments with specialists/consultants (one participant waited 2.5 years for an appointment). Challenges are also encountered with follow-up appointments. - 30% (n=3) seemed content with their access to medical teams. One participant had urgent symptoms, and this expedited their initial appointment. - 20% (n=2) specifically stated that they progressed with private appointments and were happy with the overall process. - 10% (n=1) referred to lack of information on coeliac disease and its management.	- 55% (n=5) proposed greater access to medical teams. - 44% (n=4) proposed education and information strategies to improve awareness of coeliac disease and its symptoms. Two participants specifically mentioned that a more proactive approach to screening for this disease (via blood tests) should be considered.
	Opinions were obtained from 10 participants: - 90% (n=9) mentioned the high cost of products (e.g., gluten-free foods, food supplements) required by coeliacs. This can place a significant financial burden on families. One participant reporting bulk purchasing vitamins to make them affordable (e.g., availing of 3 for 2 offers). - 20% (n=2) commented on the process for claiming tax relief on medical expenses. Both participants noted that this process was cumbersome and is not optimal.	**Strategies were proposed by eight participants (two respondents did not propose any strategies):** - 100% (n=8) proposed additional financial support for those with medically diagnosed coeliac disease. These included: (i) availability of gluten-free food products on prescription to enable reimbursement; (ii) a flat tax rebate for the purchase of gluten-free products/food supplements; (iii) free medical tests (e.g., routine check-ups, routine screening and blood tests) for individuals on lower incomes.

	- 10% (n=1) commented on challenges sourcing gluten-free medications.	- 12% (n=1) proposed clearer labelling of medications to declare its gluten status (i.e., contains gluten/gluten-free).
	Opinions were obtained from 10 participants: Information, knowledge and support from dietician post-diagnosis All ten participants commented on the information, knowledge and support from dietitians post-diagnosis. The following are the key points:- - 60% (n=6) had access to a dietitian at some stage. The situation was unclear for the remaining 40% (n=4) of participants. - 60% (n=6) mentioned the importance of access to a dietitian at the time of diagnosis. - 20% (n=2) noted that they had to 'push hard' for both initial and follow-up appointments. - 20% (n=2) noted that the information provided by dietitians is very generic. One of these participants reported that although this information is good for the initial appointment, more specific information is required for follow-up appointments. - 20% (n=2) suggested that self-education is necessary. Support on suitable foods and brands	**Strategies were proposed by 10 participants:** - 100% (n=10) proposed that adults with coeliac disease should have access to a dietitian. Immediate access post-diagnosis was identified as important by the majority of participants, to ensure coeliacs learn more about the disease and its management. - 50% (n=5) proposed greater availability of information and resources. Relevant topics include support on coeliac disease, complications associated with coeliac disease, list of gluten-free foods, gluten-free recipes, dietary advice on the nutrients list and measures to avoid cross-contamination.

	Three out of ten participants (30%) commented on the support provided regarding suitable foods and brands: • One participant was complimentary about the resources provided by the Coeliac Society of Ireland. • Another interviewee stated that the dietitian provided support on understanding/reading food labels and the identification of the gluten status of foods.	
	Opinions were provided by eight participants (two respondents did not specify any issues): • 87% (n=7) advised of poor awareness, with many taking responsibility for bringing their own food to the school or university each day. The interviewees commented that food handlers within the canteens of these educational settings lacked awareness of coeliac disease, of the difference between gluten-intolerant and coeliac disease, and an awareness of gluten-free requirements. It was noted that schools seem to be more aware of food allergies compared to coeliac disease. This includes a lack of knowledge and awareness about coeliac disease itself, its severity, and the high risks of potential cross-contamination of gluten during food preparation and serving. In some cases, participants advised that while the mandatory listing of food allergens is provided, participants do not eat food provided by the canteen due to the fear of foods being labelled incorrectly.	**Strategies were proposed by eight participants (two respondents did not propose any strategies):** • 75% (n=6) focused on the need for greater awareness of coeliac disease by the public and within the educational systems (i.e., staff, students and parents). Awareness campaigns should be delivered via social media and traditional media routes (posters, TV adverts, etc). Regarding the educational system, it was proposed that education on coeliac disease and food allergies should form part of the primary school curriculum. One participant proposed campaigns specifically for food handlers, highlighting the impact of cross-contamination. • 37% (n=3) proposed greater availability of gluten-free options.

	• One participant noted that gluten-free food and meals for coeliacs were not provided at school events and meetings, indicating the lack of recognition of the disease by organisers. • With regard to work settings, one participant indicated the need to explain the seriousness of coeliac disease to co- workers and the risks of cross-contamination, e.g., why the same toaster could not be used by a person with coeliac disease.	• 12% (n=1) proposed greater availability of allergy-free zones for people with food allergies/sensitivities.
	Opinions were obtained from nine participants (one respondent did not specify any issues): • 55% (n=5) stated that counselling/psychological services are either 'not necessary for everyone' or 'are not for them'. One of these participants expressed concern about attending such services and suggested that there is a social stigma associated with a gluten-free diet. • 22% (n=2) stated that they have not attended or are not aware of any existing counselling/psychological services for adults with coeliac disease. • 11% (n=1) currently attends a local support group and has benefited greatly from this. • 11% (n=1) spoke about the psychological problems when first diagnosed.	**Strategies were proposed by seven participants (three respondents did not propose any strategies):** • 100% (n=7) proposed that access to counselling/psychological services should be available to people that need them. Ideally, relevant contact details would be provided at the time of diagnosis.

	Opinions were obtained from nine participants (one respondent did not specify any issues): • 56% (n=5) disagree. Key points of rationale: (i) coeliac disease is manageable and does not impact a person's life in the same way as a physical disability; and (ii) its recognition as a medical condition/auto-immune condition would be more accurate. • 22% (n=2) agree. Key points of rationale: (i) the disease has long-term health and socio-economic impacts (e.g., diagnosis may negatively impact employment prospects); and (ii) the disease is particularly challenging during flare-ups. • 22% (n=2) were ‘unsure’. Key points of rationale: (i) recognition of coeliac disease as a disability should depend on the severity of the illness; (ii) the disease is manageable, even though difficulties are encountered when first diagnosed; and (iii) there are social challenges (e.g., lack of toilet facilities). • 11% (n=1) said that it should be recognised as an auto-immune disease.	**Strategies were proposed by three participants (seven respondents did not propose any strategies):** • 66% (n=2) stated that education and awareness campaigns that recognise the impact (health, social, emotional) of coeliac disease should be considered. • 33% (n=1) suggested that ideally there should be easier access, once diagnosed, to support services such as medical cards.

Table 5.2.6: Summary of priority setting interview findings for Irish parents of children/adolescents with MDCD ($n \leq 10$)

	KEY ISSUES	PROPOSED STRATEGIES
PRIORITY 1: **Public and food industry awareness and understanding of your condition**	**Opinions were provided by 10 participants:** • 90% (n=9) commented on food industry awareness of coeliac disease. Regarding restaurants and catering establishments, mixed views were expressed (some establishments are good, some are poor, and some are improving). Two participants noted that they only eat in trusted restaurants and another two participants noted that if going to a new restaurant, they would always check in advance about the availability of gluten-free food. Regarding the broader food sector, two participants noted that the availability of gluten-free food has increased in supermarkets; however, one participant noted a lack of availability at sporting and other outdoor events. • 60% (n=6) identified cross-contamination as a major concern. Two participants noted that fruit and vegetables are the only loose food (i.e., non-pre-packed) they will purchase. A number of participants mentioned poor practices by the food sector, e.g., the removal of	**Strategies were proposed by eight participants (two respondents did not propose any strategies):** • 50% (n=4) proposed greater education and awareness of coeliac disease within the food sector. • 37% (n=3) proposed stricter measures within establishments to ensure no cross-contamination. • 25% (n=2) focused on greater availability of gluten-free foods. • 25% (n=2) proposed better labelling to identify all foods that do not contain gluten, and the standardisation of this labelling.

	bread/grains from the plate of a coeliac child without any understanding of the risk of cross-contamination. • 50% (n=5) commented on public awareness of coeliac disease. The majority (n=4) stated that public awareness is very poor. Only one participant noted that awareness is higher in Ireland than in other countries. • 30% (n=3) commented on allergen labelling. One participant trusts food labelled as ‘gluten-free’, another participant would like to see precautionary labelling (‘may contain’ statements) become mandatory, while another participant stated that allergen labelling is not easy to access.	
PRIORITY 2: **Accessing medical teams, e.g., consultants, specialist nurses etc. to treat your condition**	**Opinions were obtained from 10 participants:** • 50% (n=5) indicated that their child had difficulties accessing medical teams. ○ One participant waited three years for an appointment with an immunologist to confirm diagnosis. Another participant referred to current delays on account of COVID-19. • 30% (n=3) noted no issues with access to medical teams.	**Strategies were proposed by seven participants (three respondents did not propose any strategies):** • 57% (n=4) proposed improved medical access for initial diagnosis and follow up appointments, if possible. • 28% (n=2) suggested they would like greater input from their GP regarding the management and treatment of the condition.

	• 20% (n=2) referred to a lack of expertise and collaboration between health care professionals. • 10% (n=1) of participants noted that they felt there was a lack of collaboration between health professionals when dealing with their child's condition.	14% (n=1) suggested that they would like treatment of coeliac disease to be personalised for each individual.
PRIORITY 3: **Dietetic support for your condition**	**Opinions were obtained from nine participants (one respondent did not specify any issues):** Information, knowledge and support from dietician post-diagnosis • 55% (n=5) stated that their child had access to a dietitian post-diagnosis. The consensus was generally positive regarding the initial appointment and the information provided. Regarding follow-up appointments, two participants noted that a third appointment was not necessary, as adequate information on management of the condition was obtained at that stage. • 44% (n=4) stated that their child had no access/poor access to a dietitian post-diagnosis. One participant noted that parents needed to 'push hard' to obtain dietetic support. Another participant noted that self-	**Strategies were proposed by 10 participants:** 100% (n=10) proposed that children/adolescents with coeliac disease should have access to a dietitian. Immediate access to a dietitian post-diagnosis would be preferable, and regular follow-up appointments were deemed important.

	education is essential (this participant was particularly concerned about the link between coeliac disease and eating disorders). Support on suitable foods and brands • 33% (n=3) commented on the support available regarding suitable foods and brands. Mixed views were expressed. Two participants received adequate information, whilst one participant claimed that the information provided was poor.	
PRIORITY 4: **Awareness and training regarding your condition in an educational setting**	**Opinions were provided by 10 participants:** • 90% (n=9) commented on awareness of coeliac disease within educational settings. ○ 66% (n=6) noted a lack of awareness and understanding within educational settings, i.e., the differences between food allergies, food intolerances and coeliac disease are not always understood. ○ 33% (n=3) noted a greater level of awareness. One participant noted that at pre-school level their child was provided with a specific plate (an easily	**Strategies were proposed by 10 participants:** • 100% (n=10) proposed greater education and awareness for school staff and students. Topics proposed include: greater understanding of foods containing gluten; impact of the disease (physical and social); risk management strategies (avoidance of cross-contamination); and labelling. Both the Coeliac Society of Ireland and the Department of Education were identified as

	identifiable coloured plate) for their own use only (to minimise the risk of cross-contamination). Others reported that if treats are provided by teachers, gluten-free treats are always provided. • 80% (n=8) commented on provisions available within educational settings for students with coeliac disease. In primary schools, many students bring their own lunch to school. Lack of canteen facilities appears to be a factor. In secondary schools, canteen facilities are more common; however, all canteens do not provide coeliac options. In schools where canteen facilities provide coeliac options, participants reported mixed standards. One participant noted an incident where their child was either served food containing (or cross-contaminated by) gluten. • 40% (n=4) commented on awareness amongst peers and parents of peers, and a general acceptance amongst peers of this condition. For instance, parents of peers were reported to be mindful of coeliac disease when organising parties or events at school. However, one participant noted that their child is often excluded from events as it could be considered troublesome to cater for a child with coeliac disease.	potential partners for this education and awareness. • 10% (n=1) proposed that food menus should clearly indicate the gluten-free status of foods. 10% (n=1) proposed that schools should be obliged to meet the dietary needs of students on school trips. Information on dietary requirements could be captured on the consent form used for the school trip.

PRIORITY 5: **Counselling/psychological services for those affected and their families**	**Opinions were obtained from 10 participants:** • 70% (n=7) noted that these services are particularly important for older children as they become more aware of their condition and its management but strive to 'fit in' with their peers. • 50% (n=5) stated that they have not accessed or are not aware of existing counselling/psychological services for children/adolescents with coeliac disease.	**Strategies were proposed by seven participants (three respondents did not propose any strategies):** 100% (n=7) proposed that counselling/psychological services should be available to children/adolescents with coeliac disease.
PRIORITY 6: **Cost and availability of medication & supplements to treat your condition**	**Opinions were obtained from 10 participants:** • 60% (n=6) focused on the cost of gluten-free foods. There was consensus that products positioned as 'gluten-free' are very expensive compared to their conventional counterparts (i.e., products not positioned as 'gluten-free'). However, it was noted that many conventional products do not contain gluten and are reasonably priced alternatives, when identified. • 30% (n=3) focused on the high cost of food supplements (Vitamin D) and/or probiotics. • 20% (n=2) noted difficulties sourcing gluten-free Vitamin D and medications.	**Strategies were proposed by eight participants (two respondents did not propose any strategies):** • 50% (n=4) focused on price controls for gluten-free foods. • 25% (n=2) focused on labelling of foods and medication, and suggested that, every product which does not contain gluten should be labelled as gluten-free. • 25% (n=2) focused on tax rebates. Rather than using a receipt-based system for tax rebates, the government should consider issuing a flat refund.

		• 12% (n=1) focused on packaging. Gluten-free foods are typically packaged in small quantities; larger pack sizes should be available (this would be helpful from both a cost and packaging perspective). • 12% (n=1) focused on further research to identify an effective treatment (or the possibility of a future cure) for coeliac disease.
PRIORITY 7: **Recognition of condition as a 'disability'?**	**Opinions were obtained from eight participants (two respondent did not specify any issues):** • 50% (n=4) disagreed with this idea. Participants noted that coeliac disease is a medical condition, not a disability. • 38% (n=3) were 'unsure'. One participant noted that this would depend on the definition of a disability, and suggested that coeliac disease can be managed by diet (and thus differs from other disabilities). • 12% (n=1) agreed. This participant noted that it would be a way to increase awareness of the disease.	**Strategies were proposed by two participants (eight respondents did not propose any strategies):** • One participant (n=1) agreed with the implementation of disability status for the condition. • Another participant (n=1) suggested instead that the focus should remain on government-driven support of improved standards in the food sector.

5.3.1 Priority setting interview ranking for adults and parents of children/adolescents with MDFA in Northern Ireland

Adults and parents of children/adolescents with MDFA interviewed in Northern Ireland (n=20) were requested to rank each of the issues discussed in order of priority, with 1 being the most important issue and 8 being the least important. Similarly, they were asked to rank which issues were easiest to resolve, with 1 being the easiest to resolve and 8 being the most difficult.

Table 5.3.1: Priority setting interviews ranking by adults and parents of children/adolescents with MDFA in Northern Ireland (n=20) of issues of importance (1-8, most to least) and how easy they perceived these issues to resolve (1-8, easiest to most difficult)

Priority Rank	**Eight issues considered: Northern Irish adults with MDFA (n=10)**	**Ease of resolution**
1	Public and food industry awareness and understanding of your (or your child's) condition	2
2	Accessing medical teams, e.g., consultants, specialist nurses etc. to treat your (or your child's) condition	7
3	Awareness and training regarding your (or your child's) condition in an educational setting	1
4	Adrenaline auto-injectors to be available in all public spaces in case of emergency (similar to automated external defibrillator, AED)	5
5	Cost and availability of medication and supplements to treat your (or your child's) condition	3
6	Dietetic support for your (or your child's) condition	8
7	Recognition of your (or your child's) condition as a 'disability'	4
8	Counselling/psychological services for those affected and their families	6
Priority Rank	**Eight issues considered: Northern Irish parents of children/adolescents with MDFA (n=10)**	**Ease of resolution**
1	Awareness and training regarding your (or your child's) condition in an educational setting	1
2	Accessing medical teams, e.g., consultants, specialist nurses etc. to treat your (or your child's) condition	5
3	Public and food industry awareness and understanding of your (or your child's) condition	2
4	Adrenaline auto-injectors to be available in all public spaces in case of emergency (similar to automated external defibrillator, AED)	6
5	Dietetic support for your (or your child's) condition	7
6	Counselling/psychological services for those affected and their families	8
7	Cost and availability of medication and supplements to treat your (or your child's) condition	3
8	Recognition of your (or your child's) condition as a 'disability'	4

* NMDFA - Medically Diagnosed Food Allergy

5.3.2 Priority setting interview ranking for adults and parents of children/adolescents with MDCD in Northern Ireland

Adults and parents of children/adolescents with MDCD interviewed in Northern Ireland (n=16) were requested to rank each of the issues discussed in order of priority, with 1 being the most important issue and 8 being the least important. Similarly, they were asked to rank which issues were easiest to resolve, with 1 being the easiest to resolve and 8 being the most difficult.

Table 5.3.2: Priority setting interviews ranking by adults and parents of children/adolescents with MDCD in Northern Ireland (n=16) of issues of importance (1-8, most to least) and how easy they perceived these issues to resolve (1-8, easiest to most difficult)

Priority Rank	**Seven issues considered: Northern Irish adults with MDCD (n=10)**	**Ease of resolution**
1	Public and food industry awareness and understanding of your (or your child's) condition	1
2	Accessing medical teams, e.g., consultants, specialist nurses etc. to treat your (or your child's) condition	7
3	Cost and availability of medication and supplements to treat your (or your child's) condition	3
4	Dietetic support for your (or your child's) condition	6
5	Awareness and training regarding your (or your child's) condition in an educational setting	2
6	Counselling/psychological services for those affected and their families	5
7	Recognition of your (or your child's) condition as a 'disability'	4
Priority Rank	**Seven issues considered: Northern Irish parents of children/ adolescents with MDCD (n=6)**	**Ease of resolution**
1	Public and food industry awareness and understanding of your (or your child's) condition	6
2	Accessing medical teams, e.g., consultants, specialist nurses etc. to treat your (or your child's) condition	4
3	Dietetic support for your (or your child's) condition	2
4	Awareness and training regarding your (or your child's) condition in an educational setting	1
5	Counselling/psychological services for those affected and their families	3
6	Cost and availability of medication and supplements to treat your (or your child's) condition	5
7	Recognition of your (or your child's) condition as a 'disability'	7

* MDCD - Medically Diagnosed Coeliac disease

Table 5.3.3: Summary of priority setting interview findings for Northern Irish adults with MDFA ($n \leq 10$)

	Key Issues	Proposed Strategies
PRIORITY 1: Public and food industry awareness and understanding of your child's condition	**Opinions were provided by 10 participants:** • 90% (n=9) commented on food industry awareness of food allergies. These comments ranged from 'not very confident in restaurants' to 'restaurants go to extraordinary lengths'. One participant noted differences in allergy awareness between franchise and independent restaurants (the suggestion being that franchises were better). Furthermore, within establishments, many participants noted a lack of awareness amongst waiting staff. Seven participants noted that they adopt a cautionary approach to dining out, i.e., they only consume trusted meals in trusted establishments. • 70% (n=7) commented on the risk of cross-contamination. Three participants noted that tend to purchase pre-packed products (as they consider the risk of cross-contamination to be lower). Two participants specifically mentioned bakeries and noted that although allergen information is always available on site (e.g., in a folder), staff are not always equipped to answer questions.	**Strategies were proposed by 10 participants:** • 60% (n=6) proposed campaigns to increase public awareness. • 50% (n=5) proposed campaigns/training to increase awareness in the food industry. One participant noted that allergen training should be mandatory for all food handlers. Another participant suggested that training should address all allergens, not only the 14 EU allergens. • 50% (n=5) focused on the provision of allergen information to consumers. Participants are looking for more accurate and complete information. Suggestions included reduction in the use of precautionary statements ('may contain') and the provision of more clearer allergen information on both food labels and food menus.

	Key Issues	Proposed Strategies
	• 70% (n=7) commented on public awareness of food allergies. Five participants noted that awareness is poor/could improve, whilst two participants noted that awareness is moderate/good. • 40% (n=4) commented on labelling. Frustration was expressed about the over-use of precautionary 'may contain' statements/labels and in particular the lack of specificity for some allergens (e.g., nut species).	
PRIORITY 2: Accessing medical teams, e.g., consultants, specialist nurses etc. to treat your condition	**Opinions were obtained from 10 participants:** • 70% (n=7) focused on diagnosis. There were mixed views: ○ five participants noted speedy diagnosis (two participants attributed this to the severity of their symptoms); ○ two participants noted lengthy delays in their diagnosis (one participant reported that it took them many years to be diagnosed). • 70% (n=7) focused on difficulties securing follow-up appointments. One participant referred to the impact caused by COVID-19 in this regard.	**Strategies were proposed by nine participants (one respondent did not propose any strategies):** • 100% (n=9) would like to greater access to medical treatment. To this end, two participants suggested increasing the number of allergy specialists in Northern Ireland.

	Key Issues	Proposed Strategies
PRIORITY 3: Awareness and training regarding your condition in an educational setting	**Seven participants commented on allergy awareness within educational settings (three respondents did not specify any issues):** • 71% (n=5) advised that most schools had poor awareness and training on food allergies. These interviewees noted that most school canteens could not guarantee nut-free food and that the canteen environment was not free of allergens. As a result, some children brought their own lunch to school as they could not eat in the school canteen. • 28% (n=2) advised of good awareness, allergen management and training within schools, and in some cases a lack of training and awareness within the third level educational institutes.	**Strategies were proposed by eight participants (two respondents did not propose any strategies):** • 75% (n=6) proposed enhanced awareness and education of food allergies. Proposed topics include greater awareness of symptoms and severity of food allergies, of food allergy management and about the administration of adrenaline auto-injectors. • 12% (n=1) proposed that adrenaline auto-injectors should be stored in the teacher's room or locker rather than the main office cabinet (to ensure quicker access if needed). • 12% (n=1) proposed improved listing of ingredients (and allergens) on food menus.
PRIORITY 4: Adrenaline auto-injectors to be available in all public spaces in case of emergency (similar to	**Opinions were obtained from 10 participants:** • 100% (n=10) stated that they would like to see adrenaline auto-injectors available in public spaces such as shopping centres, premises serving food, chemists, play centres and on public transport.	**Strategies were proposed by seven participants (three respondents did not propose any strategies):** • 85% (n=6) stated that adrenaline auto-injectors should be located in public spaces and all premises serving food. One person noted that the locations

	Key Issues	Proposed Strategies
automated external defibrillator, AED)	- 10% (n=1) elaborated that there should be an allergy emergency box similar to an AED box in public places, containing adrenaline auto-injectors, antihistamines and inhalers. This emergency box should be accessed with a key by trained personnel (similar to the AED box).	of adrenaline auto-injectors should be identified via an app. - 14% (n=1) stated that awareness should be increased in the administration of adrenaline auto-injectors.
PRIORITY 5: Cost and availability of medication and supplements to treat your condition	**Opinions were raised by 10 participants:** - 90% (n=9) commented on medications (antihistamines and adrenaline auto-injectors) under this heading. Regarding cost, no issues were raised. Participants noted that these products are available free of charge by the NHS (however, one participant noted that antihistamines are purchased over the counter, but they are affordable). Another interviewee reported issues with the availability of adrenaline auto-injectors in pharmacies (i.e., those with food allergy often need to visit multiple pharmacies before securing their prescription). - 50% (n=5) commented on the high cost of foods labelled as ‘free-from’. One participant noted that many conventional products (i.e., products not labelled as ‘free-from’) do not contain allergens and are reasonably priced alternatives.	**Strategies were proposed by eight participants (two respondents did not propose any strategies).** - 37% (n=3) proposed greater availability of ‘free from …’ foods and food supplements, where possible. One of these interviewee suggested the additional inclusion of food supplements on prescription. - 37% (n=3) proposed strategies relating to Adrenaline auto-injector, i.e., longer shelf-lives would be prefereable and the establishment of a system to address availability challenges in pharmacies. - 25% (n=2) proposed consideration of price control on ‘free-from …’ foods

	Key Issues	Proposed Strategies
	However, consumers must spend time reviewing labels to identify these products.	
PRIORITY 6: Dietetic support for your condition	**Opinions were obtained from 10 participants:** Information, knowledge and support from dietician post-diagnosis • 40% (n=4) were referred to a dietitian post-diagnosis. Poor feedback was provided on these referrals: ○ One participant was simply advised to obtain a medical ID bracelet to inform others of their nut allergy. ○ One participant commented on poor information at initial consultation and a lack of follow-up. ○ One participant noted that each consultation was with a student dietitian. From a patient perspective this was very unsatisfactory because: (i) each appointment was carried out by a different student, and (ii) the students continually referred to their supervisor for advice. ○ One participant commented on inconsistency in advice from medical professions (e.g., avoidance of all nuts versus avoidance of peanuts). ○	**Strategies were proposed by 10 participants:** • 60% (n=6) proposed that greater dietetic support should be available for adults with medically diagnosed food allergies. • 50% (n=5) proposed that availability of resources (e.g., leaflets, books, apps) should be improved. Resources should focus on how to read food labels, how to administer an adrenaline auto-injector, information on overall diet, and general information on how to live with a food allergy.

	Key Issues	Proposed Strategies
	Support on suitable foods and brands 50% (n=5) provided comment: • All five participants noted that the support provided was poor. One participant noted that he/she had to conduct their own research regarding their condition.	
PRIORITY 7: Recognition of condition as a 'disability'?	**Opinions were obtained from 10 participants:** • 50% (n=5) disagree with this idea. They suggested that medically diagnosed food allergies were manageable and that they do not impact a person's life in the same way as other disabilities. • 30% (n=3) were 'unsure'. Participants stated that recognition could be helpful in certain circumstances, e.g., severe cases and to support time away from work due to illness. • 20% (n=2) agree. One participant stated that recognition as a disability would help protect those with food allergy from discrimination in the workplace.	**Strategies were proposed by two participants (eight respondents did not propose any strategies):** • Put in place measures to recognise medically diagnosed food allergies as a disability.
PRIORITY 8:	**Opinions were obtained from 10 participants:**	**Strategies were proposed by nine participants (one respondent did not propose any strategies):**

	Key Issues	Proposed Strategies
Counselling/psychological services for those affected and their families	• 60% (n=6) stated that they have not accessed or are not aware of existing counselling/psychological services for adults with medically diagnosed food allergies. • 30% (n=3) stated that support services should be provided. • 10% (n=1) do not believe that counselling/psychological services are required; however, they believed greater work needs to be done 'outside the home' (i.e., public awareness, informing the food industry, etc).	1. 100% (n=9) proposed that access to counselling/psychological services should be available to people that need them.

Table 5.3.4: Summary of priority setting interview finding for Northern Irish parents of children/adolescents with MDFA ($n \leq 10$)

	Key Issues	**Proposed Strategies**
PRIORITY 1: Awareness and training regarding your condition in an educational setting	**Opinions were provided by nine participants (one respondent did not specify any issues):** • 66% (n=6) provided positive comments on the awareness and management of food allergies in schools. Generally, schools are proactive, they have solid policies in place, and they have implemented innovative ways to increase awareness. Positive experiences included the provision of separate meals/treats for children/adolescents with food allergies; the display of children's photographs with details of their allergy in the school canteen; the training of teachers on food allergies and the administration of adrenaline auto-injectors; interaction with the community school nurse and the development of a health care plan including food allergy management for each child/adolescent. • 33% (n=3) reported more negative experiences regarding the awareness and management of food allergies in schools. In some schools the teachers were not trained on the use of adrenaline auto-injectors and one participant suggested (in their experience) awareness of food allergies was greater in	**Strategies were proposed by six participants (four respondents did not propose any strategies):** • 100% (n=6) proposed enhanced awareness and education on food allergies. Proposed strategies included food allergy awareness days (students to be actively involved); training on adrenaline auto-injector administration for school staff; allergy updates for school staff, parents and students via digital (website, social media accounts, mobile apps) and traditional methods (workshops, leaflets, etc). • 16% (n=1) proposed the implementation and enforcement of an allergen-free policy. The school should ask parents to ensure their children bring none of a selected list of allergens to school.

	Key Issues	Proposed Strategies
	primary schools than secondary schools. In addition, generally, there was more focus on nut allergies compared with other allergies.	
PRIORITY 2: Accessing medical teams, e.g., consultants, specialist nurses etc. to treat your child's condition	**Opinions were obtained from 10 participants:** • 70% (n=7) referred to delays in securing initial appointments with specialists/consultants, and also follow-up appointments. The overall process was reported to be more efficient for private patients. • 30% (n=3) suggested a lack of support at GP level regarding management of this condition, with participants often referring to support groups for advice.	**Strategies were proposed by nine participants (one respondent did not propose any strategies):** • 77% (n=7) proposed greater access to medical treatment, where possible. Suggestions included: ○ an increase in the number of allergy specialists recruited; ○ an increase in the number of allergy facilities (these should be provided in all local hospitals), where possible. • 33% (n=3) suggested that greater awareness, information, education and supports, in particular for newly diagnosed patients, would be very helpful.
PRIORITY 3: Public and food industry awareness and	**Responses were provided by 10 participants:** • 90% (n=9) commented on food industry awareness of food allergies. Almost all participants (n=8) said that they speak to staff about their food allergy when ordering food in	**Strategies were proposed by 10 participants.** • 70% (n=7) proposed campaigns/training to increase awareness in the food industry.

	Key Issues	**Proposed Strategies**
understanding of your child's condition	restaurants/catering establishments; however, most participants noted a general lack of awareness amongst waiting staff. One participant noted differences in allergy awareness between large chains and independent restaurants (chains are better). Three participants noted that they adopt a cautionary approach to dining out, i.e., they only consume trusted meals in trusted establishments, or they rarely dine out. • 70% (n=7) commented on public awareness of food allergies. Five participants noted that awareness is poor, whilst two participants suggested that awareness is improving. • 40% (n=4) commented on food labels. Three participants noted the overuse of the precautionary 'may contain' statement, whilst another participant suggested that further clarity should be provided on statements such as 'not suitable for individuals with nut allergy'.	• 60% (n=6) proposed campaigns to increase public awareness of food allergies. • 50% (n=5) focused on the provision of allergen information to consumers. Participants are looking for more accurate and complete information. Suggestions included reduction in the use of precautionary statements ('may contain') and the provision of more complete allergen information on both food labels and food menus.

	Key Issues	Proposed Strategies
PRIORITY 4: Adrenaline auto-injectors to be available in all public spaces in case of emergency (similar to automated external defibrillator, AED)	**Opinions were obtained from 10 participants:** • 90% (n=9) of participants stated that, ideally, adrenaline auto-injectors should be available in all public spaces. One participant was not sure, and suggested that adrenaline auto-injectors should be in kept in safe places to ensure correct use and to avoid accidental injection or misuse. • 20% (n=2) of participants suggestion that this provision could coincide with training on the administration of adrenaline auto-injectors.	**Strategies were proposed by 10 participants:** • 90% (n=9) of participants agreed with this proposal. • 50% (n=5) of participants stated that, in addition, awareness and training on the administration of adrenaline auto-injectors should also be more widely available.
PRIORITY 5: Dietetic support for your child's condition	**Opinions were obtained from 10 participants:** Information, knowledge and support from dietician post-diagnosis All ten participants commented on the information, knowledge and support from dietitians post-diagnosis: • 90% (n=9) noted that their child had access to a dietitian post-diagnosis. Four participants were very positive about their experience, i.e., the dietitian was very accessible and useful information was provided. The other five participants commented on the lack of follow-up appointments and relevant information.	**Strategies were proposed by five participants (five respondents did not propose any strategies):** • 60% (n=3) proposed that, ideally, children/adolescents with medically diagnosed food allergies should have improved access to a dietitian. • 60% (n=3) proposed that additional information and resources should be made available, where possible. Relevant topics included information on reading food labels (particularly regarding the listing of fish and nuts), menu ideas and recipe cards.

	Key Issues	**Proposed Strategies**
	• 10% (n=1) noted that their child received no dietetic support. Support on suitable foods and brands • 50% (n=5) commented on the support available regarding suitable foods and brands. Mixed views were expressed. Three participants received information, whilst one participant would have liked more information and support.	• 20% (n=1) proposed that after initial diagnosis, children/adolescents should ideally be tested for other food allergies (as children/adolescents with one allergy are more than likely to have multiple allergies).
PRIORITY 6: Counselling/psychological services for those affected and their families	**Opinions were obtained from 10 participants:** • 80% (n=8) specifically stated that access to these services for children/adolescents with medically diagnosed food allergies would be beneficial. These services are particularly important to ease anxiety and to support the child in their understanding and management of the allergy. • 40% (n=4) stated that they are not aware of the existence of services/services were not provided to them. • 20% (n=2) commented on use of existing services. One participant spoke positively about their child's experience with a counselling service. Another participant joined a support group to help manage their child's allergy.	**Strategies were proposed by six participants (four respondents did not propose any strategies):** • 100% (n=6) proposed that support services should be available to children/adolescents (and parents of children/adolescents) with food allergies. The psychological impact of a food allergy was noted by many participants.

	Key Issues	Proposed Strategies
PRIORITY 7: Cost and availability of medication and supplements to treat your child's condition	**Opinions were raised by 10 participants:** • 100% (n=10) focused on the financial support available for the purchase of medication and other products for children/adolescents with medically diagnosed food allergies. It was noted that adrenaline auto-injectors, antihistamines, infant formula and supplements are available free of charge on prescription. No issues were raised. • 30% (n=3) focused on the cost of foods positioned as 'free-from'. Two participants noted the high cost, while one participant was comfortable with the cost. Another interviewee noted that many conventional products (i.e., products not positioned as 'free-from') do not contain allergens and are reasonably priced alternatives. However, consumers must spend time reviewing labels to identify these products.	**Strategies were proposed by four participants (six respondents did not propose any strategies):** • 50% (n=2) proposed price reduction/controls for 'free-from' foods (greater pack size was proposed as a potential strategy). • 25% (n=1) proposed the establishment of a pharmacy/GP alert system to notify patients when their adrenaline auto-injector is nearing expiry and to remind them to order a new one. This may minimise problems with adrenaline auto-injectors being out of stock when needed by patients. • 25% (n=1) proposed that medicines should be available in sachets (rather than bottles) to support patients who need to carry their medication throughout the day.
PRIORITY 8: Recognition of condition as a 'disability'?	**Opinions were obtained from 10 participants:** • 50% (n=5) of participants disagreed. • 40% (n=4) of participants were 'unsure'. It was noted that this would depend on the severity of the illness and would need to be assessed on a case-by-case basis.	**Strategies were proposed by 10 participants:** • 50% (n=5) of participants agreed with consideration of MDFA as a disability.

	Key Issues	**Proposed Strategies**
	• 10% (n=1) of participants agreed. This participant noted that it would be a useful diagnosis for some people (but also mentioned that it may need to be based on severity).	• 50% (n=5) of participants believed that other strategies should be considered, rather than disability status.

Table 5.3.5: Summary of priority setting interview findings for Northern Irish adults with MDCD (n ≤ 10)

	Key Issues	Proposed Strategies
PRIORITY 1: Public and food industry awareness and understanding of your child's condition	**Opinions were provided by 10 participants:** • 100% (n=10) commented on food industry awareness/knowledge of coeliac disease. Regarding restaurants/catering establishments, participants noted considerable variation in awareness/knowledge between establishments. In addition, one participant was critical of many establishments that provide gluten-free options to accommodate a trend rather than accommodate individuals with medically diagnosed coeliac disease (the participant was concerned about the prevention of cross-contamination in these establishments). In terms of the broader food industry, four participants commented on the availability of gluten-free products (mixed views were expressed) and another two participants commented on the possibly unnecessary addition of gluten to many products. One participant highlighted challenges at airports and on flights.	**Strategies were proposed by 10 participants:** • 80% (n=8) suggested that greater awareness and education of coeliac disease amongst the public and the food industry would be advantageous. Greater awareness in the travel industry (airports and airlines) was specifically mentioned. • 30% (n=3) proposed greater availability of foods where possible, i.e., more food establishments to cater for coeliacs, more gluten-free options in catering establishments and supermarkets, and better positioning and labelling of gluten-free products within retail premises. • 10% (n=1) proposed that food labelling should be more standardised and specific, where possible, and that use of precautionary terminology 'may contain' should be reduced. • 10% (n=1) proposed that coeliacs should be encouraged to contact food manufacturers to inform them of labelling errors.

	Key Issues	Proposed Strategies
	• 70% (n=7) commented on public awareness of coeliac disease, suggesting that awareness among the general public was often poor. • 50% (n=5) commented on food information. Regarding food labelling, participants noted inaccuracies on labels (e.g., ‘gluten-free’ products sometimes contain ingredients with gluten) and over-use of precautionary statements.	
PRIORITY 2: Accessing medical teams, e.g., consultants, specialist nurses etc. to treat your condition	**Opinions were obtained from 10 participants:** • 60% (n=6) focused on follow-up appointments. Mixed feedback was provided. Three participants reported positively on the health services received, while the other three participants mentioned delays and challenges in securing appointments. • 50% (n=5) focused on their diagnosis. Mixed feedback was provided. Three participants noted a speedy diagnosis and an efficient process. On the other hand, two participants referred to challenges with initial inaccurate diagnoses (one participant reported that they were inaccurately diagnosed with shingles, whilst the	**Strategies were proposed by six participants (four respondents did not propose any strategies):** • 33% (n=2) suggested that greater access to medical services would be preferable. • 33% (n=2) proposed that greater awareness of coeliac disease, its symptoms and associated problems would be helpful. • 33% (n=2) proposed improvements in diagnosis, where possible. One participant suggested that a more consistent approach to diagnosis should be established. Another participant proposed that diagnostic services should be improved for children, and suggested

	Key Issues	Proposed Strategies
	other participant initially received a negative coeliac result).	difficulties experienced with testing methods such as biopsies.
PRIORITY 3: Cost and availability of medication and supplements to treat your condition	**Opinions were raised by 10 participants:** • 70% (n=7) commented on the high cost of gluten-free products. In Northern Ireland, certain gluten-free products (i.e., staple products) are available free on prescription. Any gluten-free product not prescribed by the GP must be purchased by the coeliac themselves. There was also discussion regarding the high cost of gluten-free products. • 20% (n=2) of participants discussed food supplements.	**Strategies were proposed by eight participants (two respondents did not propose any strategies):** • 75% (n=6) proposed that efforts should be taken to reduce the cost of gluten-free foods, where possible. • 25% (n=2) noted that products prescribed on prescription should continue to be provided free of charge. • 12.5% (n=1) suggested that clear recommendations on appropriate supplements should be provided to coeliacs.

	Key Issues	Proposed Strategies
PRIORITY 4: Dietetic support for your condition	**Opinions were obtained from 10 participants:** Information, knowledge and support from dietician post diagnosis • 60% (n=6) were critical of the support received. ○ One participant felt that he/she had to explain coeliac disease to a dietitian whilst in hospital for an operation. ○ Another participant noted that the dietitian advised him/her to conduct their own research on the disease. ○ Another participant reported that the dietitian would read information from published literature and was unable to answer any questions outside of this literature. ○ Another participant noted that the dietitian focused on body weight and avoided topics such as intolerance and intake of vitamins and minerals. • 40% (n=4) were more positive regarding the support received. Three of these participants mentioned follow-up appointments. One participant noted that he/she also attends support groups.	**Strategies were proposed by six participants (four respondents did not propose any strategies):** • 66% (n=4) proposed that adults with coeliac disease should have improved access to a dietitian, where possible. Immediate access to a dietitian post-diagnosis and regular follow-up appointments were deemed preferable. • 66% (n=4) proposed greater availability of information and resources. Relevant topics include support on coeliac disease and gluten-free diet.

	Key Issues	Proposed Strategies
	Support on suitable foods and brands - 20% (n=2) of participants commented on the support provided. These comments were positive i.e., the dietitian advised to avoid gluten and provided a list of recommended foods.	
PRIORITY 5: Awareness and training regarding your condition in an educational setting	**Opinions were provided by 10 participants:** - 90% (n=9) noted very poor awareness of coeliac disease within educational settings. Participants noted poor knowledge of the disease, its symptoms, the seriousness of the condition and the difference between gluten intolerance and coeliac disease. Furthermore, coeliac disease is more often recognised as an allergy rather than an autoimmune disease. Three participants noted that canteens often do not cater for students with coeliac disease. - 20% (n=2) noted that the awareness of coeliac disease has improved in recent years.	**Strategies were proposed by nine participants (one respondent did not propose any strategies):** - 100% (n=9) proposed greater education and awareness, where possible. Proposed topics included improving general awareness about the disease and its severity, and recognition of coeliac disease as a medical condition. It was noted that improved awareness will assist with earlier diagnosis. - 33% (n=3) proposed, ideally, the provision of greater availability of gluten-free foods in schools and universities for students with coeliac disease.

	Key Issues	Proposed Strategies
PRIORITY 6: Counselling/psychological services for those affected and their families	**Opinions were obtained from eight participants (two respondents did not specify any issues):** • 62% (n=5) of participants stated that counselling services could be very beneficial for certain groups, e.g., children, parents of newly diagnosed children, young people and people struggling to accept/manage their diagnosis. • 62% (n=5) of participants stated that they have not accessed or are not aware of existing counselling/psychological services for adults with coeliac disease. • 37% (n=3) of participants suggested that they do not need counselling services.	**Strategies were proposed by four participants (six respondents did not propose any strategies).** • 100% (n=4) proposed that access to support services should be made available to people that need them, where possible.
PRIORITY 7: Recognition of condition as a 'disability'?	**Opinions were obtained from 10 participants:** • 70% (n=7) disagree with this concept. Key points of rationale: (i) coeliac disease is manageable and does not impact a person's life in the same way as a physical disability; and (ii) recognition as a medical condition would be more accurate reflection of this condition. • 30% (n=3) agree. It was stated that coeliac disease has an impact on daily life and therefore this recognition is warranted.	**Strategies were proposed by three participants (seven respondents did not propose any strategies):** • 100% (n=3) agreed with consideration of recognition of their condition as a disability.

Table 5.3.6: Summary of priority setting interview findings for Northern Irish parents of children/adolescents with MDCD ($n \leq 6$)

	Key Issues	Proposed Strategies
PRIORITY 1: Public and food industry awareness and understanding of your child's condition	**Opinions were provided by six participants:** • 83% (n=5) commented on awareness of coeliac disease in restaurants and catering establishments. ○ 66% (n=4) adopt a cautionary approach to dining out, i.e., they only consume trusted meals in trusted establishments. ○ 66% (n=4) commented on the lack of knowledge amongst staff. Two participants noted that when asked about food allergens, staff will hand over a large document/folder and are unable to provide additional verbal answers. ○ 50% (n=3) were very critical of the selection of gluten-free food available for children/adolescents and noted that it is often necessary to order gluten-free meals from the adults' menu. • 66% (n=4) suggested that public awareness of coeliac disease is often poor; however, one participant also reported that in their opinion it is improving. • 33% (n=2) suggested that the availability of gluten-free products is increasing in supermarkets.	**Strategies were proposed by six participants:** • 66% (n=4) proposed the promotion of greater education and awareness of coeliac disease throughout the public and the food industry. • 50% (n=3) highlighted the need for greater choice and availability of gluten-free foods for children/adolescents with coeliac disease, where possible. • 33% (n=2) proposed clearer information on the gluten-free status of foods. Ideally, this would involve clear and highly visible labelling indicating gluten-free.

	• 33% (n=2) commented on precautionary statements on food labels and noted that they will not purchase any product carrying a 'may contain' label.	
PRIORITY 2: Accessing medical teams, e.g., consultants, specialist nurses etc. to treat your child's condition	**Opinions were obtained from six participants:** • 83% (n=5) referred to diagnosis. Two participants noted that the diagnosis process was efficient; however, three participants noted specific challenges, i.e., with appointments and diagnosis. • 33% (n=2) noted difficulties accessing medical teams. One participant noted that there is no continuity in consultants assigned to assess his/her child.	**Strategies were proposed by four participants (two respondents did not propose any strategies):** • 75% (n=3) proposed improving access to medical teams, where possible, or providing financial supports to assist patients in availing of private medical access. • 25% (n=1) proposed the establishment of a consistent approach for the assessment of coeliac disease.
PRIORITY 3: Dietetic support for your child's condition	**Opinions were obtained from six participants:** Information, knowledge and support from dietician post diagnosis • 83% (n=5) noted that their children had access to a dietitian post-diagnosis. Two participants were very positive about their experience, i.e., there is good access and support was provided. Three participants suggested that the waiting lists were long, and the advice provided somewhat generic. • 16% (n=1) noted that their child had no access to a dietitian.	**Strategies were proposed by two participants (four respondents did not propose any strategies):** • 100% (n=2) proposed that children/adolescents with coeliac disease should have improved access to a dietitian, where possible. • 50% (n=1) proposed that information resources should be less generic and should focus more on individual needs.

	Support on suitable foods and brands - Two participants commented on the support available regarding suitable foods and brands. One suggested it was quite 'basic', while the other reported it to be very good.	
PRIORITY 4: Awareness and training regarding your condition in an educational setting	**Opinions were provided by six participants:** - 66% (n=4) suggested that they have experienced poor awareness of coeliac disease within education settings, and an insufficient availability of gluten-free options for children/adolescents with coeliac disease. One participant noted that their child (who has severe coeliac disease) often cannot attend school trips as the provision of gluten-free food is not guaranteed. - 33% (n=2) noted very good awareness of coeliac disease within educational settings. In one secondary school, a separate desk and gluten-free products are provided for the student during home economics class The other interviewee commented that awareness among teachers and peers was good.	**Strategies were proposed by four participants (two respondents did not propose any strategies:** - 100% (n=4) proposed increased education and awareness about coeliac disease, where possible. - 25% (n=1) proposed the provision of 'kid-friendly' gluten information on food labels to enable children identify the foods they can consume/must avoid. - 25% (n=1) proposed greater availability of gluten-free foods on the school menu, where possible. - 25% (n=1) proposed the implementation of strict measures to avoid cross-contamination.

PRIORITY 5: Counselling/psychological services for those affected and their families	**Opinions were obtained from six participants:** • 66% (n=4) stated that support services should be available for children/adolescents with coeliac disease. Support services would be beneficial for newly diagnosed children (particularly older children). One participant noted that a support group rather than a counselling service would suffice. • 66% (n=4) stated that they have not accessed or are not aware of existing counselling/psychological services for children and adolescents with coeliac disease. • 50% (n=3) specifically spoke about the impact of diagnosis on the young child. In two cases, the children progressed well; however, one participant spoke about anxiety for their child.	**Strategies were proposed by four participants (two respondents did not propose any strategies):** • 100% (n=4) proposed that support services should be available to children/adolescents (and parents/families of children/adolescents) with coeliac disease, where possible.
PRIORITY 6: Cost and availability of medication and supplements to treat your child's condition	**Opinions were obtained from six participants:** • 83% (n=5) focused on the cost and availability of gluten-free products. Certain gluten-free products (i.e., staple products) are available free of charge on prescription. All other gluten-free products must be purchased. Respondents suggested that these products were often costly. On a positive note, respondents reported that the range of gluten-free products is increasing in supermarkets.	**Strategies were proposed by four participants (two respondents did not propose any strategies):** • 100% (n=4) proposed that efforts should be taken to reduce the cost of gluten-free food, where possible. One participant suggested that special offers such as 'buy one, get one free' of gluten-free products would be helpful.

	• 16% (n=1) noted the lack of recommendations on appropriate supplements for children/adolescents with coeliac disease. • 16% (n=1) noted the lack of gluten-free medications.	• 25% (n=1) noted that products prescribed on prescription should continue to be provided free of charge.
PRIORITY 7: Recognition of condition as a 'disability'?	**Opinions were obtained from six participants:** • 50% (n=3) agreed. It was noted that this disease has a significant impact on the life of those affected and for this reason should be recognised as a disability. • 33% (n=2) disagreed. However, one participant noted that the disease should be recognised in some way. • 17% (n=1) of participants were ‘unsure’.	**Strategies were proposed by six participants** • 50% (n=3) agreed that this proposal should be considered. • 50% (n=3) disagreed or were unsure of this proposal and would prefer consideration of other strategies.

5.4 Priority setting interview results: overall findings

Eight groups were interviewed by phone in this study. These consisted of the following four groups of respondents in each jurisdiction:

- Adults with MDFA (self-reported) in Ireland (n=10) and Northern Ireland (n=10);
- Parents of children/adolescents with MDFA in Ireland (n=10) and Northern Ireland (n=10);
- Adults with MDCD (self-reported) in Ireland (n=10) and Northern Ireland (n=10);
- Parents of children/adolescents with MDCD in Ireland (n=10) and Northern Ireland (n=6).

A priority ranking table for each of the eight groups is presented in Tables 5.2.1, 5.2.2, 5.3.1 and 5.3.2, and summary versions of the interviewees' ranking of the issues and perceptions of their ease of resolution are presented in Figures 5.4.1a - 5.4.3b. Seven groups ranked '*Public and food industry awareness and understanding of their/their child's condition'* as their number one priority, the exception being parents of children/adolescents with MDFA in Northern Ireland, who ranked '*Awareness and training in an educational setting'* first and the former issue third. Interestingly, the topic *Public and food fndustry awareness etc.* was ranked second in terms of the perceived ease of resolution (Figures 5.4.1a and 5.4.1b). Tables 5.2.3, 5.2.4, 5.3.3 and 5.3.4 detail concerns around knowledge, training and awareness of food allergens, coupled with a fear of cross-contamination when eating out. Issues regarding the accuracy and comprehensiveness of allergen information were raised, particularly by Northern Ireland MDFA interviewees (verbal communication of allergen information is acceptable in catering establishments in Northern Ireland compared to the mandatory requirement for written declarations in Ireland). All of these factors contributed to a range of outcomes, with some respondents eating only in trusted or franchised food businesses, while others only ate pre-packaged foods when eating outside the home. While an improvement was noted with regard to allergen awareness when eating out in recent years (possibly as a result of improvements in allergen labelling requirements for non-prepacked or 'loose' foods that came into force in 2014), participants felt more could be done by this sector. This is supported by a previous FSAI audit of 50 food businesses that found that while 68% of these outlets complied with the obligation to have a written allergen declaration, the majority required some form of corrective action due to incomplete or inaccurate allergen labelling (FSAI, 2017). In addition, a recent study by Gruenfeldova *et al.* (2019) on food safety, knowledge, awareness and practices in Ireland, found that only 16% of respondents (food handlers) were able to name the 14 foods listed in EU law as causing food allergies and intolerances. In addition, only 51% of the survey respondents were able to name seven or more food allergens. When these figures (regarding the lack of compliance and knowledge) are considered in the context of the reported prevalence of food allergy and coeliac disease (approximately 3-5% and 1% of the population, respectively), it is clear that a greater awareness and compliance is required by the food services sector in this regard (IFAN, 2019; INDI, 2019; Mustalahti *et al.* 2010; Altobelli *et al.* 2014; MacGiobuin *et al.* 2017; CSI, 2021). One additional recurring theme noted by respondents was the overuse/misuse of precautionary allergen labelling (PAL). This point was noted by many of the MDFA groups, who felt strongly that this issue limited the availability and choice of the food products that they could consume. Participants were keen for measures to be put in place to reduce the unnecessary use of this 'tag line' on food labels. The potential impact of a regulatory requirement for food companies to conduct a risk assessment of the potential for allergen cross-contamination, in order to warrant the use of such labels on pre-packaged foods, has been discussed elsewhere (DunnGalvin *et al.* 2019). Lastly, respondents noted a general lack of public awareness and understanding, particularly with regard to the symptoms, potential severity and management of food hypersensitivity.

Participants proposed many strategies to achieve improvements in the area of *'Public and food industry awareness and understanding'*. These included enhanced education and training regarding food allergens and their management in the food industry. The mechanism by which this could be achieved was mostly public awareness campaigns and included elements such as professional and workplace training to ensure the safety of susceptible co-workers. Many participants also noted that they would like to see improved allergen labelling on menus and stricter measures in catering establishments to prevent possible cross-contamination. The use of technology for effective communication of allergen information between waiting staff and kitchen staff (i.e., chefs) was also suggested. This raises the possibility that such software could also be used as a quick reference by waiting staff for all ingredients (including trace or 'compound' ingredients in pre-bought products e.g., sauces, stocks, etc.) in dishes on the menu. This system could be an effective tool to assist with allergen management and communication in food businesses, assuming it was well maintained and frequently updated. Similarly, additional filters in online shopping sites were suggested to reduce the time that food hypersensitive individuals are required to spend reading labels while shopping. For instance, a button/tab could be selected to eliminate all products containing nuts, dairy, etc. In addition, there is a possibility that this form of software could notify users of any allergen-related product recalls (or RASFF) in place on a particular food product at a given time when shopping. That said, this software would only be effective if properly managed and kept up to date. Participants with MDCD were very keen to see a greater availability and range of clearly labelled gluten-free products in the shops.

All eight groups recorded '*Accessing medical teams, e.g., consultants, specialist nurses, etc. to treat your (or your child's) condition'* as the second most important priority (Figure 5.4.3a). Many participants noted difficulties in securing medical appointments with specialists for diagnosis (overall 64%) and also follow-up appointments. This was more significant for MDFA participants (70% to 100%) than for MDCD participants (33% to 60%) in Ireland (Tables 5.2.3 - 5.2.6). It was also more significant for MDFA adults and parents (80% and 100%, respectively) in Ireland than in Northern Ireland (70% and 70%, respectively). Participants were keen to have improved access to specialists and timelier appointments and suggested the hiring of further consultants to assist with related medical services in Ireland and Northern Ireland. In addition, they proposed further engagement and support from GPs with regard to management options and the understanding of their diagnosis. Costs of medical visits, coupled with access to information, were also reported as a challenge. Notably, one participant suggested the creation of a helpline for people newly diagnosed with food allergy.

The provision of '*Adrenaline auto-injectors in public places similar to AED (automated external defibrillator)*' was the third highest priority for MDFA participants in Ireland (Figure 5.2.1) and the fourth highest priority for their counterparts in Northern Ireland (Figures 5.3.1). This issue was of relevance only to participants with MDFA. There was strong support (90% overall, with an additional 8% unsure) for placing adrenaline auto-injectors in strategic public places so that they could be accessed in an emergency (Tables 5.2.3, 5.2.4 and 5.3.3, 5.3.4). In Ireland, 80% of adults interviewed (10% advocating for school placement only) and 100% of the parents agreed with this proposal. Similarly, 100% of adults interviewed in Northern Ireland, and 90% of the parents, were interested in this idea. It was suggested that such a proposal would most likely require an increase in training on the administration of adrenaline auto-injectors and improved public awareness. Another suggestion was that an app could be developed to show the locations of adrenaline auto-injectors. This idea could be further developed - for instance, the app could release a code to a registered user to access such a device from a secure facility in the case of an emergency. The provision of adrenaline auto-injectors in public places is a system available in parts of Canada (Allergic Living, 2015).

The next most important priority noted by both MDFA and MDCD participants was '*Awareness and training regarding their condition in an educational setting'*. This was the third most important priority for MDCD participants (Figure 5.4.2a) and the fourth most important for MDFA participants (Figure 5.4.1a). A majority of both groups (60-71% for MDFA and 66-90% for MDCD groups) reported a lack of awareness, education, training and understanding of their condition in educational settings (primary, secondary and third level) (Tables 5.2.3 to 5.2.6 and 5.3.3 to 5.3.4). There was, however, one exception: 66% of the MDFA parent participants from Northern Ireland reported a positive experience (only 33% negative) with schools regarding the treatment of their food hypersensitive child. They reported separate meals and suitable treats for their children, clear identification (photographs and allergen details) of their child in the school canteen, teachers trained on food allergies and the administration of adrenaline auto-injectors, coupled with the development of a health care plan (with food allergen management) in many cases. While there was general consensus that improvements had been made with regard to the treatment of food hypersensitivities in an educational setting in recent years, the number of participants reporting positive comments was noticeably lower (28-37% for MDFA and 0-33% for MDCD groups) than those reporting negative experiences (with the exception of MDFA parents in Northern Ireland). Issues reported by adults and parents in both jurisdictions included a general lack of understanding, awareness and training of school staff. Misunderstandings regarding the medical nature of these conditions and the potential severity of food hypersensitivity were noted. So too was a lack of training on adrenaline auto-injector administration and anaphylaxis. It is worth noting that there is currently no legal or formal requirement for the provision of adrenaline auto-injector training in Irish childcare and educational environments (IFAN, 2017). Similarly, there is no legal requirement for this responsibility to be undertaken by educators in Northern Ireland; however, guidance on the use of adrenaline auto-injectors in schools from the Department of Education in Northern Ireland (DoE, 2018) is available to assist in policy creation and management. Notably, this document includes instructions for teachers who have ‘shown willingness to assist in the administration of medication’. To the best of our knowledge, there is no similar guidance available in Ireland.

Other concerns raised included:

- a lack of recognition of food allergens other than nuts,
- a lack of clear food allergen labelling on canteen menus,
- a lack of confidence in the allergen management systems and staff awareness in school canteens,
- a lack of availability of foods suitable for individuals with the condition (particularly gluten-free products for MDCD individuals), and

- exclusion of children/adolescents from school trips as a result of their dietary requirements.

There was general agreement among the MDFA and MDCD groups in both jurisdictions that awareness campaigns focused on the public and educators were necessary to increase the level of understanding of these conditions. One participant even suggested a dedicated awareness day to be included in the school calendar (for teachers and students) for this purpose. In addition, both groups proposed the need for clearer allergen labelling on school menus (which would ideally be available in advance of the school day), coupled with strict enforcement of allergen policies. MDCD participants consistently reported a lack of availability of gluten-free foods and proposed the provision of an expanded range of gluten-free products for students. One participant proposed that allergen food labelling could be made more child-friendly in school canteens. This concept could be explored to a greater degree and include symbols or colour-coding to assist children/adolescents in making quick and safe decisions regarding suitable foods in an educational setting. In addition, the provision of allergen-free zones where students can eat their meals (canteen food or packed lunches) was strongly supported by both sets (MDFA and MDCD) of participants.

The '*Cost and availability of medication and supplements'* was the fifth most important issue for MDFA and MDCD interviewees (Figures 5.4.1a, 5.4.2a and 5.4.3a). MDFA groups in Ireland pay €114 per month (CI, 2021) for medication under the Drugs Payment Scheme, unless eligible for a medical card. The majority of MDFA adults (60%) and MDFA parents (88%) reported that they found the cost of medication high, and noted that additional non-prescription medication like eczema creams, antihistamines, etc., still had to be bought over the counter. The cost of suitable foods, particularly the additional expenses associated with products labelled 'free from', was noted. For MDFA participants from Northern Ireland, both adults (90%) and parents (100%) reported no issue with regard to the cost of medication, as it is currently free of charge under the NHS (although this doesn't include over-the-counter medication such as antihistamines). While a difference in medication costs between each jurisdiction was evident, both groups proposed that they would like to see increased availability of 'free from' foods at a lower cost. In addition, research into the possibility of prolonging the shelf-life of adrenaline auto-injectors was suggested by several participants as a potential future cost saving measure, if achievable.

For the MDCD participants, discussion regarding cost was mainly focused on food and supplements (as opposed to medication). This was raised by 60-100% of the MDCD participants in Ireland and 70-83% of participants in Northern Ireland (Tables 5.2.5, 5.2.6, 5.3.5 and 5.3.6). MDCD participants (adults and parents) in Ireland would like to see certain gluten-free food products available on prescription. Similarly, a reduction in cost, price controls or further tax relief were also proposed. These suggestions were generally in agreement with the participants from Northern Ireland. However, certain gluten-free products are currently free of charge for coeliacs in Northern Ireland on prescription, and several participants noted that they would like this financial support to continue. Participants from both jurisdictions noted the lack of availability of gluten-free medicines on the market. In addition, they indicated (25-40%) a wish to see clear and prominent markings on all gluten-free food products in supermarkets i.e., statements saying '*Gluten-Free'*, so that they were clearly identifiable to consumers. This was also a recommendation of a recent Bord Bia study (Bord Bia, 2017).

'*Dietetic support*' was prioritised as the fourth most important issue for the MDCD participants and the seventh for MDFA participants (Figures 5.4.1a and 5.4.2a). There were mixed reports of access to dietetic services across all groups interviewed. The two exceptions were positive reports from parents in Northern Ireland, where 90% of MDFA participants and 83% of MDCD participants reported having good access to these services post-diagnosis (compared to 55% and 55% in Ireland, respectively). There was general agreement across all participants that services should be available for people with MDFA (ranged from 60-100%) and MDCD (ranged from 75%-100%) post-diagnosis, with follow-up appointments available. A '*lack of resources and supports*' was a common theme documented across all groups. It was proposed by participants (Table 5.4.1) that the following suggestions should be made available in electronic, leaflet or booklet format.

Table 5.4.1: Additional supporting resources suggested by MDFA and MDCD participants (adults and parents) to assist those living with food hypersensitivity in Ireland and Northern Ireland, based on information given in priority setting interviews carried out between August and December 2020 (n=76)

MDFA participants	**MDCD participants**
Recommendations on nutritional supplementation	Recommendations on nutritional supplementation, particularly what food supplements to take
Resources on how to understand food labels, and how to read them	Resources on how to understand food labels, and how to read them
Resources on practical measures to prevent cross-contamination	Resources on practical measures to prevent cross-contamination
Information on food allergy lifestyle management	An index of gluten-free foods on the market
Diet plans/recipes/recipe cards	Suggested gluten-free recipes
Resources specifically for children	Information on disease complications

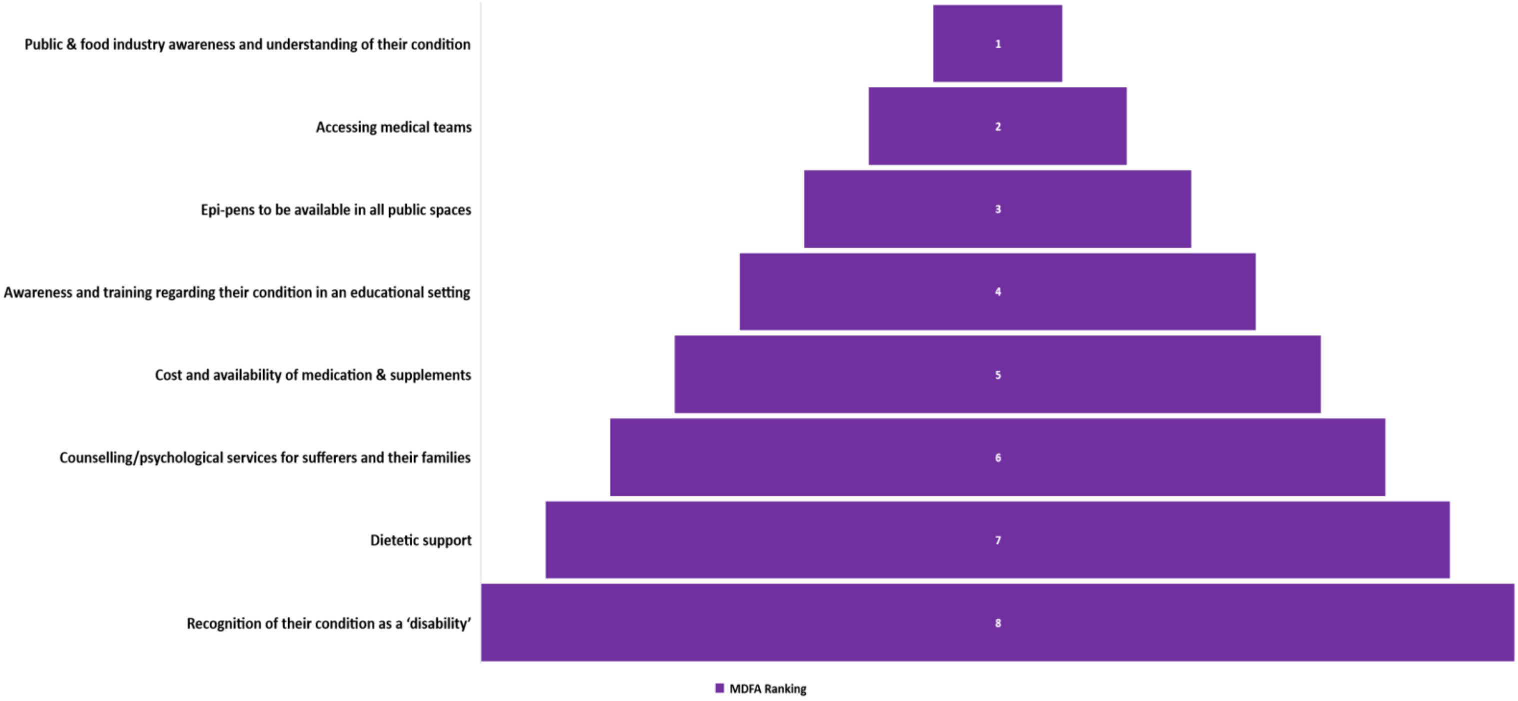
* MDFA: Medically Diagnosed Food Allergy; MDCD: Medically Diagnosed Coeliac Disease.

‘*Counselling/psychological services for food hypersensitive individuals and their families*’ was ranked sixth by both MDFA and MDCD participants (Figures 5.4.1a, 5.4.2a and 5.4.3a). Between 40% and 66% of participants reported that they currently have no access to such services; however, it is unclear if the remaining participants are accessing them. There was strong agreement among all groups interviewed (100%, except for MDFA adults in Northern Ireland (75%)) that such services should be available, particularly after the initial diagnosis. Participants discussed anxiety associated with having a food hypersensitivity, particularly for children/adolescents who are trying to ‘fit in’ with their peers. In addition, MDFA participants commented on the psychological impact of incidences of anaphylaxis and having to carry an adrenaline auto-injector daily. The benefits of support groups were discussed by many participants, although the lack of assured medical advice from healthcare professionals in these settings was raised. A helpline for food hypersensitivity was also proposed, along with a ‘buddy system’ for food hypersensitive children in a school environment.

The last priority issue for both MDFA (ranked eighth) and MDCD participants (ranked seventh) was ‘*Recognition of their condition as a disability*’ (Figures 5.4.1a and 5.4.2a). Neither of these conditions is currently recognised as a disability in Ireland or Northern Ireland. Notably, MDFA and MDCD can be considered a disability in the US (if severe enough) under the ‘Americans with Disabilities Act’ (AAFA, 2019). This Act defines a person with a disability as *“a physical or mental impairment that substantially limits one or more major life activities of such individual, a record of such an impairment or, being regarded as having such an impairment*” (ADA National Network, 2020). Even though disability status was ranked lowest, 25% of all participants believed that their (or their child’s/adolescent’s) condition should be considered as a disability (Figures 5.2.3, 5.2.4, 5.3.3 and 5.3.4). The argument in favour of such a move was that it gives recognition to food hypersensitive individuals and helps them to lobby for stricter rules in a number of settings (public, educational, food sector, etc.). It also provides protection for MDFA individuals against discrimination in the workplace or other environments. An additional 35% of participants were ‘unsure’ about the proposal and a possible decision based on severity was suggested. A further 45% disagreed with this proposal and did not believe MDFA required this status. Twenty-one per cent of MDCD participants believed that their or their child’s/adolescent’s condition should be considered a disability. One argument proposed was the long-term health implications and socio-economic effects of this condition. Thirty per cent of participants were, however, ‘unsure’ and also suggested consideration on a case-by-case basis, depending on severity. Forty-nine per cent of participants disagreed outright with recognising MDCD as a disability.

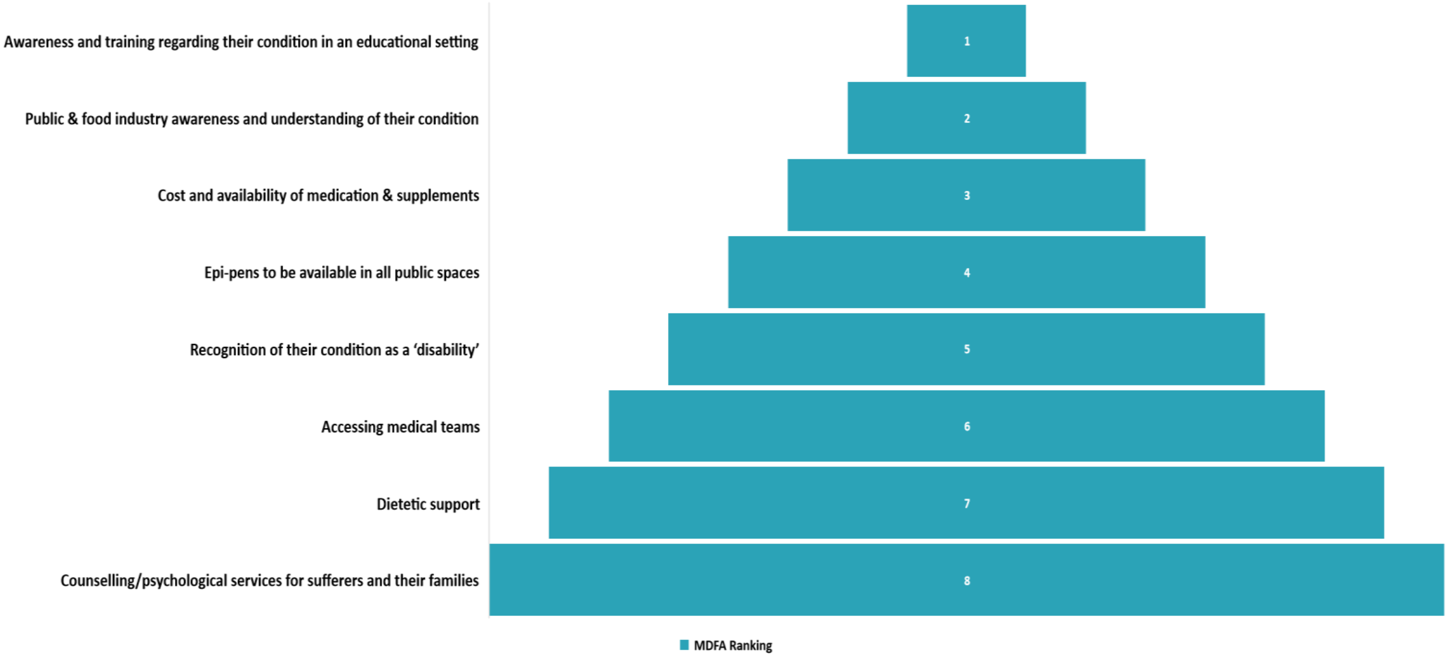
5.4.1 Priority setting interview ranking for all participants with MDFA

Figure 5.4.1a: Prioritisation of topics in order of importance by all participants* with MDFA on the IoI (n=40): Priority ranking of importance (1-8, most to least)



* 'All participants' including adults and parents of children/adolescents reporting to be MDFA (n=40) in Ireland and Northern Ireland.

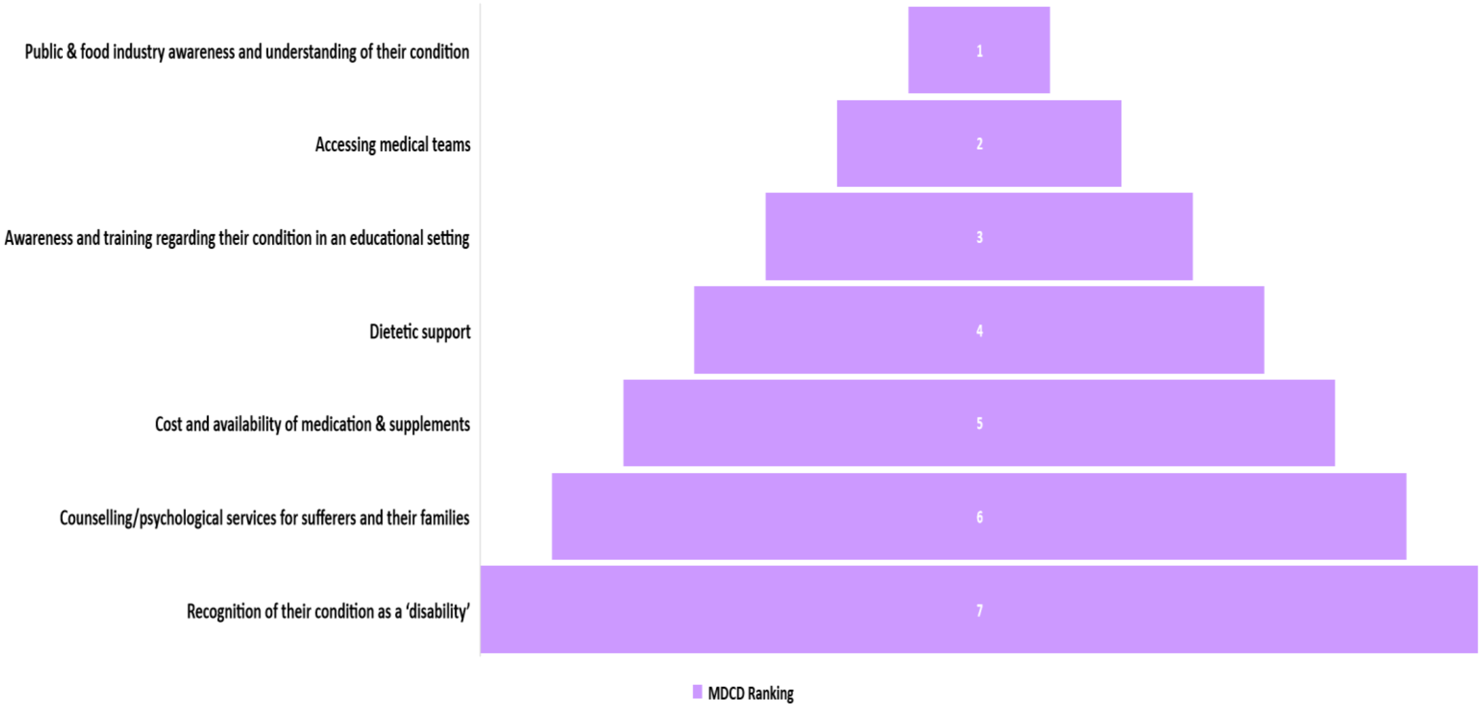
Figure 5.4.1b: Prioritisation of issues in terms of the ease of resolution by all participants* with MDFA in the IoI (n=40): Priority ranking of ease of resolution (1-8, easiest to most difficult)



* ‘All participants’ including adults and parents of children/adolescents with MDFA (n=40) in Ireland and Northern Ireland.

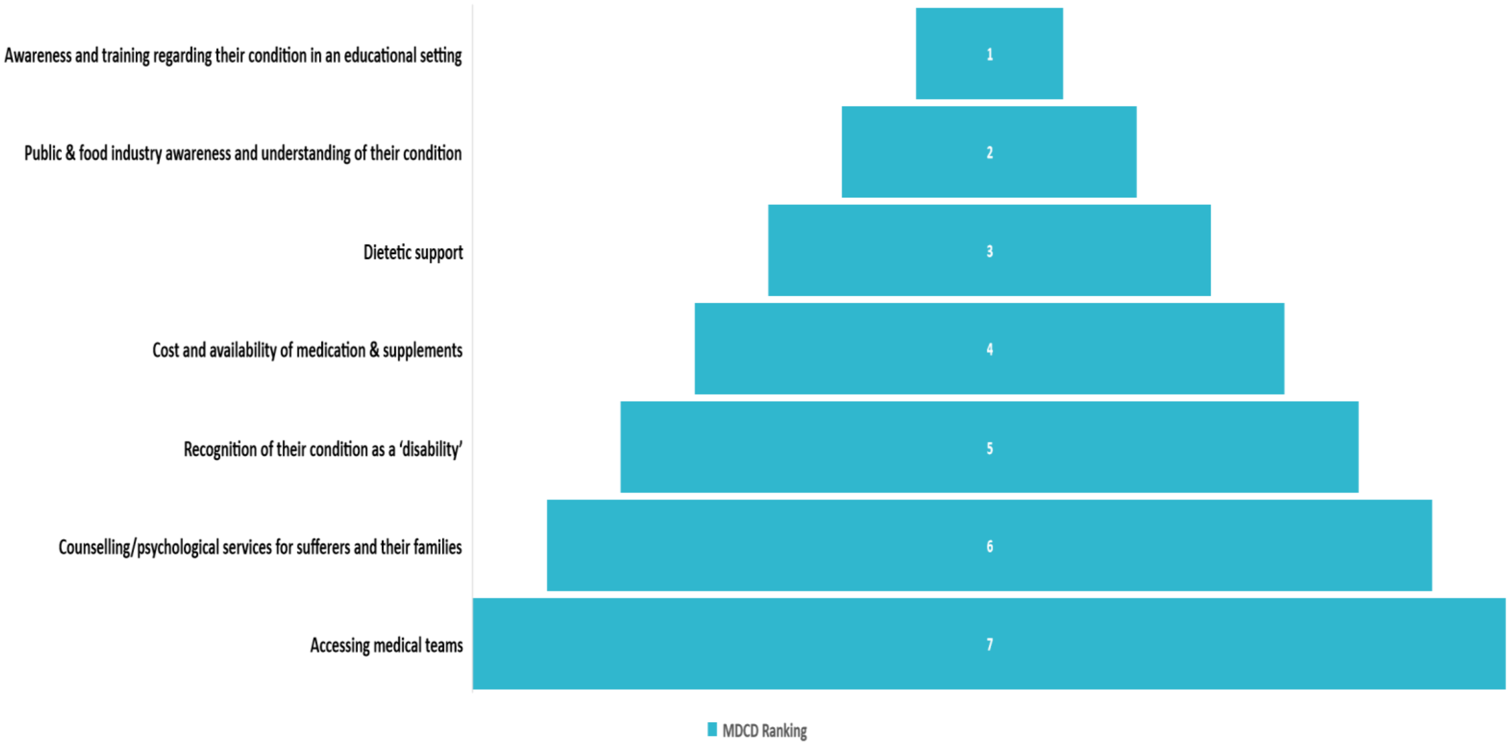
5.4.2 Priority setting interviews: Issue ranking for all participants with MDCD

Figure 5.4.2a: Prioritisation of issues in order of importance by all participants* with MDCD on the IoI (n=36): Priority ranking of importance (1-8, most to least)



* 'All participants' including adults and parents of children/adolescents with MDCD (n=36) in Ireland and Northern Ireland.

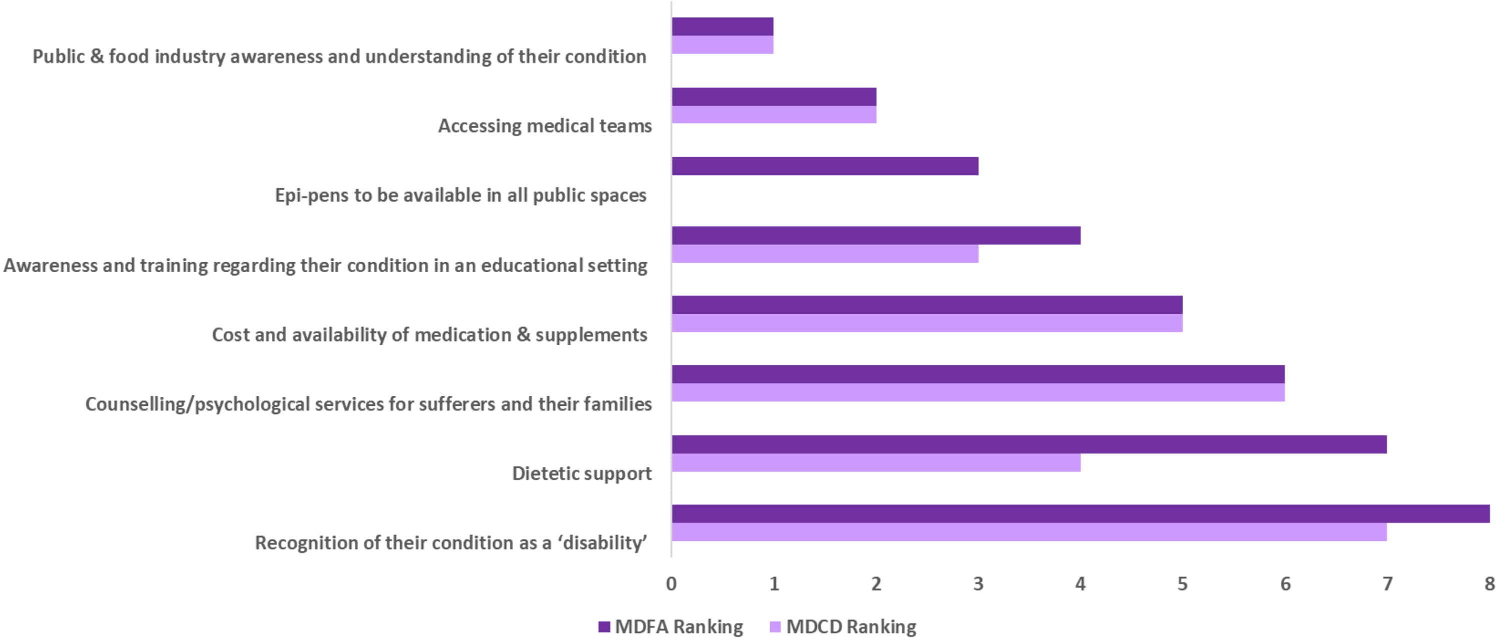
Figure 5.4.2b: Prioritisation of issues in terms of the ease of resolution by all participants* with MDCD in the IoI (n=36): Priority ranking of ease of resolution (1-8; easiest to most difficult)



* 'All participants' including adults and parents of children/adolescents with MDCD (n=36) in Ireland and Northern Ireland.

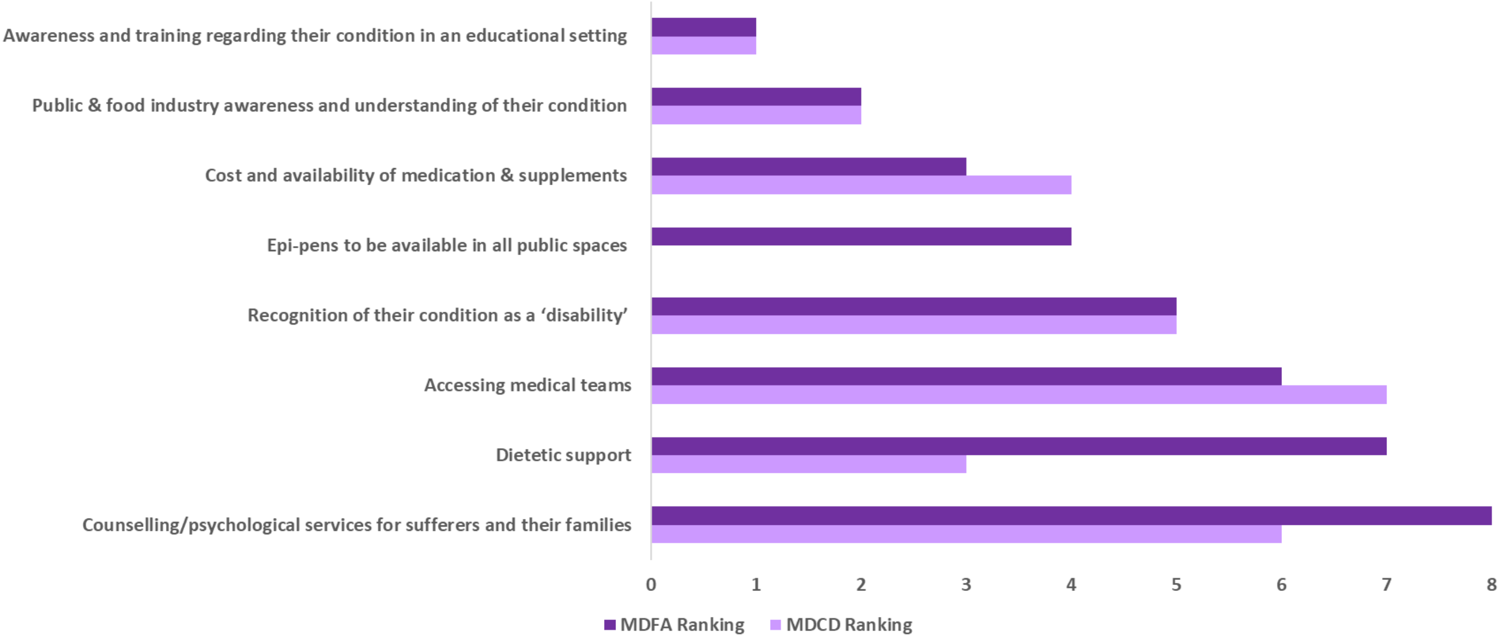
5.4.3 Priority setting interview ranking for all Respondents: MDFA versus MDCD

Figure 5.4.3a: Prioritisation of issues in order of importance by all participants* with MDFA and MDCD on the IoI (n=76): Priority ranking of importance (1-8, most to least)



* 'All participants' including adults and parents of children/adolescents (n= 76) with MDFA (n=40) and MDCD (n=36) in Ireland and Northern Ireland.

Figure 5.4.3b: Prioritisation of issues in terms of the ease of resolution by all participants* with MDFA and MDCD in the IoI (n=76): Priority ranking of ease of resolution (1-8, easiest to most difficult)



* ‘All participants’ including adults and parents of children/adolescent’s (n= 76) with MDFA (n=40) and MDCD (n=36) in Ireland and Northern Ireland

5.5 Priority Setting Interview Conclusion

Results from this study reflect the complexity of the challenges encountered by people with food hypersensitivity daily (summarised in Figures 5.4.3a and 5.4.3b). While progress has been made in the broader area of allergen awareness and management, the ongoing experiences of those affected by food hypersensitivity reflect the level of work still needed to reduce the impact of these conditions on their lives and those of their families. This report summarises key challenges and suggested strategies proposed by food hypersensitive individuals themselves as solutions to improve their QoL. These priority areas and suggestions were further considered by the project steering committee and fed into the project recommendations of this report.

6 Food hypersensitivity datasets and peer-reviewed published prevalence values

6.1 Collection and Examination of Datasets on Food Hypersensitivity in Public and Private Institutions

This task targeted existing databases of information on food hypersensitivity in early years services (EYS) (childcare facilities), primary and secondary schools and nursing homes. The method used is described in section 2.5. Surveys were sent via email to targeted institutions in Ireland and Northern Ireland. These questionnaires were designed to collect information on the (i) gender, (ii) age, and (iii) associated trigger foods (where applicable) of hypersensitive children and elderly adults. Additional information was requested as to whether those with MDFA carried an adrenaline auto-injector or had experienced previous instances of adverse reactions to food on-site. A follow-up (reminder) email was sent to EYS, schools and nursing homes approximately one month after the initial questionnaire email. Many surveys were completed with regard to the specific number of individuals in each organisation with a food hypersensitivity, but not all respondents gave further details regarding trigger foods or the carriage of adrenaline auto-injectors, etc., as requested. The number of completed surveys consisted of 164 EYS (145 in Ireland and 19 in Northern Ireland) representing 9,517 children; 15 schools (12 in Ireland and three in Northern Ireland) representing 3,233 children/adolescents; and 35 nursing homes (28 in Ireland and seven in Northern Ireland) representing 2,139 residents. These surveys sought information on all of the individuals in attendance, or residing, within these institutions/facilities, so a single completed survey could contain relevant information on several hundred individuals.

6.1.1 Reported percentages of food hypersensitivity in early years services in Ireland and Northern Ireland

A survey targeting EYS in Ireland (n=800) and Northern Ireland (n=342) was carried out between July and December of 2019. The aim of this task was to collate information on food hypersensitivity in children attending childcare and pre-school (approx. age range 1-5 years).

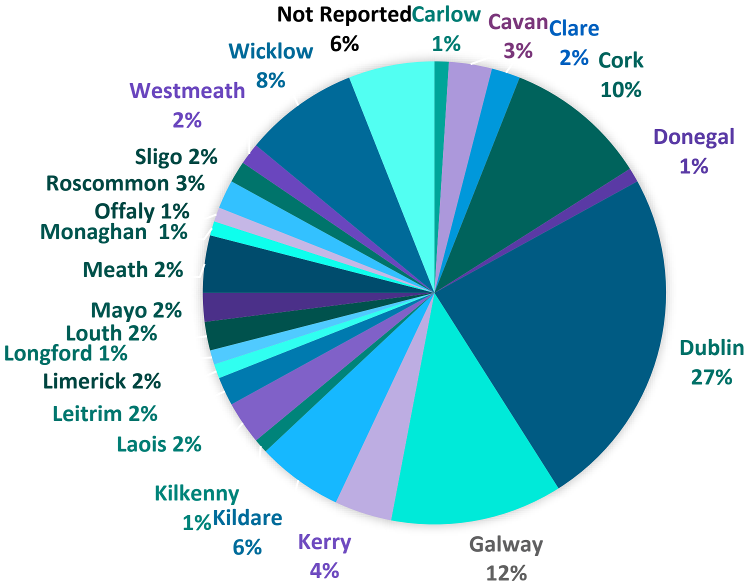
Completion of this survey by county is presented in Figures 6.1.1a and b. The survey was completed in all the counties in Ireland (in particular Dublin 27%, Galway 12% and Cork 10%) and Northern Ireland. Reported food hypersensitivity percentages associated with each gender (where recorded), and specific trigger foods (where relevant), are presented in Figure 6.1.1c and Table 6.1.1b.

In total, 145 EYS completed (or partially completed) the survey out of total of 800 EYS contacted in Ireland. The responses contained information on 8,499 children. A total of 560 (6.6%) children were reported to have a food hypersensitivity (Table 6.1.1a). These included 284 children (3.3%) who had a food allergy, 26 (0.30%) who had coeliac disease, and 250 (2.9%) who had FI.

Out of total of 342 EYS contacted in Northern Ireland, 19 completed the survey. The responses contained information on 1,018 children. A total of 86 (8.5%) children were reported to have a food hypersensitivity (Table 6.1.1a). These included 33 individuals (3.2%) who had a food allergy, five (0.5%) who had coeliac disease, and 48 (4.7%) who had FI.

A wide range of trigger foods were reported and are presented in Figure 6.1.1c and Table 6.1.1d. Nuts, eggs, dairy, sesame seeds and wheat were the five most reported food allergens on the IoI from the 164 EYS responses collected in this survey. Of the 317 children reported as having a food allergy, 17% (n=55) were recorded as carrying an adrenaline auto-injector. In addition, 11% (41 in Ireland and 14 in Northern Ireland) of the EYS respondents indicated they previously had an adverse reaction (severity unspecified) to food on-site.

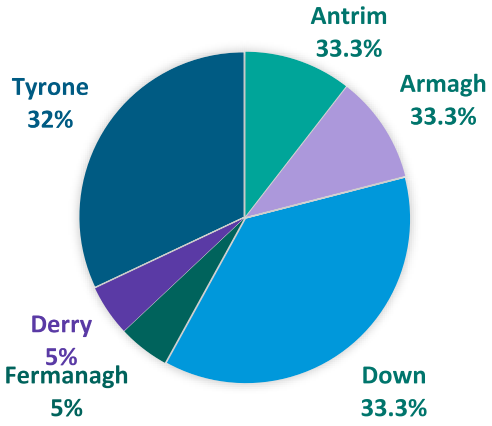
Figure 6.1.1a: Completion rates of the food hypersensitivity survey by early years services by county in Ireland (n=145)



*Carlow = 1, Cavan = 4, Clare = 3, Cork = 15, Donegal = 2, Dublin = 35, Galway = 17, Kerry = 6, Kildare = 9, Kilkenny = 1, Laois = 4, Leitrim = 3, Limerick = 2, Longford = 2, Louth = 3, Mayo = 3, Meath = 6, Monaghan = 1, Offaly = 1, Roscommon = 3, Sligo = 2, Westmeath = 2, Wicklow =1 2, not reported = 8.

**137 respondents indicated a county, eight respondents did not.

Figure 6.1.1b: Completion rate of the food hypersensitivity survey by Early Year Services by county in Northern Ireland (n=19)



*Antrim = 2, Armagh = 2, Down = 7, Fermanagh = 1, Derry = 1, Tyrone = 6.

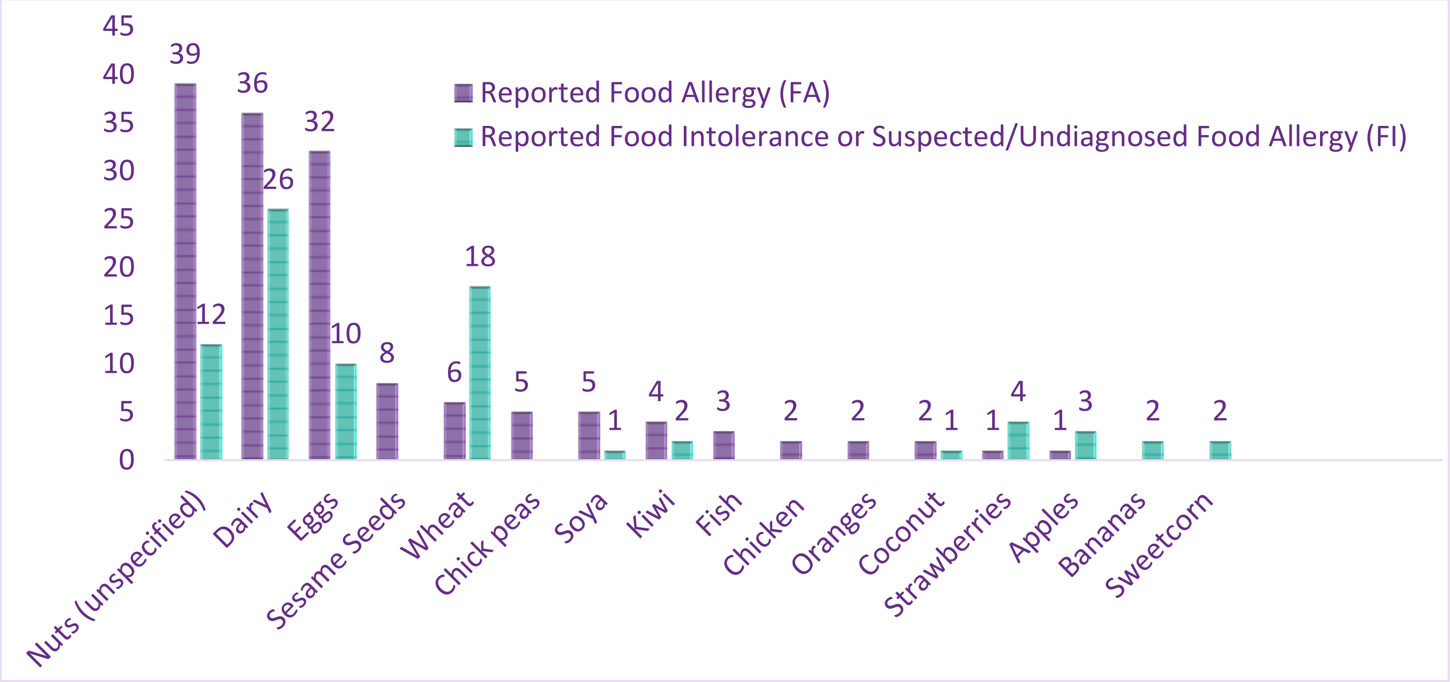
Table 6.1.1a: Reported food hypersensitivity in children enrolled in early years services in Ireland (EYS n=145; 8499 individuals) and Northern Ireland (EYS n=19; 1,018 individuals). Online survey July to December 2019.

Early years services Survey Results	**Ireland**	**Northern Ireland**	**Ireland & Northern Ireland**
EYS contacted regarding this survey	**800**	**342**	**1,142**
EYS who completed survey (% of total)	**145 (18%)**	**19 (6%)**	**164 (14%)**
No. of children represented in completed surveys	**8,499**	**1,018**	**9,517**
EYS: females (% of total) EYS: males (% of total)	4,055(48%) 4,444 (52%)	425(42%) 442 (43%)	5,120 (44%) 4,740 (40.5%)
Reported food hypersensitivity (FH) in EYS (% of children)	**560 (6.6%)**	**86 (8.5%)**	**646 (6.8%)**
EYS: females reported FH (% of FH total) EYS: males reported with FH (% of FH total) EYS: gender unknown with FH (% of FH total)	109 (20%) 114 (20%) 337 (60%)	26 (2.6%) 35 (3.5%) 25 (2.5%)	135 (1.2%) 149 (1.3%) 362 (3.1%)
Reported food allergy (FA) in EYS (% of children)	**284 (3.3%)**	**33 (3.2%)**	**317 (3.3%)**
EYS: females reported FA (% of FA total) EYS: males reported with FA (% of FA total) EYS: gender unknown with FA (% of FA total)	46 (16%) 63 (22%) 175 (62%	9 (0.9%) 13 (1.3%) 11 (1.1 %)	55 (0.5 %) 76 (0.7%) 186 (1.6%)
Reported coeliac disease (CD) in EYS (% of children)	**26 (0.30)**	**5 (0.5%)**	**31 (0.33%)**
EYS: females reported CD (% of total) EYS: males reported with CD (% of total) EYS: gender unknown with CD (% of total)	3 (12%%) 6 (23%) 17 (65%)	3 (0.3%) 1 (0.1%) 1 (0.1%)	7 (0.1%) 7 (0.1%) 18 (0.2%)
Reported food intolerance (FI) in EYS (% of total)	**250 (2.9%)**	**48 (4.7%)**	**298 (3.1%)**
EYS: females reported FI (% of total) EYS: males reported with FI (% of total) EYS: gender unknown with FI (% of total)	60 (24%) 45 (18%) 145 (58%)	14 (1.4%) 21 (2.1%) 13 (1.3%)	74 (0.6%) 66 (0.6%) 158 (1.4%)

* FA: Food Allergy; CD: Coeliac Disease; FI: Food Intolerance or Suspected/Undiagnosed Food Allergies.

** Food hypersensitivity includes FA, CD and FI.

Figure 6.1.1c: The predominant trigger foods reported by Early Year Services in Ireland and Northern Ireland for 75 of 317 food allergic children and for 132 of 298 food intolerant children (with the exception of coeliac disease), in an online survey carried out from July to December 2019



*** Ireland:**

Medically Diagnosed Food Allergy: Nuts (unspecified) = 30 plus eight reports of peanut allergy = 38, Dairy = 29, Eggs = 31, Sesame seeds = 8, Wheat = 6, Chickpeas = 5, Soya = 4, Kiwi = 4, Fish = 3, Chicken = 2, Oranges = 2, Coconut = 2, Strawberries = 1, Apples = 1.

Food Intolerance: Nuts (unspecified) = 10 plus two reports of peanut allergy = 12, Dairy = 12, Eggs = 9, Wheat = 14, Soya = 1, Kiwi = 2, Coconut = 1, Strawberries = 3, Apples = 3, Bananas = 2, Sweetcorn = 2.

**** Northern Ireland:**

Medically Diagnosed Food Allergy: Nuts (unspecified) = 1, Dairy = 7, Eggs = 1, Soya = 1.

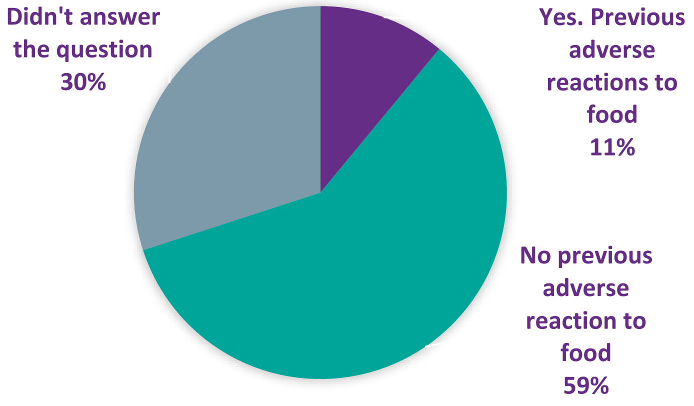
Food Intolerance: Dairy = 14, Eggs = 1, Wheat = 4, Strawberries = 1.

Table 6.1.1b: Other foods reported by Early Year Service respondents in Ireland and Northern Ireland, for 75 of 317 food allergic children and for 132 of 298 food intolerant children (with the exception of coeliac disease), reported in an online survey carried out between July to December 2019

Additional Food Allergies Reported	**Additional Food Intolerances Reported**
Shellfish, Pork, Figs, Rice, Garlic, Sultanas, Bananas, Turkey, Food colouring (unspecified).	Fruit (unspecified), Grapefruit, Watermelon, Red Pepper, Cauliflower, Potato, Oats, Sweet potato, Kidney Beans, Aspartame, Sweetener (unspecified).

*These foods are reported allergens not captured in Figure 6.1.1c (above). Each of these foods was reported just once in the surveys circulated to EYS.

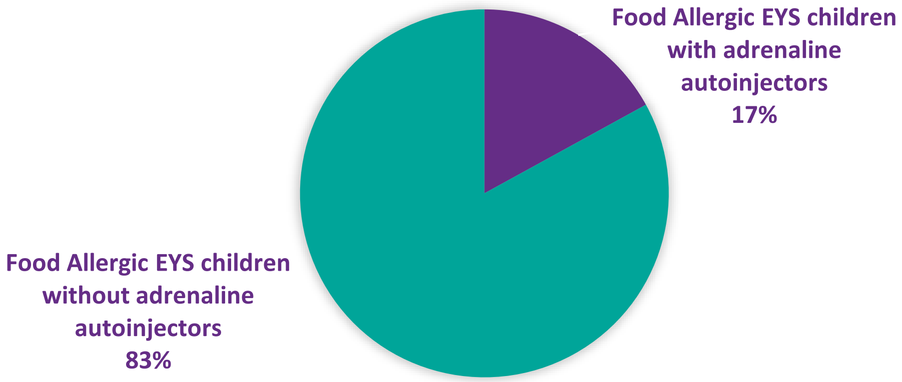
Figure 6.1.1d: Percentage of Early Year Services (n=164) that reported a previous incident of an adverse reaction (severity not specified) to food on-site, reported in an online survey carried out between July and December 2019



*EYS in Ireland (n=145): 17 facilities reported ‘Yes’, 79 facilities reported ‘No’, and 49 facilities did not answer the question.

**EYS in Northern Ireland (n=19): 1 facility reported ‘Yes’, 17 facilities reported ‘No’, and 1 facility did not answer the question.

Figure 6.1.1e: Percentage of food-allergic children attending Early Learning Services (n=317) who carry an adrenaline auto-injector (n=55) based on data collected from an online survey carried out between July and December 2019



*55 children were reported to have adrenaline auto-injector: 41 from Ireland and 14 from Northern Ireland.

6.2 Reported Percentages of Food Hypersensitivity in Primary & Secondary Schools in Ireland and Northern Ireland

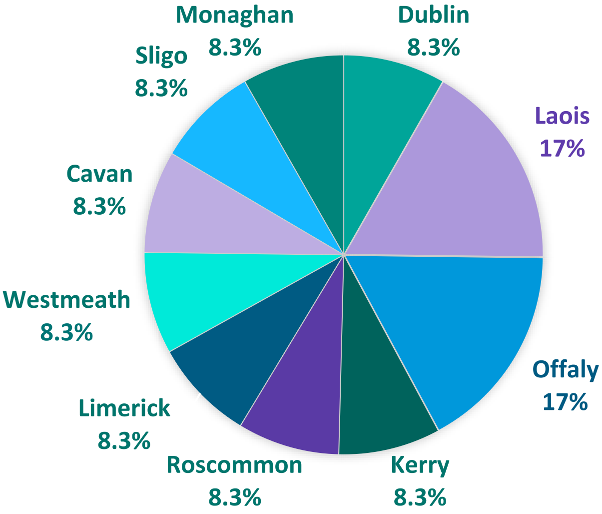
A survey targeting primary and secondary schools in Ireland (n=600) and Northern Ireland (n=136) was carried out between July and December of 2019. The aim of this study was to collate information on food hypersensitivity in children and adolescents attending primary school (approx. age range 4-12 years) and secondary school (approx. age range 12 to 18 years). The county-wide distribution of survey responses is presented in Figures 6.2.1a and 6.2.1b. Reported food hypersensitivity percentages associated with each gender, and specific trigger foods (where relevant), are presented in Figures 6.2.1c and 6.2.1d.

Eight primary schools and four secondary schools, out of a total of 600 schools contacted in Ireland, completed (or partially completed) a survey on food hypersensitivity in their student populations. The responses collected from these participating schools consisted of information on 1,349 students attending primary school and 1,090 adolescents attending secondary school in Ireland. A total of 56 (4.2%) primary school children were reported as having a food hypersensitivity by the survey respondents in Ireland (Table 6.2.1). These included 30 individuals (2.2%) who were reported as having food allergy, 11 (0.8%) with coeliac disease, and 15 (1.1%) with FI. With regard to secondary school students in Ireland, a total of 42 (3.9%) were reported as having a food hypersensitivity (Table 6.2.1). These included 29 individuals (2.7%) who were reported as having food allergy, three (0.3%) with coeliac disease, and 10 (0.9%) with FI.

One primary school, one secondary school, and one school with both a primary and secondary school on-site in Northern Ireland completed the survey on food hypersensitivity in their student population. This accounted for three schools out of total of 136 schools contacted in Northern Ireland. The information collected from these participating schools consisted of information on 794 students. A total of 13 (9%) primary school children were reported as having a food hypersensitivity (Table 6.2.1). These included five individuals (3.5%) with food allergy, zero (0%) with CD, and eight (5.5%) with FI. With regard to secondary school students in Northern Ireland, a total of 15 (2.3%) were reported as having a food hypersensitivity (Table 6.2.1). These included 12 individuals (1.9%) with FA, one (0.2%) with coeliac disease, and two (0.2%) with FI.

Trigger foods associated with the reported food allergies and intolerances are presented in Figures 6.2.1c and 6.2.1d. Nuts, dairy, eggs and soya were the four most reported food allergens in primary schools on the IoI (n=10), with nuts, eggs, dairy and kiwi being the main food allergens in secondary schools (n=6). Of the 35 children with a food allergy in primary schools, 43% (15 children in Ireland only) were noted to carry an adrenaline auto-injector, and 20% (two children in Ireland and six in Northern Ireland) out of 41 food allergic adolescents were attending second level (Figures 6.2.1g and 6.2.1h). When the respondent schools were asked about previous incidences of adverse reactions to food on-site (severity not specified), 20% of primary schools (two in Ireland) and 33% of secondary schools (two in Ireland) reported they had experienced this (Figures 6.2.1e and 6.2.1f).

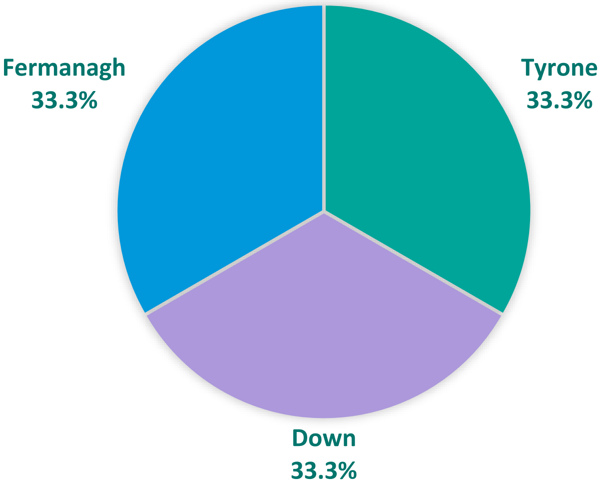
Figure 6.2.1a: Completion rate of the food hypersensitivity survey in schools in Ireland by county (n=12), following online circulation to schools between July and December 2019



*Eight primary schools responded to the survey in Ireland: Offaly = 2, Laois = 1, Monaghan = 1, Dublin = 1, Kerry = 1, Cavan = 1, Sligo = 1.

**Four secondary schools responded to the survey in Ireland: Laois = 1, Roscommon = 1, Limerick = 1, Westmeath = 1.

Figure 6.2.1b: Completion rate of the food hypersensitivity survey in schools in Northern Ireland by county (n=3), following online circulation to schools between July and December 2019



*Three schools responded to the survey in Northern Ireland: a primary school in Fermanagh, a secondary school in Tyrone and a mixed level school (primary and secondary on-site) in Co. Down

Table 6.2.1: Breakdown of reported food hypersensitivity in children/adolescents attending schools (n=12) in Ireland (2,439 individuals) and schools (n=3) in Northern Ireland (794 individuals), based on responses from an online survey circulated to schools between July and December 2019

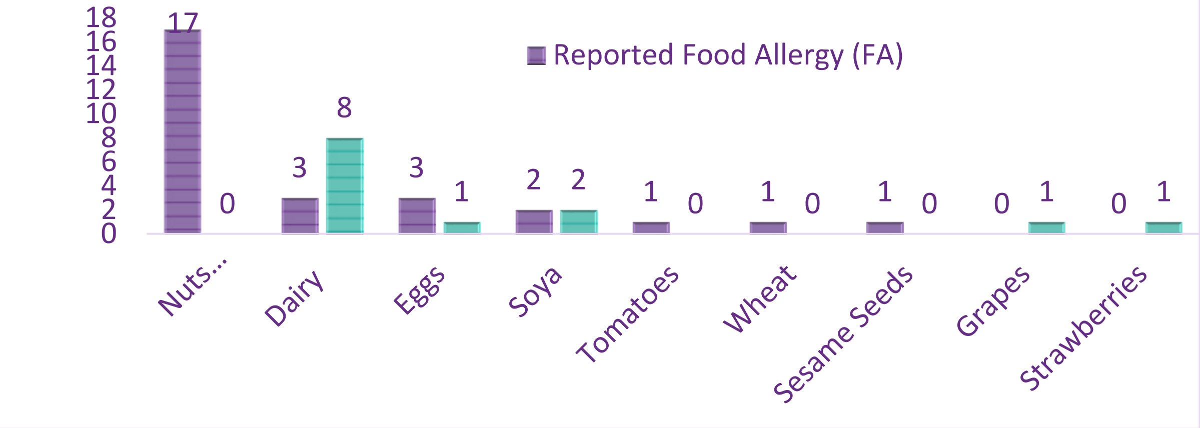
School Survey Results	**Ireland**	**Northern Ireland**	**Ireland and Northern Ireland**
Total number of schools contacted regarding this survey	**600**	**136**	**736**
Primary schools	303	68	371
Secondary schools	297	68	365
Number of schools that completed survey (% of total)	**12 (2%)**	**3 (2.2%)**	**15 (2.0%)**
Primary schools (% of total)	8 (2.6%)	1 (1.5%)	9 (2.4%)
Schools with mixed primary and secondary (% of total)	0 (0%)	1 (0.7%)	1 (0.1%)
Secondary schools (% of total)	4 (1.3%)	1 (1.5%)	5 (1.4%)
Number of students represented in completed surveys	**2,439**	**794**	**3,233**
Primary students	1,349	29	1,378
Schools with mixed primary and secondary students	0	233	233
Secondary	1,090	532	1,622
Primary schools: females (% of total)	741 (12%)	13 (0.1%)	754 (14%)
Primary schools: males (% of total)	608 (10%)	16 (2%)	624 (12%)
Mixed primary and secondary: females (% of total)	0 (0%)	58 (7%)	58 (1%)
Mixed primary and secondary on-site: males (% of total)	0 (0%)	175 (22%)	175 (3%)
Secondary schools: females (% of total)	388 (16%)	268 (34%)	656 (20%)
Secondary schools: males (% of total)	702 (29%)	264 (33%)	966 (30%)
Reported Food Hypersensitivity Primary (% of primary)	**56 (4.2%)**	**13 (9%)**	**69 (4.6%)**
Reported Food Hypersensitivity Secondary (% of secondary)	**42 (3.9%)**	**15 (2.3%)**	**57 (3.5%)**
Primary schools: females reported FH (% of primary)	11 (0.8%)	2 (1.4%)	13 (0.9%)
Primary schools: males reported with FH (% of primary)	11 (0.8%)	10 (7%)	21 (1.4%)
Primary schools gender unknown with FH (% of primary)	34 (2.5%)	1 (0.7%)	35 (2.3%)
Secondary schools: females reported FH (% of secondary)	0 (0%)	3 (0.5%)	3 (0.05%)
Secondary school: males reported with FH (% of secondary)	13 (0.3%)	12 (1.9%)	25 (0.4%)
Secondary schools: gender unknown with FH (% of second.)	29 (0.6%)	0 (0%)	29 (0.5%)

School Survey Results	**Ireland**	**Northern Ireland**	**Ireland and Northern Ireland**
Reported Food Allergy in Primary (FA) (%)	**30 (2.2%)**	**5 (3.5%)**	**35 (2.3%)**
Reported Food Allergy in Secondary (FA) (%)	**29 (2.7%)**	**12 (1.9%)**	**41 (2.5%)**
Primary schools: females reported FA (% of total)	8 (0.6)	1 (0.7%)	9 (0.6 %)
Primary schools: males reported with FA (% of total)	10 (0.7)	3 (2.1%)	13 (0.9%)
Primary schools: gender unknown with FA (% of total)	12 (0.8)	1 (0.7 %)	13 (0.9%)
Secondary schools: females reported FA (% of total)	0 (0%)	1 (0.2 %)	1 (%)
Secondary schools: males reported with FA (% of total)	12 (0.2%)	11 (1.7 %)	23(%)
Secondary schools: gender unknown with FA (% total)	17 (0.3%)	0 (%)	17(%)
Reported Coeliac Disease in Primary (CD (% of total)	**11 (0.8%)**	**0 (0%)**	**11 (0.7%)**
Reported Coeliac Disease in Secondary (CD) (% of total)	**3 (0.3%)**	**1 (0.2%)**	**4 (0.3%)**
Primary schools: females reported CD (% of total)	1 (0.07%)	0 (0%)	1 (0.1%)
Primary schools: males reported with CD (% of total)	0 (0%)	0 (0%)	0 (0%)
Primary schools: gender unknown with CD (% of total)	10 (0.7%)	0 (0%)	10 (0.7%)
Secondary schools: females reported CD (% of total)	0 (0%)	1 (0.2%)	1 (0.02%)
Secondary schools: males reported with CD (% of total)	0 (0%)	0 (0%)	0 (0%)
Secondary schools: gender unknown with CD (% total)	3 (100%)	0 (0%)	3 (0.05%)
Reported Food Intolerance in Primary (FI) (% of total)	**15 (1.1%)**	**8 (5.5%)**	**23 (1.5%)**
Reported Food Intolerance in Secondary (FI) (% of total)	**10 (0.9%)**	**2 (0.2%)**	**12 (0.7%)**
Primary schools: females reported FI (% of total)	2 (0.2%)	0 (0%)	2 (0.1%)
Primary schools: males reported with FI (% of total)	1 (0.07%)	7 (7%)	8 (0.5%)
Primary schools: gender unknown with FI (% of total)	12 (0.9%)	1 (0.7%)	13 (0.9%)
Secondary schools: females reported FI (% of total)	0 (0%)	1 (0.2%)	1 (0.02%)
Secondary schools: males reported with FI (% of total)	1 (0.02%)	1 (0.2%)	2 (0.04%)
Secondary schools: gender unknown with FI (% total)	9 (0.2%)	0 (0%)	9 (0.2%)

* FA: Food Allergy; CD: Coeliac disease; FI: Food Intolerance or Suspected/Undiagnosed Food Allergies (FI).

** Food Hypersensitivity includes FA, CD and FI.

Figure 6.2.1c: Trigger foods reported for primary school children in Ireland and Northern Ireland for 20 out of 23 food-intolerant individuals (with the exception of coeliac disease) and 22 out of 35 food allergic individuals reported in an online survey carried out between July and December 2019



*** Ireland:**

Medically Diagnosed Food Allergy: Nuts (unspecified) = 16, Dairy = 1, Eggs = 1, Sesame seeds = 1.

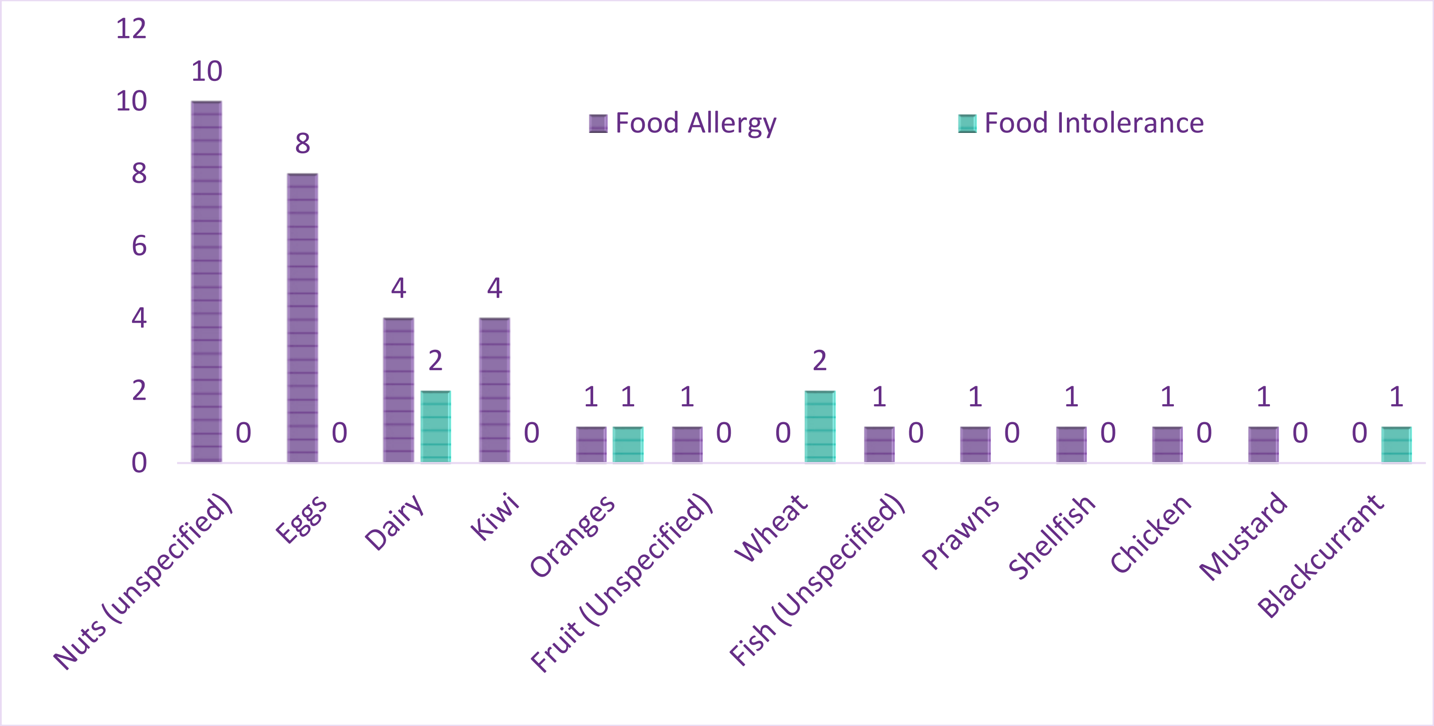
Food Intolerance: Dairy = 2, Egg s= 1.

**** Northern Ireland:**

Medically Diagnosed Food Allergy: Nuts (unspecified) = 1, Dairy = 2, Eggs = 2, Soya = 2 Tomatoes = 1, Wheat = 1.

Food Intolerance: Dairy = 6, Soya = 2, Grapes = 1, Strawberries = 1.

Figure 6.2.1d: Trigger foods reported for secondary school children in Ireland and Northern Ireland for two out of 12 food intolerant individuals (with the exception of coeliac disease) and 24 out of 41 food allergic individuals reported in an online survey carried out between July and December 2019



*** Ireland:**

Medically Diagnosed Food Allergy: Nuts (unspecified)=3, Eggs=6, Dairy =4, kiwi=2, Fruit (Unspecified)=1, shellfish=1, chicken=1, mustard=1

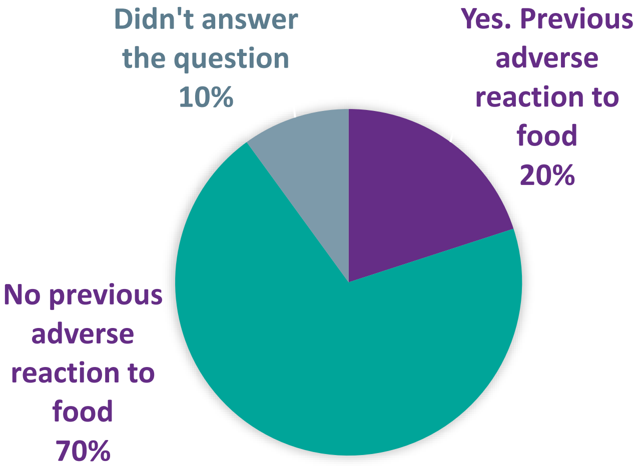
Food Intolerance: wheat=2, Dairy=1

**** Northern Ireland:**

Medically Diagnosed Food Allergy: Nuts (unspecified)=7, Eggs=2, Kiwi =2, Oranges=1, Fish (unspecified) =1, Prawns=1

Food Intolerance: Dairy=1, Orange=1, Blackcurrant=1

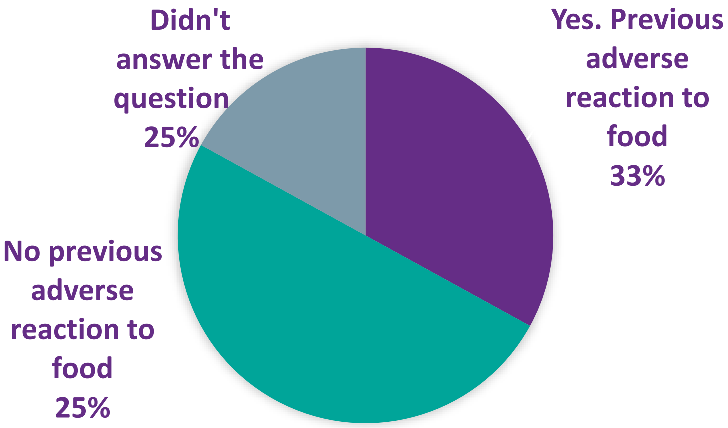
Figure 6.2.1e: Percentage of primary schools (n=10) that reported a previous incident of an adverse reaction (severity not specified) to food on-site as reported in an online survey carried out between July and December 2019



*Primary Schools in Ireland (n=8): Two schools reported ‘Yes’, five schools reported ‘No’, and one school did not answer the question.

**Primary Schools in Northern Ireland (n=2, one of which was mixed primary and secondary): Two schools reported ‘No’.

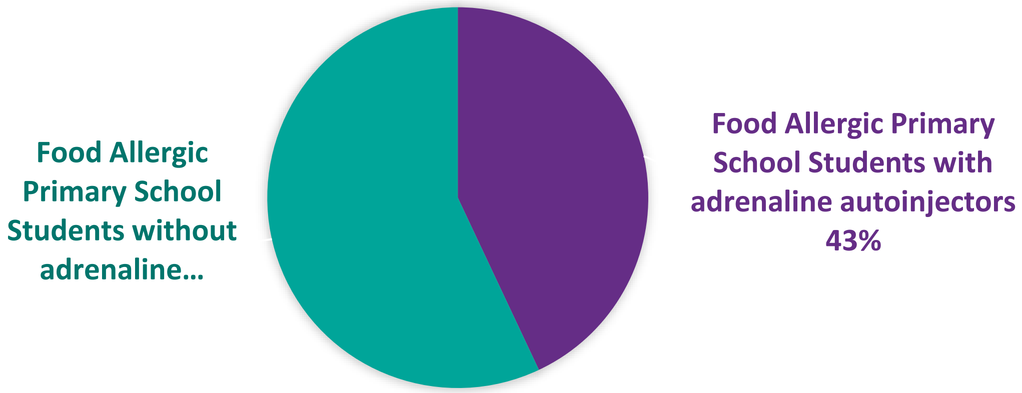
Figure 6.2.1f Percentage of secondary schools (n=6) that reported a previous incident of an adverse reaction (severity not specified) to food on-site as reported in an online survey carried out between July and December 2019



*Secondary Schools in Ireland (n=4): Two schools reported ‘Yes’, one school reported ‘No’, and one school did not answer the question.

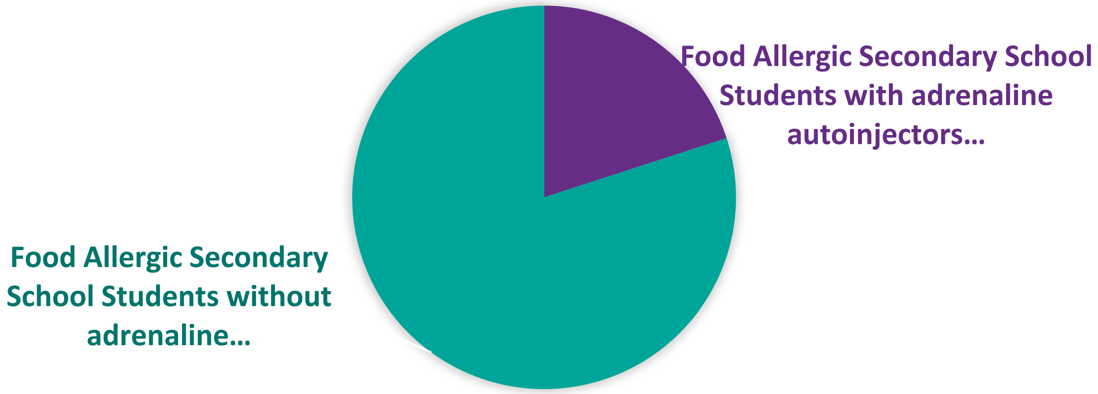
**Secondary Schools in Northern Ireland (n=2, one of which was mixed primary and secondary): Two schools reported ‘No’.

Figure 6.2.1g: Percentage of primary students reported with a food allergy (n=35) who carry an adrenaline auto-injector (n=15), based on data collected from an online survey carried out between July and December 2019



*Fifteen food allergic primary school students were reported to carry an adrenaline auto-injector, all of whom were from Ireland and zero in Northern Ireland. The total number of students reported with food allergies in Ireland was 30 and in Northern Ireland was five.

Figure 6.2.1h: Percentage of secondary students reported with a food allergy (n=41) who carry an adrenaline auto-injector (n=8), based on data collected from an online survey carried out between July and December 2019



*Two food allergic secondary school students in Ireland, and six in Northern Ireland, were reported to carry an adrenaline auto-injector. The total number of secondary students reported to have food allergies was 29 in Ireland and 12 in Northern Ireland.

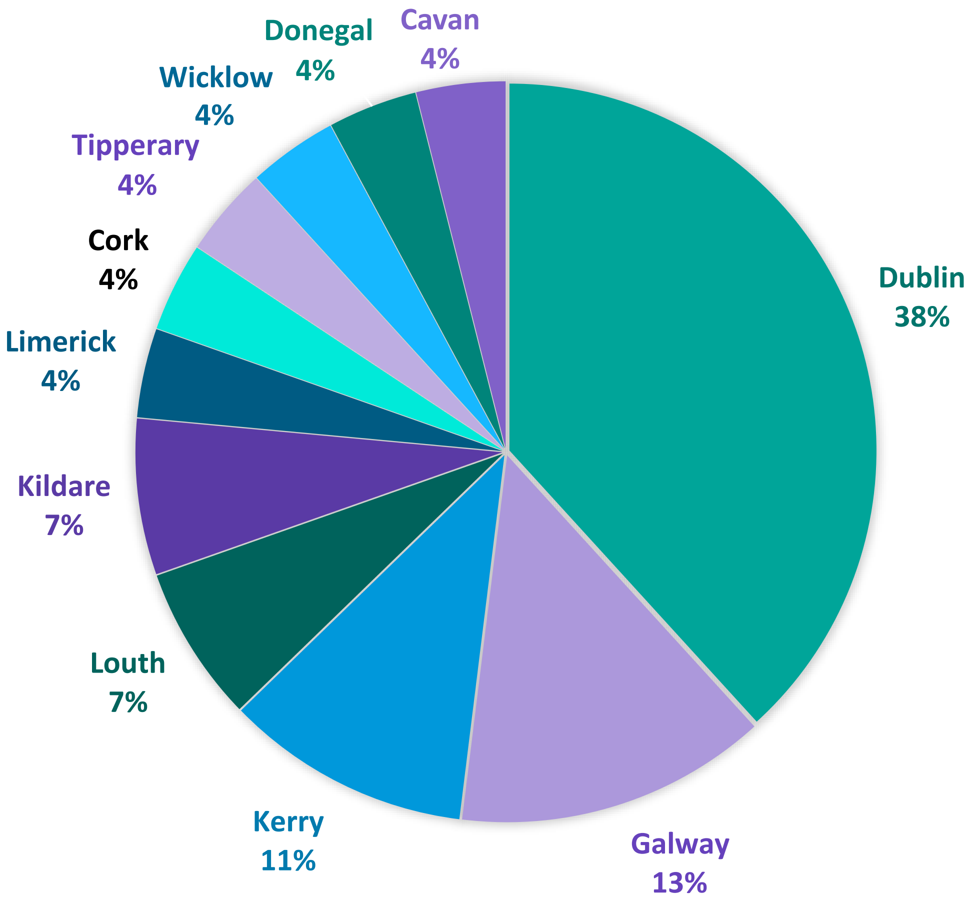
6.3 Reported Percentages of Food Hypersensitivity in Nursing Homes in Ireland and Northern Ireland

A survey targeting all the nursing homes in Ireland (n=423) and Northern Ireland (n=212) was carried out between July and December of 2019. The aim of this study was to collate information on food hypersensitivity among the residents (age range 49-103, predominantly 70-95 years old). Survey returns by county are presented in Figures 6.3.1a and 6.3.1b. Reported food hypersensitivity percentages associated with each gender and specific trigger foods (where relevant) are presented in Figure 6.3.1c.

Twenty-eight nursing homes in Ireland (out of 423 contacted), representing 1,973 residents, completed (or partially completed) a survey on food hypersensitivity (Table 6.3.1). A total of 122 (6.2%) residents were reported to have a food hypersensitivity. These included 43 individuals (2.2%) with food allergy, 31 (1.6%) with coeliac disease and 54 (2.4%) with FI. Three nursing homes (9%) reported residents having previously had adverse reactions to food (severity not specified) on their premises, 18 nursing homes reported no previous adverse reactions, while seven nursing homes did not answer the question (Figure 6.3.1d). Ten nursing homes (29%) had an adrenaline auto-injector on site, seven didn’t have one, three didn't know, and eight didn’t answer the question (Figure 6.3.1e).

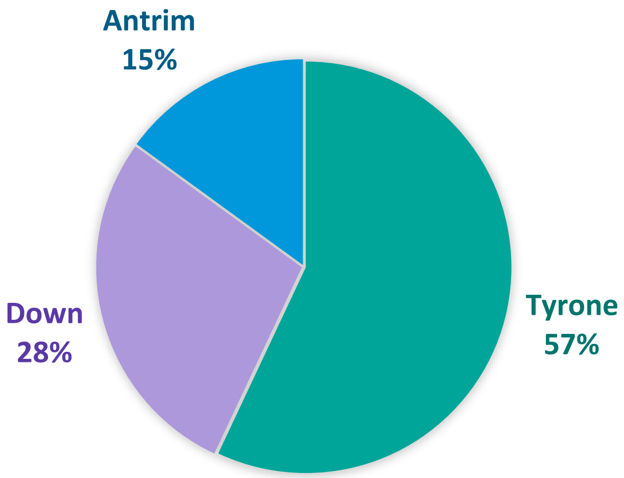
Seven nursing homes in Northern Ireland (out of 212 contacted), representing 166 residents, completed (or partially completed) a survey on food hypersensitivity (Figure 6.3.1). A total of five (3%) residents were reported to have a food hypersensitivity. These included two individuals (1.2%) with food allergy, two (1.2%) with coeliac disease and one (0.6%) with FI. Only a small number of trigger foods were reported and the allergens noted were nuts, dairy and eggs (Figure 6.3.1c). Five nursing homes (71%) reported residents having previously had adverse reactions to food (severity not specified) on their premises, while the other two nursing homes did not answer the question (Figure 6.3.1d). Three nursing homes (43%) had an adrenaline auto-injector available on site, while two nursing homes reported none and two did not answer the question (Figure 6.3.1e).

Figure 6.3.1a: Completion rate of the food hypersensitivity survey in nursing homes by county in Ireland (n=28) following online circulation to nursing homes between July and December 2019



*Twenty-eight nursing homes responded to the survey in Ireland: Dublin = 11, Galway = 4, Kerry = 3, Louth = 2, Kildare = 2, Limerick = 1, Cork = 1, Tipperary = 1, Wicklow = 1, Donegal =1 , Cavan = 1.

Figure 6.3.1b: Completion rate of the food hypersensitivity survey in nursing homes by county in Northern Ireland (n=7) following online circulation to nursing homes between July and December 2019



*Seven nursing homes responded to the survey in Northern Ireland: Tyrone = 4, Antrim = 2 Down = 1.

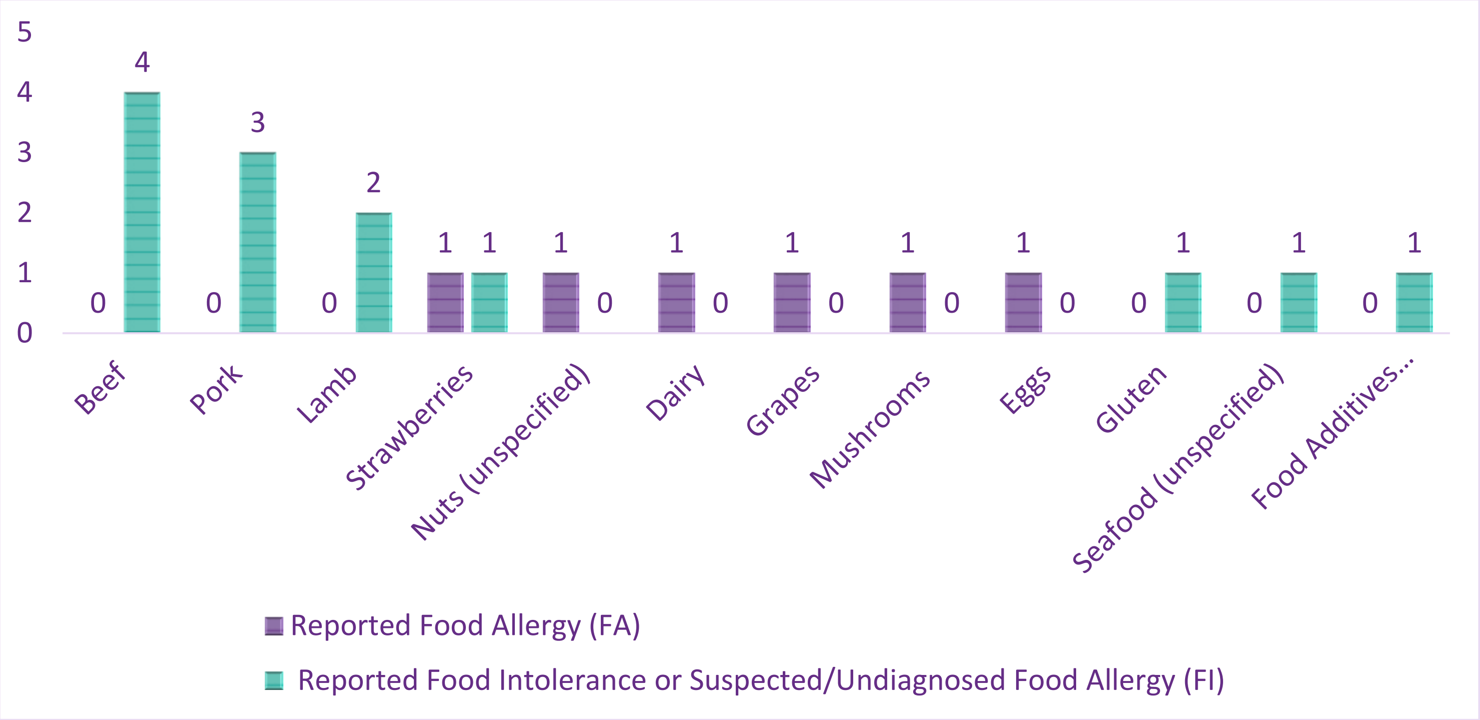
Table 6.3.1 Food hypersensitivity in nursing homes in Ireland (n=28; 1,973 individuals) and Northern Ireland (n=7; 2,139 individuals) from an online survey circulated to nursing homes between July and December 2019

Nursing homes residents survey results	**Ireland**	**Northern Ireland**	**Ireland and Northern Ireland**
Nursing homes contacted regarding this survey	423	212	635
No. of nursing homes that completed survey (% of total)	28 (7%)	7 (3%)	35 (6%)
No. of residents represented in completed surveys	**1,973**	**166**	**2,139**
Female residents (% of total)	1,118 (57%)	127 (77%)	1,245 (58%)
Male residents (% of total)	610 (31%)	39 (23%)	649 (30%)
Gender unknown (% of total)	245 (12%)	0 (0%)	245 (12%)
Reported Food Hypersensitivity: (% of total)	**122 (6.2%)**	**5 (3%)**	**127 (5.9%)**
Female residents reported with FH (% of total)	17 (0.9%)	2 (1.2%)	19 (0.9%)
Male residents reported with FH (% of total)	8 (0.4%)	3 (1.8%)	11 (0.5%)
Gender unknown reported with FH (% of total)	97 (4.9%)	0 (0%)	97 (4.5%)
Reported Food Allergy (% of total)	**43 (2.2%)**	**2 (1.2%)**	**45 (2.1%)**
Female residence reported with FA (% of total)	4 (0.2%)	1 (0.6%)	5 (0.25)
Male residents reported with FA (% of total)	0 (0%)	1 (0.6%)	1 (0.05%)
Gender unknown reported with FA (% of total)	39 (2%)	0 (0%)	39 (1.8%)
Reported Coeliac Disease (% of total)	**31 (1.6%)**	**2 (1.2%)**	**33 (1.5%)**
Female residents reported with CD (% of total)	10 (0.5%)	1 (0.6%)	11 (0.5%)
Male residents reported with CD (% of total)	4 (0.2%)	1 (0.6%)	5 (0.2%)
Gender unknown reported with CD (% of total)	17 (0.9%)	0 (0%)	17 (0.8)
Reported Food Intolerance or Suspected/Undiagnosed Food Allergies	**48 (2.4%)**	**1 (0.6%)**	**49 (2.3%)**
Female residents reported with FI (% of total)	3 (0.2%)	0 (0%)	3 (0.1%)
Male residents reported with FI (% of total)	4 (0.2%)	1 (0.6%)	5 (0.2%)
Gender unknown reported with FI (% of total)	41 (2%)	0 (0%)	41 (2%)

* FA: Food Allergy; CD: Coeliac Disease; FI: Food Intolerance or Suspected/Undiagnosed Food Allergies (FI).

**Food Hypersensitivity (FH) includes FA, CD and FI.

Figure 6.3.1c Trigger foods reported by 12 food intolerant residents (with the exception of coeliac disease) (36 unknown, n=48) and four medically diagnosed residents (39 unknown, n=43) in nursing homes in Ireland and Northern Ireland from a survey carried out between July to December 2019



*** Ireland:**

Medically Diagnosed Food Allergy: Strawberries = 1, Grapes = 1, Mushrooms = 1, Eggs = 1.

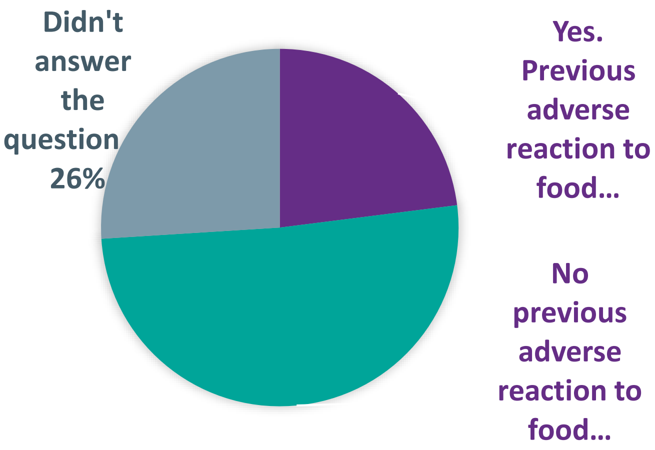
Food Intolerance or Suspected/Undiagnosed Food Allergy: Beef = 4, Pork = 3, Lamb = 2, Strawberry = 1, Seafood (not specified) = 1, Food additives = 1(not specified).

**** Northern Ireland:**

Medically Diagnosed Food Allergy: Nuts (unspecified) = 1, Dairy = 1.

Food Intolerance or Suspected/Undiagnosed Food Allergy: Gluten = 1.

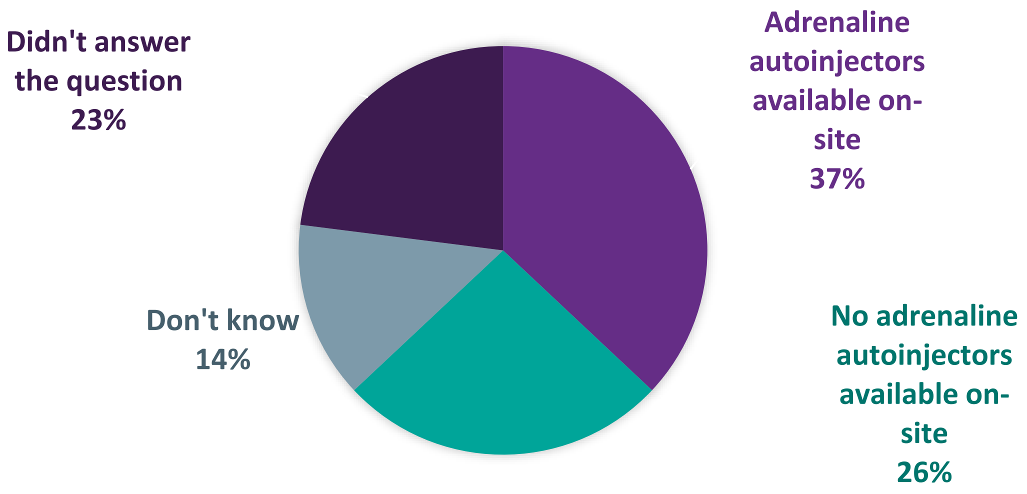
Figure 6.3.1d: Reported incidence of adverse reactions to food (severity not specified) in nursing homes in Ireland (n=28) and Northern Ireland (n=7) based on an online survey carried out between July and December 2019



* Three nursing homes in Ireland reported that residents had previously had adverse reactions to food on-site, 18 respondents reported none, and seven did not answer the question.

** Five nursing homes in Northern Ireland reported that residents had previously had adverse reactions to food on-site, and the other two nursing homes did not answer the question.

Figure 6.3.1e: Reported availability of adrenaline auto-injectors in nursing homes in Ireland (n=28) and Northern Ireland (n=7) based on an online survey carried out between July and December 2019



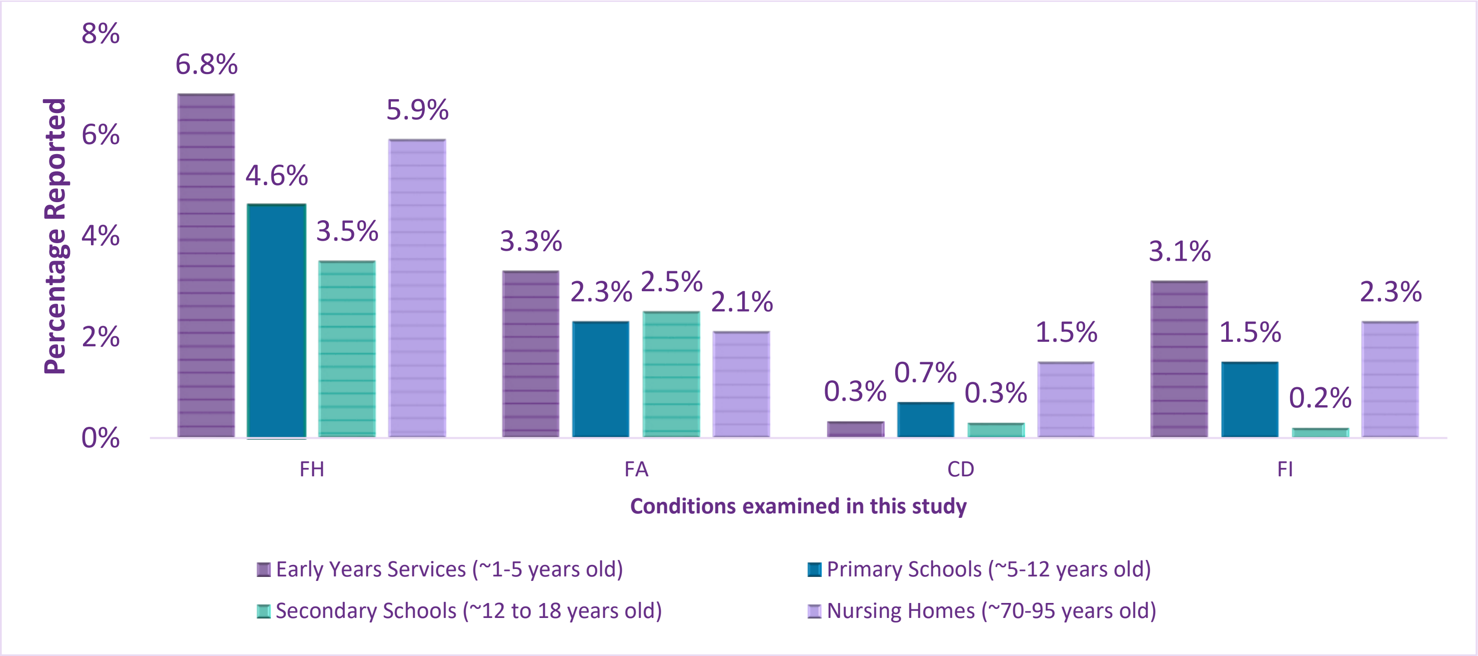
* 10 nursing homes in Ireland reported having an adrenaline autoinjector available in their facilities in case of emergencies, 7 respondents reported none; 3 didn't know, 8 did not answer the question.

** 3 nursing homes in Northern Ireland reported having an adrenaline autoinjector available in their facilities in case of emergencies, 2 respondents reported none; 2 didn't know

6.4 Overview of the prevalence of food hypersensitivity in Early Years Services, Schools and Nursing Homes

An overview of the reported percentages of food hypersensitivity by organisational category and condition is presented in Figure 6.4. It should be noted that this data is self-reported (based on the respondents' knowledge and information) and therefore may not necessarily reflect the full spectrum of food hypersensitivities in all of the 14,889 individuals from the 214 organisations represented in this survey. An example would be schools that do not serve food on a daily basis and therefore may only record severe food allergies and not food hypersensitivities that are mild and non-life-threatening. The nature of the data (i.e., resident versus attendee), and the varying amounts of personal data retained by different organisations, make it difficult to directly compare the four organisational datasets. Therefore, this chapter represents a 'snap-shot' of some of the food hypersensitivity information currently stored in public and private organisations in Ireland and Northern Ireland and provides data with regard to trends associated with these conditions.

Figure 6.4. Reported percentages of food hypersensitivity in 14,889 individuals in 214 organisations on the IoI based on an online survey circulated to nursing homes between July and December 2019



* Surveys were collected from 145 EYS in Ireland and 19 EYS in Northern Ireland; eight primary schools and four secondary schools in Ireland and one primary school, one secondary school and one mixed primary and secondary school in Northern Ireland, and 28 nursing homes in Ireland and seven in Northern Ireland.

Higher levels of food hypersensitivity (with the exception coeliac disease) were reported in EYS than in schools and nursing homes. This agrees with published studies that reported higher levels of FA and FI in pre-school children than in older children (Lyons *et al.* 2020; De Martinis *et al.* 2019). The low level of coeliac disease reported in the EYS group is not unexpected as this condition is generally diagnosed later in life (Price & Howard, 2017). The percentage of coeliac disease was 1.5% in nursing homes (2,239 residents in Ireland and Northern Ireland) compared to 0.3-0.7% in the younger groups in this study. Coeliac disease is typically reported at 1% in adults in Ireland (CSI, 2019). A lower percentage of FI (0.2%-1.5%), leading to a lower overall reported percentage of food hypersensitivity (3.5-4.6%), was reported for primary and secondary school children and adolescents. This finding could potentially be a result of the under-reporting of milder food hypersensitivity in schools that do not provide meals for their students.

Food hypersensitivity was found to range from 3.5-6.8% (FA from 2.1-3.3%, coeliac disease from 0.3-1.5%, and FI 0.2-3.1%) in the groups examined in this study. Among the individuals who had FA, 17-43% of carried an adrenaline auto-injector, including on average 20% of EYS children and school-goers. Thirty-seven per cent of nursing homes reported having an adrenaline auto-injector on-site. Approximately 11% of EYS, 20% of primary schools, 23% of nursing homes and 33% secondary schools reported previous incidences of an adverse reaction to food on-site (30 organisations, 14% of all surveyed). Although the severity of these incidents was not investigated in the surveys, some respondents specified that severe reactions had occurred, and that adrenaline auto-injectors had been used in some of these incidences.

6.5 Examination of Food Hypersensitivity Datasets on the Island of Ireland

During this study, databases with information on food hypersensitivity for the IoI were examined for prevalence of food hypersensitivity, distribution by age and gender, and the associated trigger foods (where available). The databases reviewed were:

- 6.5.1 Self-reported food allergy/hypersensitivity data from registered students (19,929 students) attending Technological University Dublin (2018-2019): This dataset includes the self-reported food allergy/hypersensitivity data (often including the trigger food) by gender for 19,929 students registered in the academic year 2018/2019.
- 6.5.2 The ‘Growing Up in Ireland’ study from the Economic & Social Research Institute (ERSI): This includes the percentage of food hypersensitivity in 11,134 infants when

they are nine months old, three years old (n=9,783) and five years old, between 2008-2013. The gender of each of the food hypersensitive groups (Waves 1, 2, and 3) is also examined. Available at: https://www.growingup.ie/about-growing-up-in-ireland/

- 6.5.3 Central Statistics Office (CSO) survey for 5,348 secondary school students from 155 secondary schools (2015): This includes the breakdown of specific food allergies within this group. Available at: www.censusatschool.ie
- 6.5.4 'Dining Out: The Challenge for Those with a Food Allergy or Food Intolerance in the Republic of Ireland and Northern Ireland' (2013). This includes information of trigger foods associated with food hypersensitivity for 241 individuals in Ireland and 111 in Northern Ireland. Available at the following links:
    - https://www.safefood.net/getmedia/62903d02-8532-4659-a7e6-59ba365ec00f/Final-report-IRELAND-Jan2015.aspx?ext=.pdf
    - https://www.safefood.net/getmedia/3f1e9d08-a448-47c9-bfbb-0305513ef6b7/Final-report-NI-Jan2015.aspx?ext=.pdf
- 6.5.5 FSAI Food Allergy Survey (2011): The FSAI carried out an online food allergy and intolerance survey in Ireland (n=509) as part of their 'Monitoring and Surveillance Series Food Allergens and Labelling Survey'. Associated food allergens are reported. Available at: https://www.fsai.ie/resources_publications/allergen_labelling_2011.html.html
- 6.5.6a Irish Hospital Inpatients Enquiry (HIPE 1) data for Ireland: Information on the predominant food associated with food anaphylaxis between 1995 to 2004.
- 6.5.6b Irish Hospital Inpatients Enquiry (HIPE 2) data for Ireland: HIPE 2 is a dataset of the number of individuals discharged from hospital as a result of food anaphylaxis (principal diagnosis) between 2008 and 2018. Figures on hospital discharge numbers, associated age categories and gender are reviewed.
- 6.5.7 Data from a study on the incidence and prevalence of coeliac disease in the UK (per region) over two decades (1990-2011): Population-based study: This study provides information on the prevalence of coeliac disease in Northern Ireland, England, Scotland & Wales in 2011. This data is also examined with regard to gender and age of individuals diagnosed with coeliac disease. Available at: https://journals.lww.com/ajg/Fulltext/2014/05000/Incidence_and_Prevalence_of_Celiac_Disease_and.22.aspx
- 6.5.8 Coeliac Society of Ireland dataset of 2,899 individuals reporting to have MDCD in 2019: The Coeliac Society of Ireland 2019 dataset includes information on 2,899 members (by gender) with MDCD. This information was also available by age

category: infants and young children (0-3 years), children (4-12 years), adolescents (13-17 years), adults (18-64 years) and adults (>65 years).

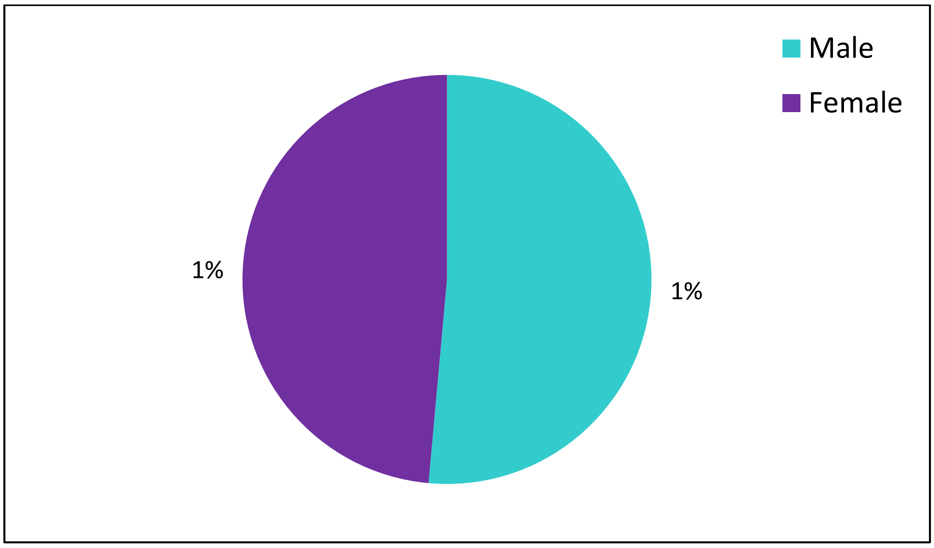
- 6.5.9 Prevalence values reported in the literature

6.5.1 Self-reported food allergy/hypersensitivity data from registered students (19,929 students) attending the Technological University Dublin (2018-2019)

Gender breakdown of students with a food allergy

The database was acquired for the academic year 2018-2019 and consists of anonymised food hypersensitivity information on 19,929 students (11,818 males and 8,111 females) who were registered in Technological University Dublin at this time. On their registration form, students were asked to give information regarding any 'food allergies' they may have. However, no other option was included to record other food hypersensitivities, so this information may have also been recorded under the 'food allergy' heading. For this reason, the data presented will be reported as % food allergy/hypersensitivity. For the academic year in question, 313 students (161 males and 152 females), or 1.57%, reported having a food allergy/hypersensitivity (Figure 6.5.1a). Out of this group, 65 (0.33%) students stated they carried an adrenaline auto-injector. There was no age breakdown of this dataset.

Figure 6.5.1a: Breakdown of students by gender with food allergy/hypersensitivity (n=313) following registration at the Technological University Dublin in the academic year 2018-2019



When trigger foods were examined, nuts (n=121, 39%), cereals containing gluten (n=71, 23%), crustaceans (n=48), eggs (n=41) and milk (n=35) were the five most reported trigger allergens (n=313 students; Figure 6.5.1b and Table 6.5.1a).

Figure 6.5.1b: Trigger allergens among students registering at the Technological University Dublin in the academic year 2018-2019 who reported a food allergy/hypersensitivity (n=313)

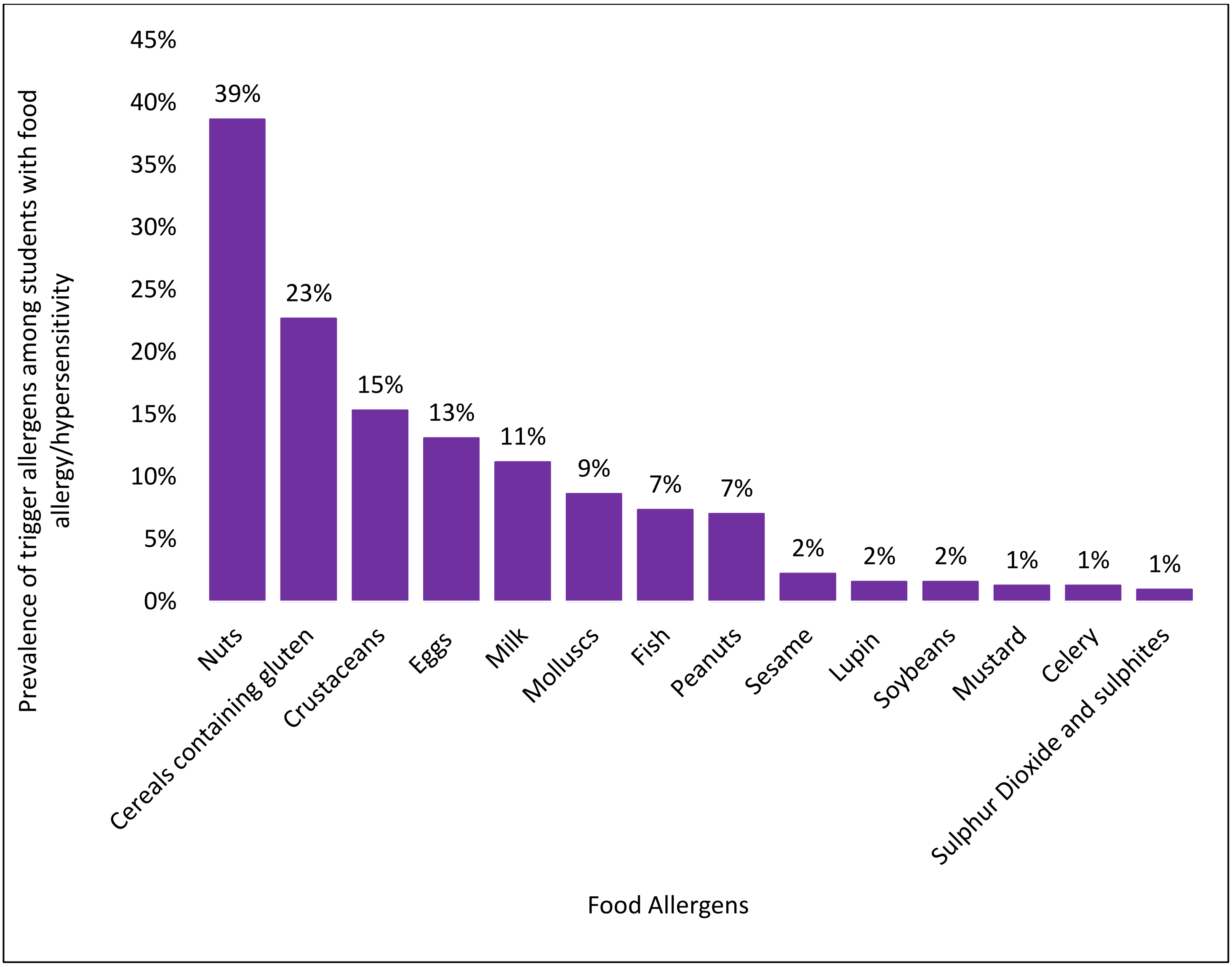


Table 6.5.1a: Percentage of students who reported a food allergy/hypersensitivity (n=313) to any of 14 EU allergens when registering at the Technological University Dublin in the academic year 2018-2019 (n=19,929)

EU 14 Food allergens (Regulation (EU) No. 1169/2011)	No. of students who reported FA/FH (n=313)	Prevalence of FA/FH among affected students (n=313)	% of all students with FA/FH to that allergen (n=19,929)
Nuts	121	39%	1%
Cereals containing gluten	71	23%	0.4%
Crustaceans	48	15%	0.2%
Eggs	41	13%	0.2%
Milk	35	11%	0.2%
Molluscs	27	9%	0.1%
Fish	23	7%	0.1%
Peanuts	22	7%	0.1%
Sesame seeds	7	2%	0.04%
Lupin	5	2%	0.03%
Soybeans	5	2%	0.03%
Mustard	4	1%	0.02%
Celery	4	1%	0.02%
Sulphur Dioxide and sulphites	3	1%	0.02%

*FA: Food Allergy; FH: Food Hypersensitivity.

Outside of the 14 regulated EU allergens, fruit (unspecified) (15%, n=48, Figure 6.5.1c) and other foods (5%, n=17, Figure 6.5.1d) – vegetables (2%, n=6), herbs and spices (1%, n=4), meat (0.3%, n=1), poultry (0.3%, n=1), yeast (0.3%, n=1), food additives (unspecified) (0.3%, n=1), oats (0.3%, n=1), sugar (0.3%, n=1) and chocolate (0.3%, n=1) – were reported. Seve per cent (n=21) of these students and 0.1% of all students reported an allergy/hypersensitivity to kiwi (Figure 6.5.1c), 3% to pineapple (0.04% of all students) and 2% to apples or citrus fruit (0.03% of all students).

Figure 6.5.1c: Students with a food allergy/hypersensitivity to fruit (n=48) when registering at the Technological University Dublin in the academic year 2018-2019 (n=19,929)

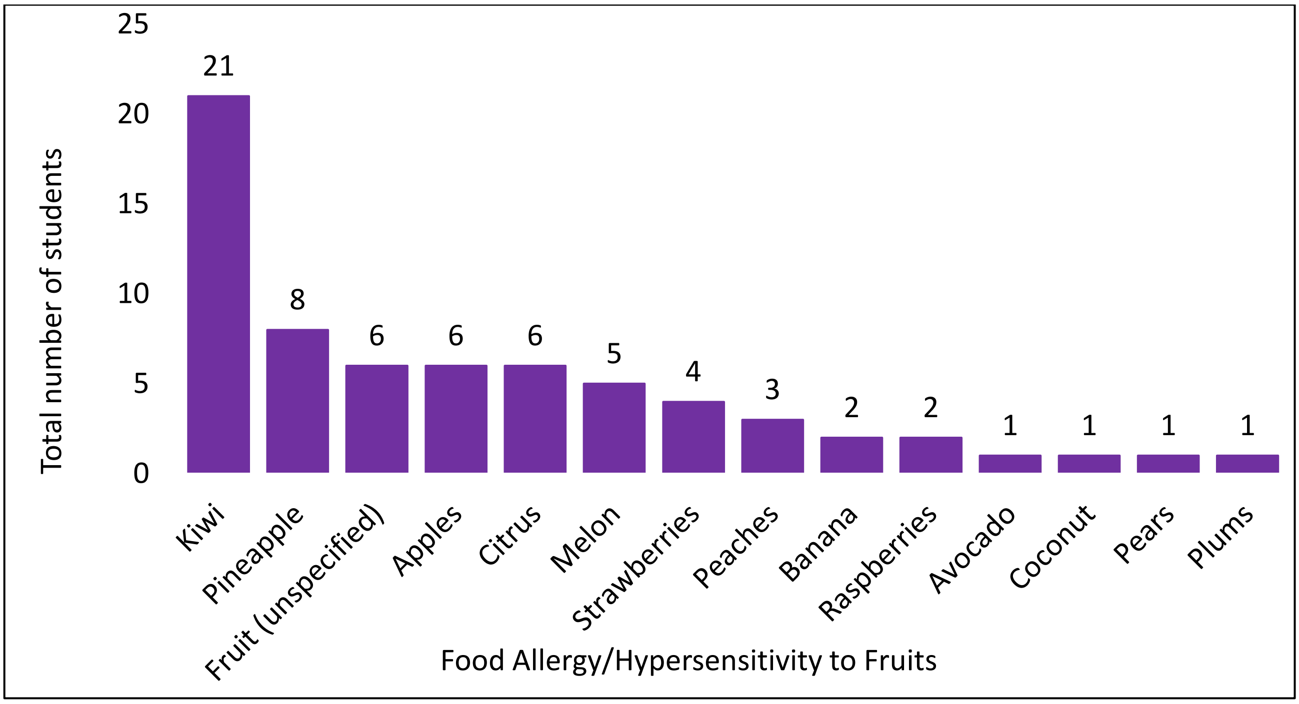
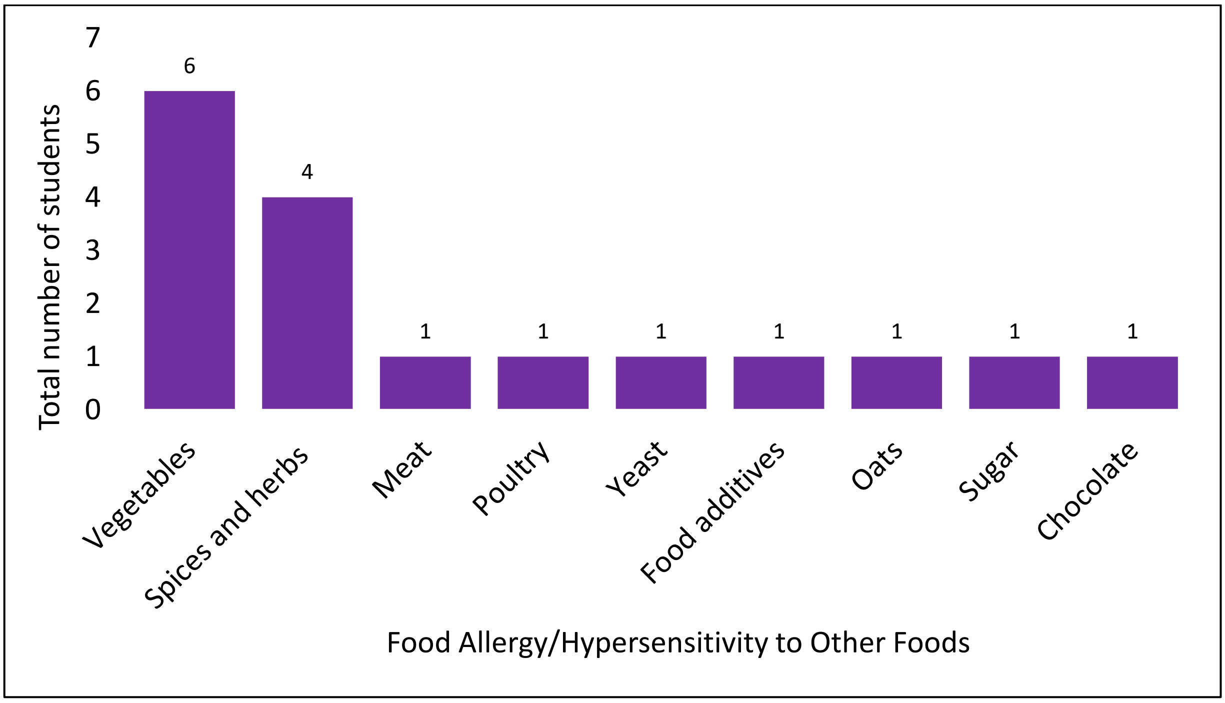


Figure 6.5.1d: Students with a food allergy/hypersensitivity to other foods (n=17) when registering at the Technological University Dublin in the academic year 2018-2019 (n=19,929)



6.5.2 The Growing Up in Ireland Study from the Economic & Social Research Institute (2008-2013)

The Growing Up in Ireland Study was an Irish government-funded study of children jointly carried out by the Economic & Social Research Institute (ESRI) and Trinity College, Dublin. It was managed by the Department of Children, Equality, Disability, Integration and Youth (formerly Department of Children and Youth Affairs) in association with the Central Statistics Office. Details available at: https://www.growingup.ie/about-growing-up-in-ireland/

The study started in 2006 and followed the progress of two groups of children: 8,500 nine-year-olds (Child Group/Group'98) and 11,134 nine-month-olds (Infant Group/Group'08). Parents of the infant group were asked a question regarding 'food or digestive allergy (or food intolerance)' in each of three surveys 'waves'.

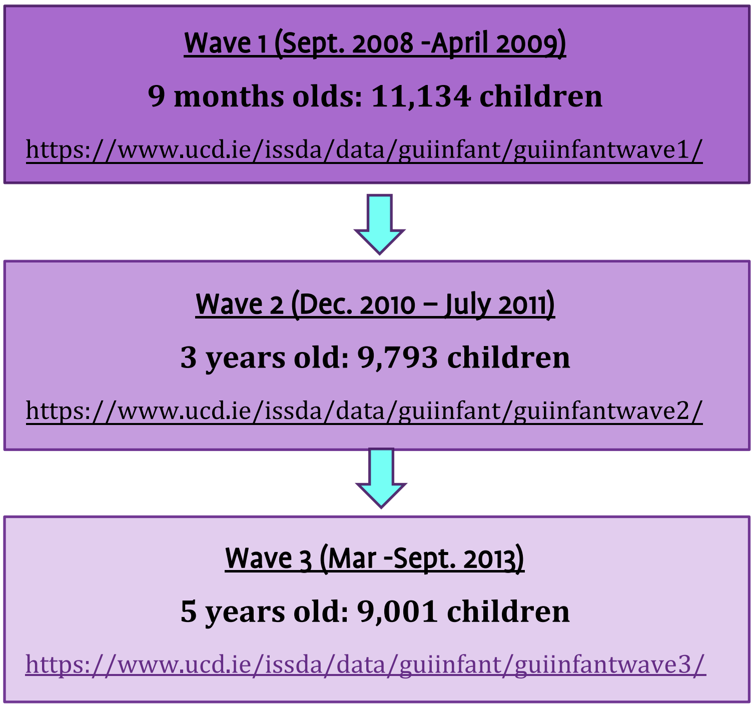
Wave 1: "Has a medical professional ever told you that baby has "digestive allergies" (e.g., lactose intolerant)"?

Wave 2: "Any kind of food or digestive allergy?"

Wave 3: "Any kind of food or digestive allergy or food intolerance?"

Given the slightly confusing description included in these survey questions (particularly the question and example for wave 1, the data will henceforth be described in terms of food hypersensitivity instead of food allergy. The same group was questioned on three occasions between 2008 and 2013 in waves 1, 2, and 3 (Figure 6.5.2a). A summary of the data collected in the three waves is included here. The gender of the infants/children with food hypersensitivity was statistically analysed by a two-sample test. No information regarding associated trigger foods was reported from these surveys.

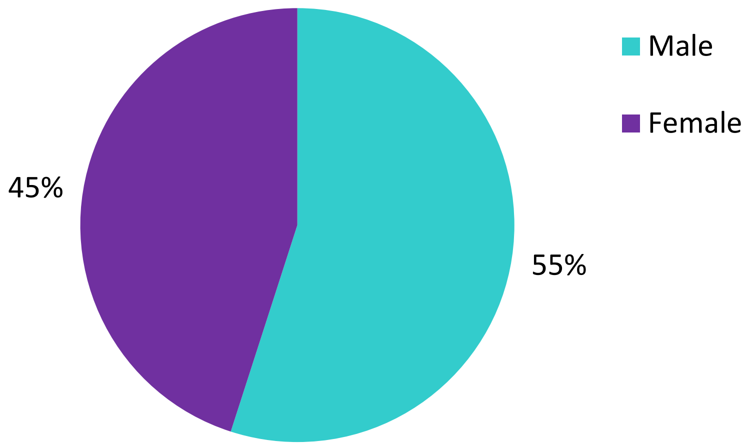
Figure 6.5.2a: Outline of the infant subgroup and source link of the Growing up in Ireland Study carried out in three waves on the same set of children between 2008 and 2013 (n=11,134, n=9,793, n=9,001 children) by the ERSI



Wave 1: Parental survey of nine-month-old infants (Sept 2008 – April 2009)

In wave 1, 11,134 parents were surveyed when their children were nine months old. A total of 433 (3.9%) participants answered *yes* to the question “Has a medical professional ever told you that your baby has “digestive allergies” (e.g., lactose intolerant)”. The gender breakdown was 238 (55%) male and 195 (45%) female infants, the difference not being statistically significant (p = 0.11; Figure 6.5.2b).

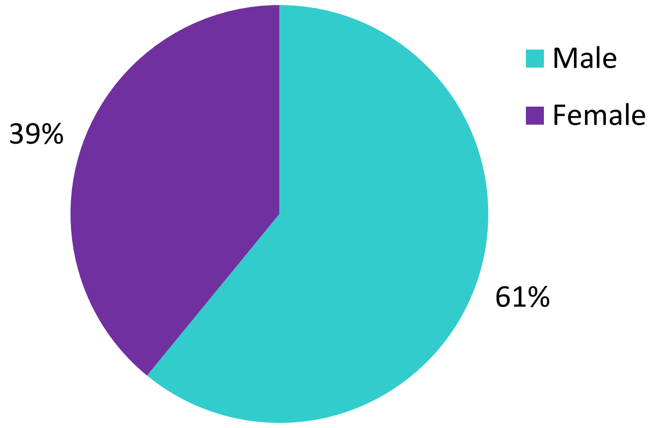
Figure 6.5.2b: Breakdown of infants aged nine months by gender reported by their parents (n=433) to have food hypersensitivity in the Growing Up in Ireland Study (Sept. 2008 – April 2009)



Wave 2: Parental survey of three-year-old children (December 2010 – July 2011)

In wave 2, parents who completed wave 1 were surveyed when their child reached three years of age (9,793 participants). A total of 151 (1.3%) parents answered ‘yes’ to their child having “Any kind of food or digestive allergy” (Figure 6.5.2c). The food hypersensitive children consisted of 92 males (61%) and 59 females (39%), with boys being more likely to have food hypersensitivity than girls ($p = 0.01$).

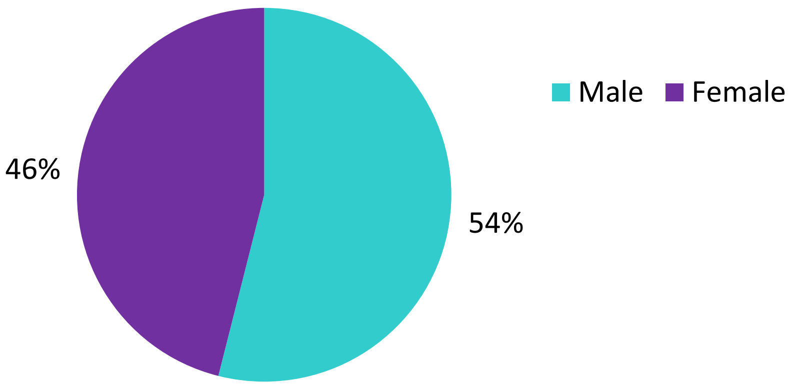
Figure 6.5.2c: Gender breakdown of three-year-old children with food hypersensitivity (“any kind of food or digestive allergies”) (n=151), as reported by their parents in the *Growing Up in Ireland* study (Dec. 2010 – July 2011)



Wave 3: Parental survey of five-year-old children (Mar -Sept. 2013)

In wave 3, parents (9,001 participants) from waves 1 and 2 were surveyed when their child reached five years of age. A total of 165 participants (1.8%) reported their child as having "any kind food or digestive allergy, or food intolerance" (Figure 6.5.2d). The gender breakdown consisted of 89 (54%) males and 76 (46%) females and the difference was not statistically significant (p = 0.5).

Figure 6.5.2d: Gender breakdown of five-year-old children with food hypersensitivity ("any kind of food or digestive allergy, or food intolerance") (n=165), as reported by their parents in the *Growing Up in Ireland* study (Mar -Sept 2013)



6.5.3 Central Statistics Office Survey (CSO) of 5,348 students attending 155 secondary schools

In 2009, the Professional Development Service for Teachers (PDST), the CSO, Project Maths and the National Council for Curriculum and Assessment (NCCA) collaborated to set up the Irish website Census-at-School (www.censusatschool.ie). From this, 5,348 (1.5%) of an estimated 368,000 secondary school students completed the Phase 14 questionnaire of the 'CensusAtSchool' survey between September 2014 and August 2015. Details available at:

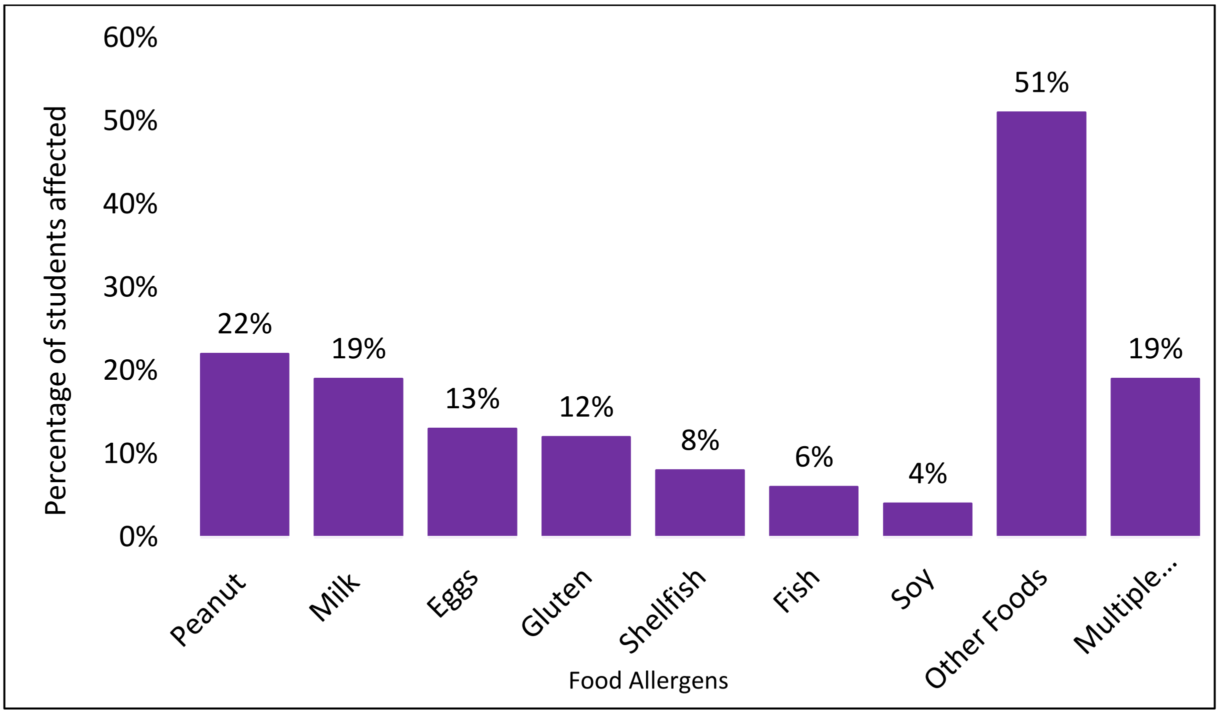
https://www.cso.ie/en/interactivezone/censusatschoolsreleases/censusatschool2015/

The questionnaire covered a variety of topics, ranging from how often students participated in family activities each week to the number of text messages they sent daily. One of the questions asked students what foods they were allergic to. The percentage of students with food allergies (or possibly hypersensitivity) was not reported, just associated trigger foods. The age range of students was 12-18 years.

Trigger Foods:

The most reported food allergy/hypersensitivity was to peanuts (22%), followed by milk (19%), eggs (13%) and gluten (12%). Over half (51%) of students cited a trigger food that was not one of the listed allergens on the questionnaire. Nineteen per cent of the students reported having multiple food allergies.

Figure 6.5.3: Percentage of students reporting an allergy to specified foodstuffs in a survey of Irish secondary school students (n=5,348; CSO, 2015)



6.5.4 Dining Out: The challenge for those with a food allergy or food intolerance (Ireland and Northern Ireland Studies, 2013)

A joint survey was carried out on an all-island basis by ***safe*****food** (Ireland) and a ***safe*****food**-FSANI (Northern Ireland) between January and February 2013. Details are available at the following links:

- https://www.safefood.net/getmedia/62903d02-8532-4659-a7e6-59ba365ec00f/Final-report-Ireland-Jan2015.aspx?ext=.pdf
- https://www.safefood.net/getmedia/3f1e9d08-a448-47c9-bfbb-0305513ef6b7/Final-report-NI-Jan2015.aspx?ext=.pdf

The purpose of the survey was to examine the experiences and opinions of food hypersensitive consumers with regard to eating out in catering establishments such as restaurants, hotels, cafes, etc. The survey was circulated electronically and exclusively to the members of two patient support organisations in operation at that time – Anaphylaxis Ireland and Allergy Northern Ireland.

A total of 241 valid responses were collected in Ireland. Forty-five per cent of survey responses were completed by parent/guardians/carers of food hypersensitive children (0-12 year olds). This number increased to 73% when food hypersensitive adolescents/young adults (13-20 year olds) were included. Ninety-seven per cent of respondents reported that their 'food allergy or food intolerance had been medically diagnosed'. In terms of prevalence, the top five most reported food allergies were to peanut (71%), tree-nuts (59%), eggs (41%), crustaceans (21%) and milk (19%) (Figure 6.5.4a). The respondents also reported hypersensitivity to other foods (non-regulated food allergens in EU food law), such as fruit, vegetables and different meats. Allergy to kiwi (10%) was more prevalent than to some EU-regulated food allergens, including soybean (6%), cereals containing gluten (5%) mustard (3%), lupin (2%), sulphur dioxide (1%) and celery (0% reported).

A total of 111 valid responses were collected for Northern Ireland in the same study. Sixty-nine per cent of the survey responses were completed by parent/guardians/carers of food hypersensitive children (0-12 year olds). This number increased to 86% when food hypersensitive adolescents/young adults (13-20 year olds) were included. Ninety-nine per cent of the respondents reported that their 'food allergy or food intolerance had been medically diagnosed'. In terms of prevalence, the top five reported food allergens were to peanut (68%), tree-nuts (66%), eggs (41%), milk (30%) and sesame seeds (14%) (Figure 6.5.4b). Allergies to other foods (non-regulated food allergens in EU food law) were also reported, including varieties of fruit and vegetables and different meats. Allergy to kiwi (10%) was more prevalent than to some EU-regulated food allergens, including soybean (9%), fish (8%), crustaceans (5%), celery (4 %), sulphur dioxide (4%), lupin (2%) and mustard (1%).

Figure 6.5.4a: Distribution of allergies to the 14 EU-regulated foods among survey respondents in Ireland from the ***safe*****food** "Dining Out" Study in Ireland in 2013 (n=241)

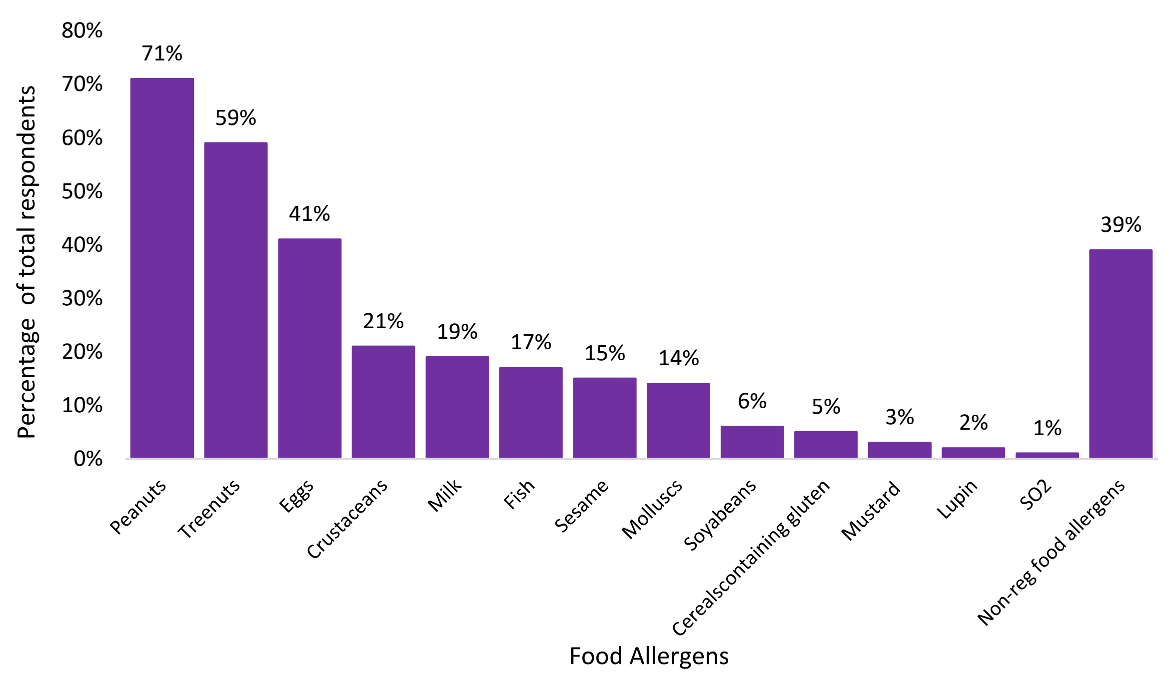
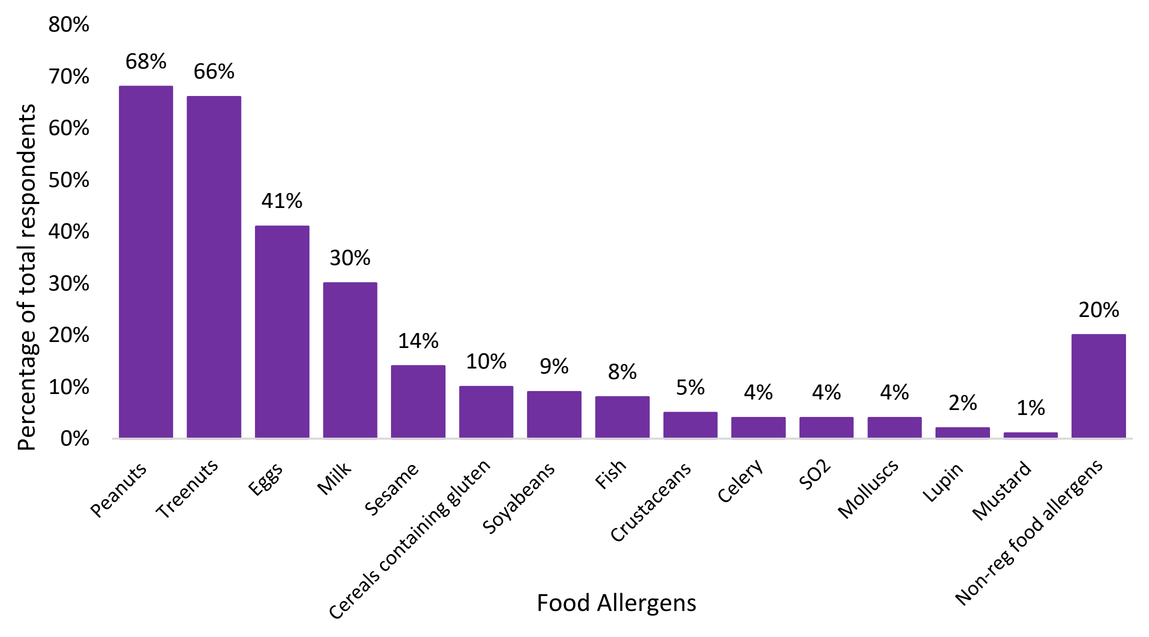


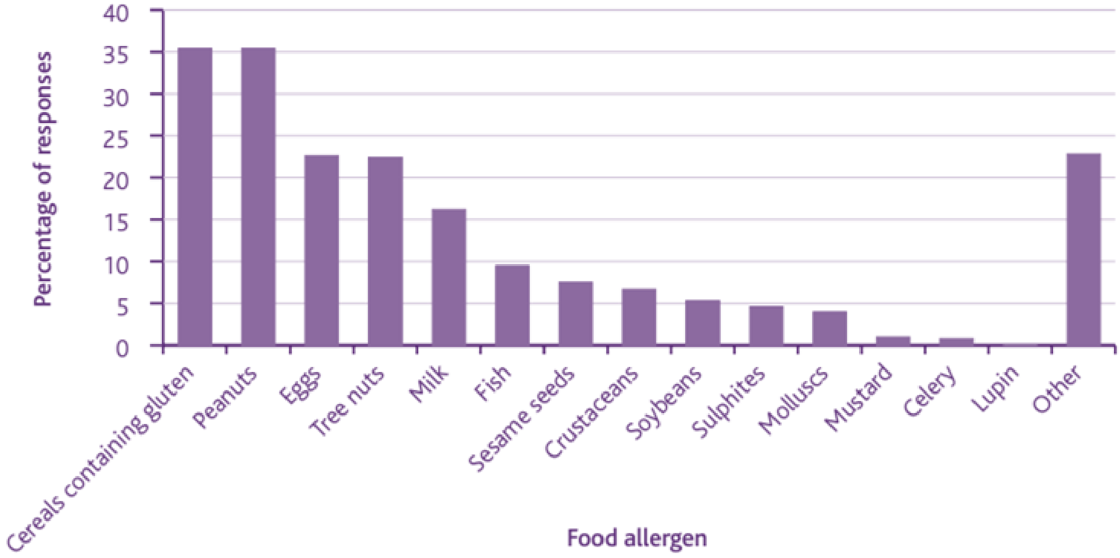
Figure 6.5.4b: Distribution of allergies to the 14 EU-regulated foods among survey respondents in Northern Ireland from the ***safe*****food** "Dining Out" Study in Northern Ireland in 2013 (n=111)



6.5.5 FSAI Food Allergy Survey 2011

The FSAI carried out an electronic survey in 2011 to provide an estimate of the Irish population living with food allergies and intolerances as specified in EU legislation. This survey was open to the public, and members of Anaphylaxis Ireland and the Coeliac Society of Ireland were informed of this study. A total of 509 responses consisting of 67% (n=339) females and 33% (n=170) males were gathered, and 85% (n=434) of respondents claimed to have been medically diagnosed. The most reported allergies in this group were to cereals containing gluten, peanuts, eggs and tree nuts (Figure 6.5.5).

Figure 6.5.5 FSAI electronic food allergy and intolerance survey, 2011 (n=509)



*Source: FSAI, 2011.

https://www.fsai.ie/resources_publications/allergen_labelling_2011.html.html

https://www.fsai.ie/WorkArea/DownloadAsset.aspx?id=17186

6.5.6a Irish Hospital Inpatients Enquiry (HIPE) data for Ireland: Foods associated with anaphylaxis which resulted in hospital admissions between 1995 and 2004

The Irish Hospital Enquiry (HIPE) database of hospital admissions in Ireland associated with food anaphylaxis from 1995 and 2004 indicate that peanuts, fish, eggs, tree nuts, milk and crustaceans were the main causative foods resulting in hospitalisation during this time (Figure 6.5.6a). However, it has been suggested by the medical community during this study, and by other published sources (FSAI, 2019), that there is a lack of confidence with regard to the overall reliability of this data. That said, the data indicates general trends among consumers with food allergies in the Irish population.

Figure 6.5.6a: Foods associated with anaphylaxis-related hospital admissions in Ireland from 1995 to 2004

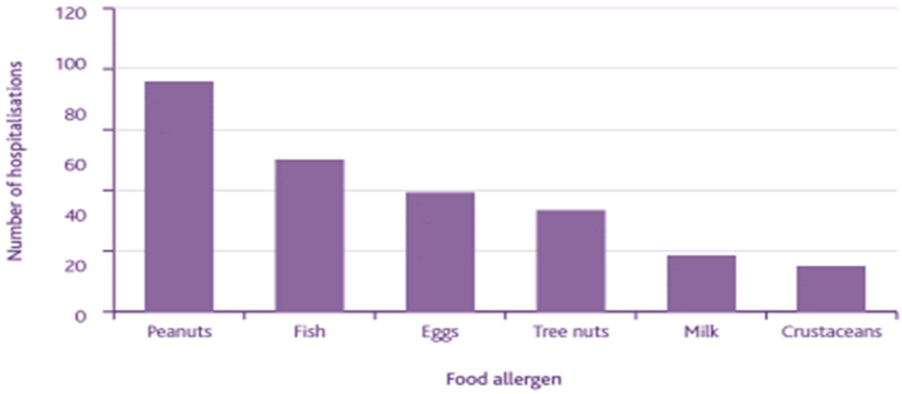
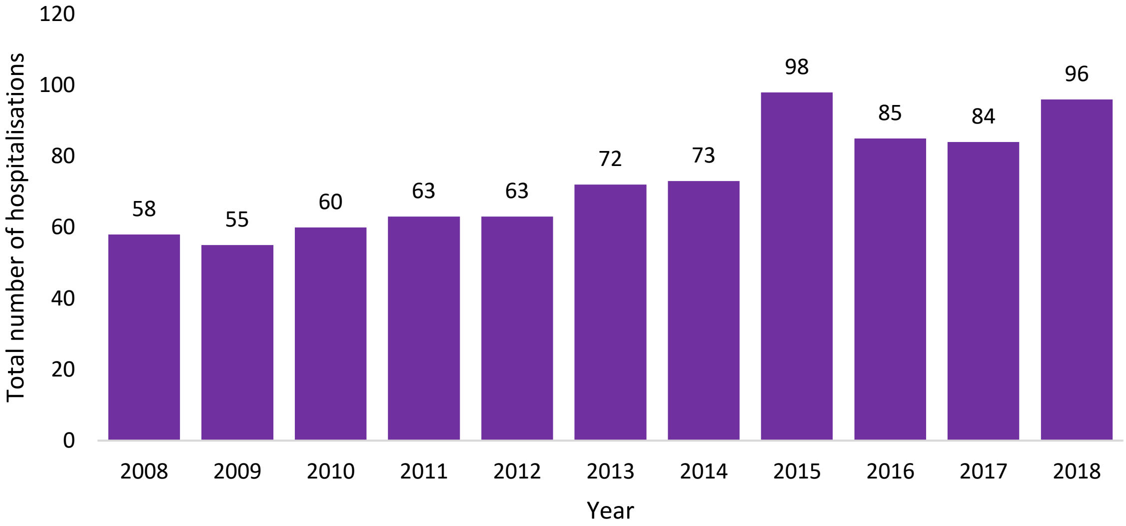


*Image Source: FSAI, 2019
https://www.fsai.ie/WorkArea/DownloadAsset.aspx?id=17186

6.5.6b Irish Hospital Inpatients Enquiry (HIPE) data for Ireland: recorded number of hospital discharges for 2008 and 2018 due to food-related anaphylaxis

The record of the Irish HIPE data for 2008-2018 provides a general indication of the number of hospitalisations in Ireland where food-related anaphylaxis was the principal diagnosis (n=807; Figure 6.5.6b). The data presented are based on patient discharge records from January 2008 to December 2018 from the Health Service Executive (HSE) in Ireland. While there is a general query over the reliability of this data (as previously mentioned), information on hospital discharge numbers (Figure 6.5.6b), age categories (Figure 6.5.6c) and associated gender (Figure 6.5.6d) are presented here.

Figure 6.5.6b: Total number of hospitalisations in Ireland due to food-related anaphylaxis recorded by the Health Service Executive (HSE) between 2008 and 2018 (n=807)

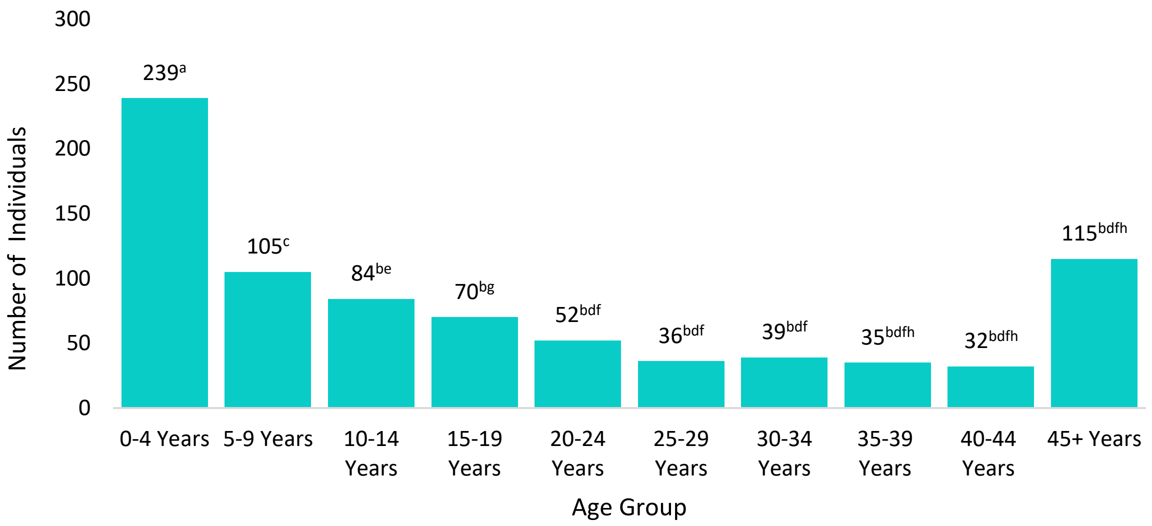


*Source: HSE: HIPE discharge data for food-associated anaphylaxis

When age categories were reviewed, it was noted that 30% of all food anaphylaxis admissions were in the 0-4 years age group, and 43% were between 0-9 years of age (Figure 6.5.6c). The 0-4 years age category was significantly higher ($p<0.01$) than all the other age categories examined, with the exception of 5-9 year olds. This finding suggests that children, four years and younger, are more likely to be admitted to hospital as a result of food anaphylaxis than older children (9+ years), adolescents or adults. Similarly, the 5-9 year olds were significantly more likely to be admitted to hospital than those aged 20 years and over ($p<0.01$).

Differences in gender were also noticeable in this dataset, with a higher percentage of 0-14 year old boys admitted to hospital as a result of food anaphylaxis than girls – 33% and 39%, respectively (Figure 6.5.6d). The male-to-female admission ratios were similar in the 15-24 year olds. However, from 25 years and above, hospital admissions were higher for females than for males – 63% and 57%, respectively.

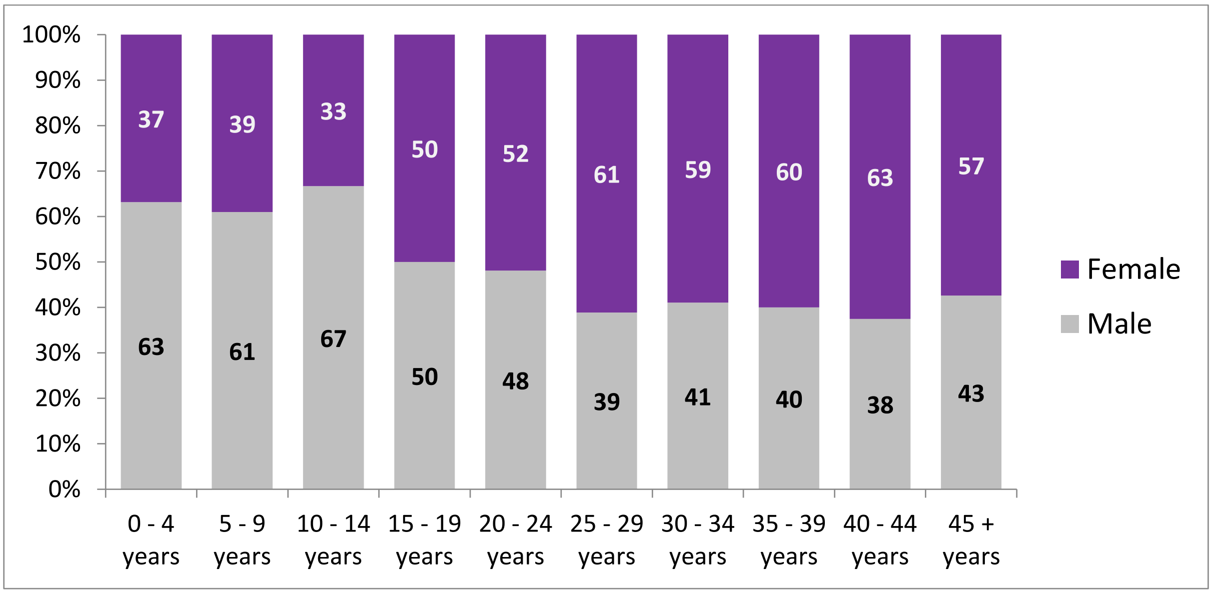
Figure 6.5.6c: Total number of individuals reported (n=807) by age group who were admitted to hospital in Ireland as a result of food anaphylaxis (principal diagnosis) between 2008-2018



* The following age categories are statistically significant ($p<0.01$) a versus b, c versus d, e versus f, g versus h.

**Source: HSE: HIPE discharge data for food-associated anaphylaxis.

Figure 6.5.6d: Total number of individuals reported (n=807) by age group and gender who were admitted to hospital in Ireland as a result of food anaphylaxis (principal diagnosis) between 2008-2018



*0-4 years: 151 males, 88 females; 5-9 years: 64 males, 41 males; 10-14 years: 56 males, 28 females; 15-19 years: 35 males, 35 males; 20-24 years: 25 males, 27 females; 25-29 years: 14 males, 22 males; 30-34 years: 16 males, 23 females; 35-39 years: 14 males, 21 males; 40-44 years: 12 males, 20 females; 45+ years: 49 males, 66 females.

**Source: HSE: HIPE discharge data for food-associated anaphylaxis.

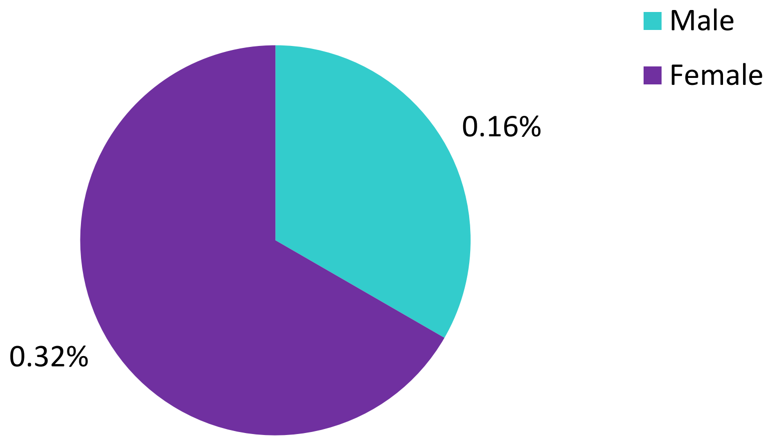
6.5.7 Data from a study on the incidence and prevalence of coeliac disease in the UK (per region) over two decades (1990-2011): Population-based study

A study carried out by West *et al.* (2014) identified individuals with coeliac disease in the 'Clinical Practice Research Datalink'. Details available at:

https://journals.lww.com/ajg/Fulltext/2014/05000/Incidence_and_Prevalence_of_Celiac_Disease_and.22.aspx

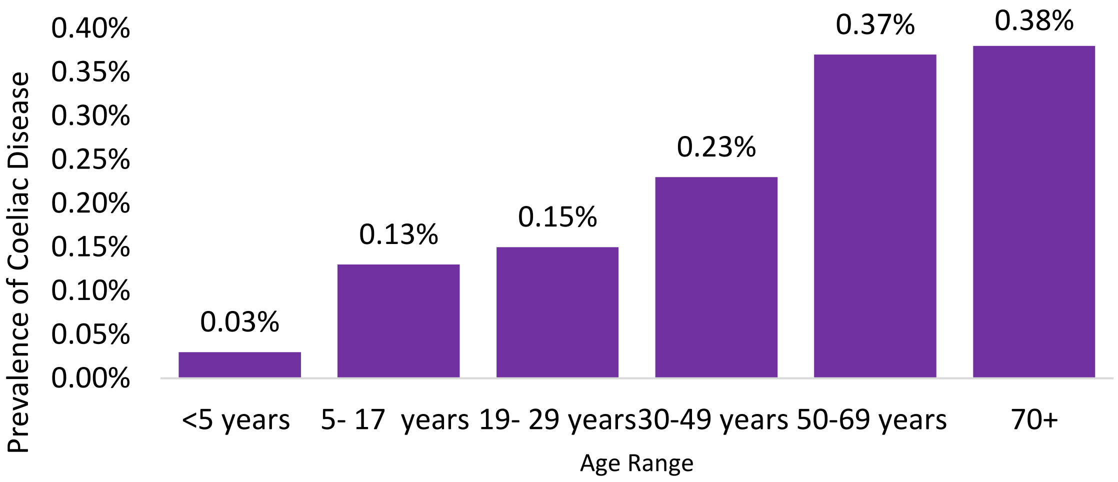
This study reported an 'overall point prevalence' of coeliac disease of 0.24% across the entire population of the UK in 2011, based on a figure of 10,872 individuals reported to have coeliac disease. In other words, this study suggests that 1 in every 420 people in the UK had coeliac disease in 2011. Examined by gender, females (n= 7,210; 0.32%) were twice as likely as males (n=3,662; 0.16%) to be diagnosed with this condition in 2011 (Figure 6.5.7a).

Figure 6.5.7a: Prevalence of coeliac disease by gender in the United Kingdom (n=10,872; West *et al.* (2014))



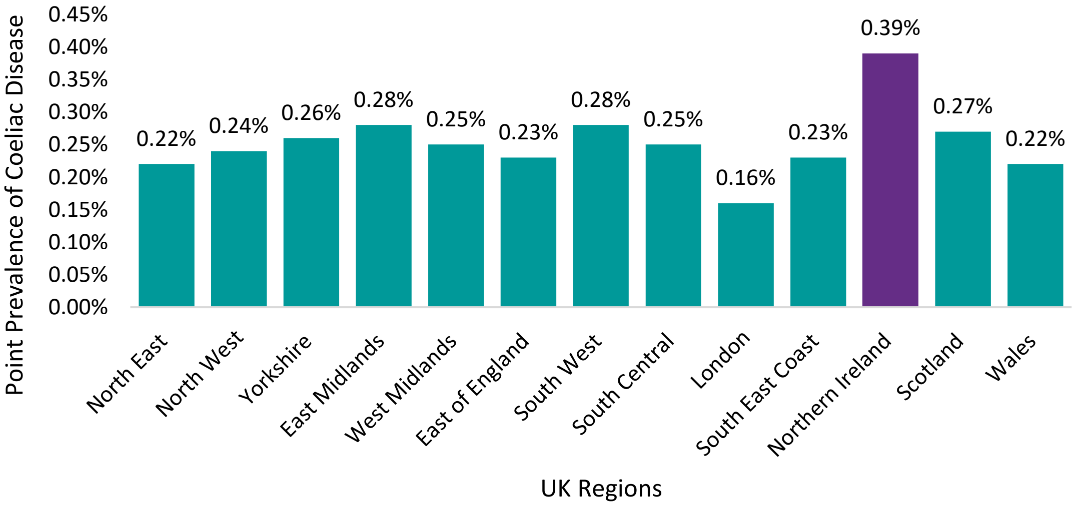
The data also suggests a direct relationship between prevalence of coeliac disease and age. A clear trend emerges with the lowest prevalence reported in the <5 years old age group (0.03%) and the highest in the 70+ year age group (0.38%) (Figure 6.5.7b).

Figure 6.5.7b: Prevalence of coeliac disease by age group in the United Kingdom (n= 10,872), as reported by West *et al.* (2014)



There were large regional variations in the reported prevalence of coeliac disease. For example, a prevalence rate of 0.16% (n=905; 95%, CI 0.15% to 0.17%) was reported for London compared to 0.39% (0.36% to 0.42%) for Northern Ireland. This data suggested that Northern Ireland had the largest prevalence of coeliac disease (0.39%) when compared to other regions of the UK (0.16-0.28%). (Figure 6.5.7c). The possible reason/s for differences in regional prevalence rates was not discussed in the paper.

Figure 6.5.7c: Point prevalence of coeliac disease per region in the United Kingdom in 2011 (n=10,872; West *et al.* (2014))

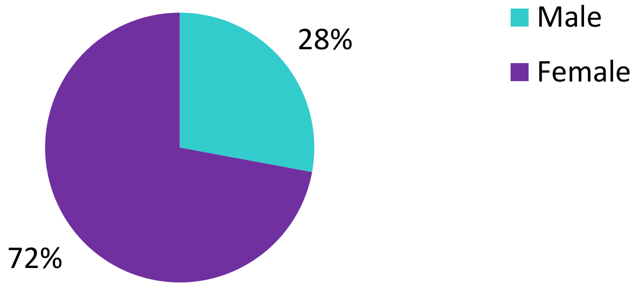


6.5.8 Coeliac Society of Ireland dataset of 2,899 individuals reporting to have medically diagnosed coeliac disease in 2019

The Coeliac Society of Ireland provides support and information to those with MDCD or gluten intolerance in Ireland and strives to improve their quality of life while increasing the general level of awareness and understanding of these diseases in the community (Coeliac Society of Ireland, 2020). Website: https://coeliac.ie/

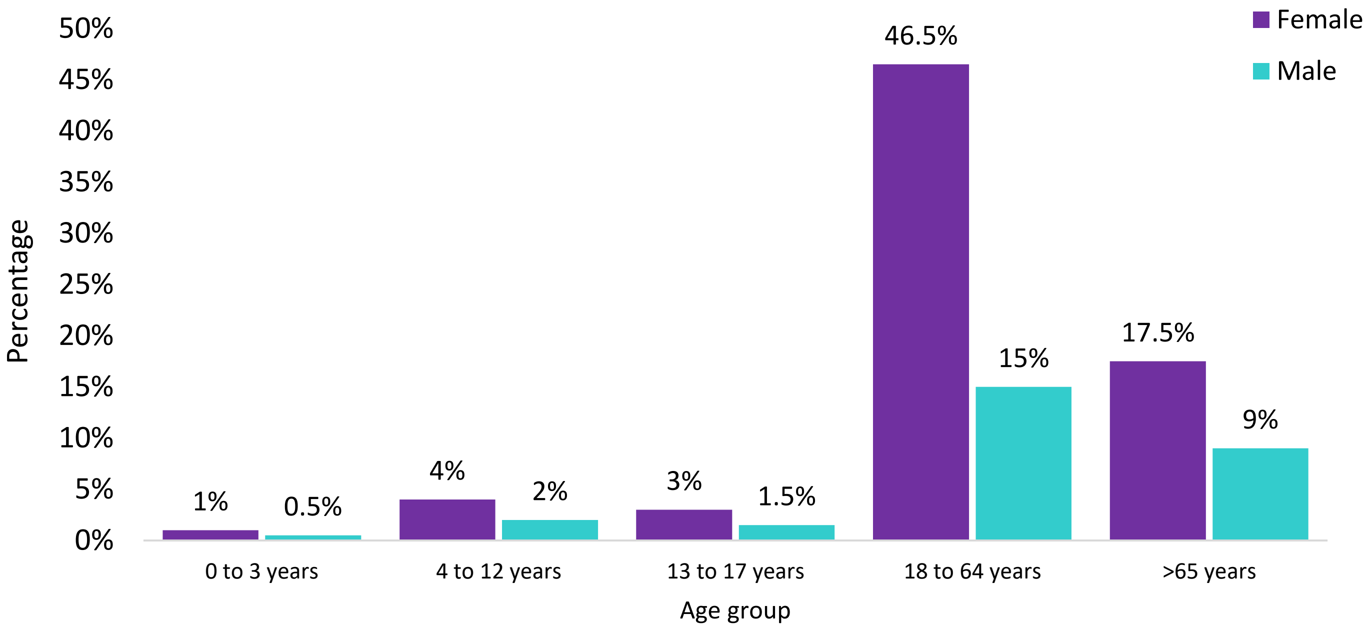
In 2019, the CSI estimated that they had 3,688 active members, of which 2,899 individuals (children, adolescents and adults) reported MDCD. The overall gender breakdown of the MDCD members was 28% male (n=809) and 72% female (n=2,090) (Figure 6.5.8a).

Figure 6.5.8a: Gender distribution of Coeliac Society of Ireland members with MDCD in 2019 (adult self-reported or parent-reported for children/adolescents; n=2,899)



When this MDCD membership dataset (self-reported) was examined by age group, most (62%) were found to be adults aged 18-64 years (n=1,796). An additional 12% were children/adolescents aged 0-17 years (n=337, many parent-reported), and 26% were aged >65 years (n=766). A further breakdown by age category is presented in Figure 6.5.8b.

Figure 6.5.8b: Gender and age distribution of Coeliac Society of Ireland members in 2019 who had MDCD (n=2,899)



*Associated number of individuals who reported to be 0–3 years: 18 males and 28 females; 4–12 years: 51 males and 110 females; 13–17 years: 45 males and 85 females; 18–64 years: 442 males and 1,354 females; >60 years: 253 males and 513 females.

6.6 Prevalence values for MDFA and MDCD reported in the literature

Prevalence values published in the literature for food allergy and coeliac disease are presented in Annex 8. A total of 130 peer-reviewed papers have been included, ranging from 1973 to 2021, and figures reported by 26 institutions on food hypersensitivity. The information is tabulated in Annex 8 as follows:-

- Peer-reviewed prevalence figures from food allergy studies in children/adolescents (<18 years) from 52 papers published between 2000 and 2020.
- Peer-reviewed prevalence figures from food allergy studies in children/adolescents (<18 years) with peanut, egg or milk allergy from 41 papers published between 2000 and 2020.
- Peer-reviewed prevalence figures from food allergy studies in children/adolescents (<18 years) for foods other than peanut, egg or milk from 15 papers published between 1996 and 2019.

- Peer-reviewed prevalence figures from food allergy studies in children/adolescents and adults (all ages) where data is presented together from 14 papers published between 2001 and 2021.
- Peer-reviewed prevalence figures from food allergy studies in adults (≥18 years) from 12 papers published between 2001 and 2019.
- Peer-reviewed prevalence figures from food allergy studies in adults (≥18 years) by food group from nine papers published between 2001 and 2019.
- Reported prevalence figures from food allergy studies in children/adolescents (<18 years) and adults (>18 years) from 17 published papers and other reports and institutions between 2006 and 2019.
- Reported prevalence figures from food allergy studies in children/adolescent (<18 years) and adults (≥18 years) from seven institutions world-wide between 1997 and 2015.
- Reported prevalence figures from coeliac disease studies in children/adolescent (<18 years) and adults (≥18 years) from 28 published papers and other reports and institutions between 1973 and 2019.

These data make clear the wide range of prevalence values reported in the literature. The large variation in figures was more pronounced for MDFA than MDCD and is most likely the result of differences in study parameters, geographical locations and sample group characteristics (age, gender, etc.).

7 Project discussion and key findings

7.1 Distribution of MDFA, MDCD and FI among survey respondents

Following the analysis of 744 surveys completed by MDFA respondents (adults or parents), peanuts (47%), milk (36%), other nuts (35%), eggs (30%) and fruit (19%, including 6% kiwi) were the five most reported trigger foods on the IoI. These foods were also the most frequently reported causes of food-related anaphylaxis: peanuts (7%), other nuts (6%), eggs (4%), milk (3%), and fruit (2%, including 1% kiwi). These findings concur with those of other studies carried out in Ireland and Northern Ireland (FSAI, 2011; ***safe*food**, 2013a; ***safe*food**, 2013b; Colver, 2005; McClain *et al.*, 2014; Kelleher *et al.*, (2016); MacGiobuin, 2017). With regard to age category, milk allergy was more prominent (45%) among children than adolescents (24%) and adult groups (29%), while MDFA to cereals containing gluten (23%), fruit (23%, including 8% kiwi), crustaceans (13%) and molluscs (9%) were more pronounced in MDFA adults than in children/adolescents. These results agree with the findings of a number of other studies (Ben-Shoshan *et al.,* 2010; Burney *et al.,* 2010; McGowan and Keet, 2013; Kamdar *et al.,* 2015; and Moonesinghe *et al.,* 2016). There was very little difference between male and female children/adolescents with regard to the trigger foods associated with MDFA, which ranged from 0-5%.

Kiwi fruit was found to be a prominent trigger food associated with MDFA (6% overall, with 1% reporting previous incidences of kiwi-related anaphylaxis) and FI (3%) in this study. Food hypersensitivity to kiwi is commonly reported in the EU (Mattila *et al.,* 2003; Lucas *et al.,* 2004; Bublin *et al.,* 2010; Bublin *et al.,* 2011; Le *et al.,* 2013; Burney *et al.,* 2014). MDFA to kiwi was more prevalent than to some of the foods listed in Annex 2 of Regulation EU No. 1169/2011. This has been recorded in other European studies as well (Rancé *et al.,* 2005; Lyons *et al.,* 2020). Of the 318 MDFA in adults documented in this study, 8% was to kiwi, 8% was to fish, while 5% was to soybeans, 5% sesame seeds, 4% celery, 3% mustard, 3% sulphites/SO_2, and 2% lupin. This concurs with the findings of two previous ***safe*food** studies (***safe*food**, 2013a, ***safe*food**, 2013b).

A total of 1,222 respondents completed the FI survey and 1,035 respondents completed the MDCD survey (adults or parents of children/adolescents). Milk (59%) and cereals containing gluten (45%) were reported as the most prominent FI trigger foods, while peanut and ‘other nut' ranked fifth (9%) and sixth (6%), respectively. This contrasts starkly with MDFA respondents who ranked peanut first (47%) and other nuts third (35%).

This study reports the relative frequency of different food allergies and intolerances in the populations of Ireland and Northern Ireland based on 3001 detailed survey returns, and corroborates many previous research findings in this regard.

7.2 The socio-economic cost of having a food hypersensitivity

The socio-economic costs of food hypersensitivity in Ireland and Northern Ireland were calculated by determining the direct and indirect costs associated with each kind of food hypersensitivity – MDFA, MDCD and FI. The survey focussed on either adult (self-reported) or household (parent-reported for children/adolescents) expenditure. A total of 2,066 completed surveys from food hypersensitive respondents and 735 from control (non-food hypersensitive) respondents were investigated. Direct costs consisting of healthcare-related expenses (medical visits, associated travel, hospital stays, medication, etc.) and total food costs per condition were calculated. Indirect costs (lost time, missed days, or lost earnings due to food hypersensitivity) were also determined, and together with direct costs allowed for the calculation of overall total costs for MDFA, MDCD and FI.

Additional direct costs per annum associated with having MDFA ranged from €1,115 for children/adolescents to €1,325 for adults in Ireland, and from £847 (adults) to £1,208 (children/adolescents) in Northern Ireland. Similarly, additional direct costs per annum associated with MDCD were found to range from €444/501 (adults; including/excluding a tax rebate) to €903/993 (children/adolescents; including/excluding a tax rebate) in Ireland, and from £737 (adult) to £1,608 (children/adolescents) in Northern Ireland. Additional direct costs per annum associated with FI ranged from no real difference for children/adolescents to €350 (adults) in Ireland, and from £292 (children/adolescents) to £377 (adults) in Northern Ireland.

Higher direct costs were noted for 11 out of the 12 food hypersensitive groups investigated. The exception was the child/adolescent FI group in Ireland. However, statistical significance was not achieved for any FI group or for MDCD adults in Ireland. The overall findings are in agreement with many published studies, which report higher costs associated with medication, healthcare and travel to see medical professionals as a result of having a food allergy (Voordouw *et al.,* 2010; Fox *et al.,* 2013; Jansson *et al.,* 2014; Cerecedo *et al.,* 2014; Protudjer *et al.,* 2015), and coeliac disease (Long *et al.,* 2010; Violato *et al.,* 2012; Picarelli *et al.,* 2014; Cappaci *et al.,* 2018; Lee *et al.,* 2019; Hanci and Jeanes, 2019), but not specifically for food intolerance.

The indirect costs were lower than the direct costs and ranged up to €277/€324 for adults/children in Ireland, £628/£206 for Northern Ireland adults/children. The main driver for indirect costs was found to be 'missed days of work/school/college', which tended to be higher in Northern Ireland (£122 to £418) compared to Ireland (€0 to €302). Indirect costs have been reported in the literature as a general contributor to the total cost of food hypersensitivity (Voordouw *et al.,* 2010; Fox *et al.,* 2013; Jansson *et al.,* 2014; Cerecedo *et al.,* 2014; Protudjer *et al.,* 2015).

Higher total additional costs (direct plus indirect) were reported for all of the food hypersensitive groups examined. Costs for MDFA ranged from €1,439 (children/adolescents) to €1,602 p.a. (adults) in Ireland, and £1,259 p.a. (adults) to £1,414 p.a. (children/adolescents) in Northern Ireland. The additional total costs associated with MDFA were statistically significant ($p < 0.05$). The additional total costs associated with MDCD of €1,033/1,123 p.a. (children/adolescents with/without a tax rebate) in Ireland, and £1,365 (adults) to £1,690 p.a. (children/adolescents) in Northern Ireland, were statistically significant ($p < 0.01$), while those for adults in Ireland (€438/€495 p.a. with/without tax rebate; n=609) were not significant. MDCD adults in Ireland reported fewer medical expenses than other MDFA or MDCD groups, and zero additional 'missed days' compared to controls (n=531). Higher additional total costs were calculated for adult FI respondents in Ireland and Northern Ireland (€504 and £565 p.a., respectively) compared to children/adolescents (€70 and £59 p.a., respectively). The main driver behind the adult FI costs were higher healthcare costs and 'missed days'.

These higher total additional costs were comparable to costs previously reported in the literature. These ranged from €1,791 to €23,468 p.a. for food allergy (Flabbee *et al.,* 2008; Voordouw *et al.,* 2010; Alanne *et al.,* 2012; Fox *et al.,* 2013; Gupta *et al.,* 2013; Jansson *et al.,* 2014; Cerecedo *et al.,* 2014; Protudjer *et al.,* 2015; Bilaver *et al.,* 2019), and from €226 to €4,470 p.a. for coeliac disease (Long *et al.,* 2010; Violato *et al.,* 2012; Picarelli *et al.,* 2014; NICE, 2015). No studies examining the socio-economic costs of non-coeliac gluten sensitivity or food intolerance were found, suggesting that this is the first study of its kind. Health care related expenses were the main driver of costs for food hypersensitive respondents in both jurisdictions, although total food costs, lost earnings, and lost days at work/college/schools were in themselves (independently) statistically significant expenses ($p < 0.05$) for a number of groups.

Out of pocket costs borne by adults and parents ranged from €499 to €1,141 p.a. for MDFA in Ireland, and £542 to £550 p.a. in Northern Ireland. The equivalent for MDCD ranged from €290 to €607 p.a. in Ireland (€347 to €697 p.a. before a tax rebate for gluten-free food), and £965 to £1,011 p.a. in Northern Ireland. Respondents incurred healthcare costs in conjunction with (or shared with) their healthcare provider. The cumulative additional cost was €461 to €940 p.a. (Ireland) and £717 to £964 p.a. (Northern Ireland) for MDFA, and €148 to €426 p.a. (Ireland) and £400 to £679 p.a. (Northern Ireland) for MDCD. These findings indicate the often substantial additional expenses incurred by individuals and families with food hypersensitivity. These costs were more pronounced for MDFA and MDCD participants than for FI participants, although all conditions were associated with additional costs. These data provide grounds for consideration of measures to support food hypersensitive individuals/families who incur these expenses because of food hypersensitivity.

7.3 Impact of food hypersensitivity on quality of life (QoL)

Intangible costs (non-monetary) were also investigated in this survey. This was done by using a set of standardised HRQoL questions called the EQ-5D. This study found that children, adolescents and adults with MDFA, MDCD or FI had a statistically significantly lower quality of life compared to their control counterparts ($p < 0.05$). On closer examination of the data reported on the specific dimensions of the EQ-5D, children and adults from all groups had significantly higher levels of 'pain and discomfort' ($p < 0.05$), while adults from all groups and adolescents from MDFA and FI groups had significantly higher levels of 'anxiety and depression' ($p < 0.05$).

These findings highlight the frequently significant impact of food hypersensitivity on the quality of life of those affected by food hypersensitivity. Our findings are in general agreement with previous studies (Fong *et al.*, 2017; Shaker *et al.*, 2017; Du Toit *et al.*, 2016; Greenhawt, 2016; Walker *et al.,* 2015), and particularly two studies in Swedish children and adults that used the same EQ-5D model as in this study (Protudjer *et al.,* 2015; Jansson *et al.,* 2013). While not examined in this study, a 'poorer' quality of life and higher levels of anxiety have also been reported for caregivers of children with food hypersensitivity, highlighting the wider effect of a diagnosis (DunnGalvin, 2020; Ascaster, 2020; Birdi *et al.,* 2016) and offering further evidence of the need for supports for individuals and their families. There is evidence to suggest that the Covid-19 pandemic has further exacerbated the quality of life of those affected by food hypersensitivity (Protudjer *et al.,* 2019). Unexpected challenges associated with food shopping and delays in food allergy testing and therapy were some of the reasons cited.

With regard to areas of life affected by food hypersensitivity, the 'ability to eat out' was the most cited parameter affecting QoL by MDFA respondents (74% to 86%). The most reported parameter affecting QoL in those with MDCD (96-98%) and FI respondents (68-88%) and their families was the 'cost of food shopping'. These challenges have been previously reported for people with MDFA (DunnGalvin *et al.,* 2015; Jansson *et al.,* 2013; Jansson *et al.,* 2015) and MDCD (MacCulloch and Rashid, 2014; Altobelli *et al.,* 2013; Black & Orfila, 2011; Roma *et al.,* 2010).

7.4 Interviews with food hypersensitive consumers on the island of Ireland

A complementary study involving 76 priority setting phone interviews with MFDA and MDCD respondents was also carried out. The semi-structured interviews investigated a wide range of key issues that emerged from the surveys and considered measures that could be taken to ameliorate same. All MDFA and MDCD groups prioritised '*Public and food industry awareness and understanding of their/their child's condition'* as their top issue of concern, except for parents of children/adolescents with MDFA in Northern Ireland, who ranked '*Awareness and training in an educational setting'* first and the former option third. The issues of most concern mainly pertained to problems associated with eating out, the adequacy of training and awareness in the food sector (as previously reported by Gruenfeldova *et al*., 2019; FSAI, 2017; EFSA, 2014), and overuse/misuse of precautionary allergen labelling (PAL). Many solutions were suggested to improve allergen management systems. A clinically validated, tiered risk assessment approach to PAL is being considered at EU level in order to develop systems of transparency regarding food labelling (DunnGalvin, *et al*., 2019; Reese *et al.,* 2015). Targeted measures to address these two issues would benefit those affected by food hypersensitivity on the IoI. Issues concerning awareness and training in food hypersensitivity in educational settings were ranked third for all MDCD participants and fourth for MDFA participants. Many suggestions to ameliorate these day-to-day challenges were proffered by participants. For example, while guidance on policy creation and management has been issued to educators in Northern Ireland (DoE Northern Ireland, 2018), there is no such equivalent in Ireland. A similar standardised approach to the formulation of guidance in association with stakeholders would be worth investigating at departmental level in Ireland, as it would assist both parents and educators in co-managing the needs of food hypersensitive students.

All groups reported '*Accessing medical teams, e.g., consultants, specialist nurses etc., to treat your (or your child's) condition'* as the second most important issue. Issues associated with accessing dietetic and counselling services are also highlighted. The development of clinical pathways with improved access to medical services could greatly support those diagnosed with food hypersensitivity. Greater difficulties with regard to accessing medical treatment and dealing with food hypersensitivity during the Covid-19 pandemic have been reported (Cianferoni and Voto, 2020; D'Auria*, et al.,* 2020; Mack *et al.,* 2020), highlighting the importance of having well established clinical pathways for those affected.

The provision of '*Adrenaline auto-injectors in public places, similar to AED'* was the overall third most important issue for MDFA participants (90% approval with an additional 8% unsure). Schemes to achieve this have been implemented in parts of Canada (Allergic Living, 2015) while a petition to the UK parliament with 13,098 signatures in 2019 advocated this policy (UK Parliament, 2019). The feasibility of introducing such measures in Ireland or Northern Ireland warrants further investigation.

Other important issues include the cost and availability of medication, access to counselling and dietetic services, and the consideration that food allergy and coeliac disease could be recognised as disabilities (similar to measures currently in place for severe food hypersensitivity in the US). The results of this study reflect the complexity of challenges which those affected by food hypersensitivity experience. While progress has been made in allergen awareness and management in recent years, the data presented here confirms that this is a work in progress and further measures to reduce the impact of food hypersensitivity on the lives those affected should be considered. A number of considerations were reviewed by the project team and are included in the key recommendations.

8 Project conclusions

This study provides evidence of the socio-economic costs associated with food hypersensitivity on the IoI. Statistically significant higher total costs were found for seven out of the eight MDFA and MDCD study groups examined, highlighting the financial burden typically associated with these conditions. Healthcare-related expenses were found to be the main driver of costs, although total food costs and the loss of time/days were also found to be significant for many of the groups examined. Additional total costs reported by respondents with FI were found to be higher than those of controls but (unlike most MDFA and MDCD groups) not significantly so. Measures to address expenses incurred by those who have food hypersensitivity could greatly ameliorate costs associated with these conditions.

The intangible costs (non-monetary) associated with food hypersensitivity were investigated and the overall effect on health-related quality of life (HRQoL) was examined. Intangible costs were significant for all food hypersensitivities studied (MDFA, MDCD and FI) and for all age groups (child, adolescent and adult) using the standardised EQ-5D model. The deleterious effect on HRQoL associated with having a food allergy was particularly pronounced with regard to the dimensions of ‘pain and discomfort’ and ‘anxiety and depression’. These findings further highlight the physical and psychological stresses associated with these conditions, and the need for focused measures to support those who have food hypersensitivity in this regard.

To this end, challenges and associated solutions were reviewed in the priority setting interviews. Public and food industry awareness and training was the overall number one priority for both MDCD and MDFA, indicating that this area should be targeted for improvement, where possible. Other concerns included improved access to medical teams, consideration of making adrenaline auto-injectors available in public places and increasing awareness of food hypersensitivity in educational settings. This study provides the evidence necessary for targeted interventions and supports to improve the lives of IoI consumers who have food hypersensitivity, and for continued research into the areas highlighted in this study.

9 Added value and anticipated benefits of research

This study provides data on the additional monetary costs (direct and indirect) associated with food hypersensitivity (MDFA, MDCD, and FI) for children/adolescents and adults. These data can be used to assist in the development of policy, guidance, assistance and supports in this area.

In addition, this report provides evidence of intangible costs (non-monetary) associated with food hypersensitivity (MDFA, MDCD, and FI) for children, adolescents and adults separately. This impact was particularly evident with regard to 'pain and discomfort' and 'anxiety/depression'. These findings highlight the need for measures to assist those with food hypersensitivity with regard to the deleterious effects associated with having food hypersensitivity on HRQoL. It is hoped that these findings will inform policy, supports, guidance and further research in this area.

Furthermore, the results of the priority setting workshop highlights key areas that can be targeted and offers potential solutions for consideration. These data, coupled with the study recommendations, provide information to assist stakeholders and policy makers in the formulation of interventions in this area.

In more general terms, this study provides detailed (anonymised) information on 3,001 food hypersensitive individuals on the IoI. This data is presented clearly in six detailed annexes and is a repository which can be used for further investigation (for other trends, relationships, observations, etc.) by researchers. In addition, the suite of food hypersensitive and controls surveys developed during the course of the study can be used at a future date (i.e., 10, 20 years from now) to compare data (i.e., changes in costs, potential changes in trigger foods due to dietary changes, etc.) over a given time-frame. From this perspective, direct comparisons can also be made with other countries, if the same surveys are used. These data, and developed surveys, may be valuable instruments to further investigate food hypersensitivity on the IoI in the immediate and long-term future.

Finally, the collation of Irish datasets, prevalence rates, and the collection of information on food hypersensitivity from 9,517 children in early years services, 3,233 school children (primary and secondary) and 2,139 residences in nursing homes on the IoI, will add to existing publicly available datasets. These data will also help to build a picture of the prevalence rates of food hypersensitivity on the IoI, thereby assisting scientists, researchers, policy makers and other stakeholders in understanding these conditions and their rate of occurrence on the IoI.

10 Bibliography

2. AA Ireland Car Insurance (2020). Cost of motoring 2019. Available at: https://www.theaa.ie/aa/motoring-advice/cost-of-motoring.aspx.
3. Abenavoli, L., Delibasic, M., Peta, V., Turkulov, V., Lorenzo, A.D. and Medi´c-stojanosk, M. (2015). 'Nutritional profile of adult patients with celiac disease'. *Eur. Rev. Med. Pharmacol.* Sci. 19, 4285–4292.
4. Acaster, S., Gallop, K., Vries, J., Ryan, R., Vereda, A. and Knibb, R. (2020). 'Peanut allergy impact on productivity and quality of life (PAPRIQUA): Caregiver-reported psychosocial impact of peanut allergy on children'. *Clinical and Experimental Allergy*, 50(11), pp. 1249-1257.
5. Adams, R., Walsh, C., Veale, D., Bresnihan, B., FitzGerald, O. and Barry, M. (2010). Understanding the relationship between the EQ-5D, SF-6D, HAQ and disease activity in inflammatory arthritis. *Pharmacoeconomics*, 28:477-87.
6. Alanne, S. (2012). 'Nutrition economic evaluation of allergy treatment in infants and children: background for probiotic studies', *Microbial Ecology in Health and Disease*, 23:18584.
7. Alanne, S., Maskunitty, A., Nermes, M., Laitinen, K., Pekurinen, M. (2012). 'Costs of allergic diseases from birth to two years in Finland', *Public Health*, 126(10), 866-872.
8. Aldiss, S., Fern, L.A., Phillips, R.S., Callaghan, A., Dyker, K., Gravestock, H., Groszmann, M., Hough, L.H.R., McGeachy, D., Morgan, S., Smith, S., Upadhyaya, S., Veitch, H., Veitch, L., Williamson, M., Whelan, J.S., and Gibson, F. (2019). 'Research priorities for young people with cancer: a UK priority setting partnership with the James Lind Alliance': *British Journal of Medicine*, 9(8).
9. Allen, B. and Orfila, C. (2018). 'The Availability and Nutritional Adequacy of Gluten-Free Bread and Pasta', *Nutrients*, 10, 1370.
10. Allen, K. J., Remington, B. C., Baumert, J. L., Crevel, R. W., Houben, G. F., Brooke-Taylor, S., Kruizinga, A. G. and Taylor, S. L. (2014). 'Allergen reference doses for precautionary labelling (VITAL 2.0): clinical implications', *Journal of Allergy and Clinical Immunology.* 133,156-64.
11. Allergic Living (2015), 'The Canadian Town Where Stock Epinephrine is the New AED - Allergic Living', Allergic Living. Available at:

https://www.allergicliving.com/2015/09/01/the-canadian-town-where-stock-epi-is-the-new-aed.

12. Allergy Ireland (2019), Allergy. Available at: https://www.allergy-ireland.ie/allergy
13. Almqvist, C., Pershagen, G., Wickman, M. (2005). 'Low socio-economic status as a risk factor for asthma, rhinitis and sensitization at 4 years in a birth cohort', *Clinical and Experimental Allergy*, 35(5):612-618.
14. Althumiri, N.A., Basyouni, M.H., AlMousa, N., AlJuwaysim, M.F., BinDhim, N.F., Alqahtani, S.A. (2021). 'Prevalence of Self-Reported Food Allergies and Their Association with Other Health Conditions among Adults in Saudi Arabia', *International Journal of Environmental Research and Public Health*. 18(1):347.
15. Altobelli E., Paduano R., Gentile T., Caloisi C., Marziliano C., Necozione S. and Orio, F. (2013). 'Health-related quality of life in children and adolescents with celiac disease: survey of a population from central Italy'. Health and Quality of Life Outcomes, 11(204), 1477-7525. Available at: https://hqlo.biomedcentral.com/track/pdf/10.1186/1477-7525-11-204
16. Altobelli E., Paduano R., Gentile T., Caloisi C., Marziliano C., Necozione S., and Orio F. (2013). 'Health-related quality of life in children and adolescents with celiac disease: survey of a population from central Italy'. Health and Quality of Life Outcomes, 11(204), 1477-7525. Available at: https://hqlo.biomedcentral.com/track/pdf/10.1186/1477-7525-11-204
17. Altobelli, E., Paduano, R., Petrocelli, R., and Di Orio, F. (2014). 'Burden of celiac disease in Europe: a review of its childhood and adulthood prevalence and incidence as of September 2014', *Annali di igiene: medicina preventive di comunita,* 26(6), 485-498.
18. Americans with Disabilities National Network (2020). 'What is the definition of disability under the ADA?', Available at: https://adata.org/faq/what-definition-disability-under-ada
19. Antolin-Amerigo, D., Cerecedo Carballo, I., Muriel, A., Fernández-Rivas, M., Diéguez Pastor, M., Flokstra-de Blok, B., Dubois, A., de la Hoz Caballer, B. (2015). 'Validation of the Spanish version of the food allergy quality of life questionnaire-adult form (S-FAQLQ- AF)'. *J Investig Allergol Clin Immunol*. 25(4), 270 - 275.
20. Antolin-Amerigo, D., Manso, L., Caminati, M., de la Hoz Caballer, B., Cerecedo, I., Muriel, A., Rodriguez-Rodriguez, M., Barbarroja-Escudero, J., Sanchez-Gonzalez, M.J., Huertas- Barbudo, B., and Alvarez-Mon, M. (2016). 'Quality of life in patients with food allergy', *Clinical and Molecular Allergy,* 14, 4.

21. Arshad, S.H., Tariq, S.M., Matthews, S., and Hakim, E. (2001). ‘Sensitization to common allergens and its association with allergic disorders at age 4 years: a whole population birth cohort study’, *Pediatrics*, 108(2), E33.
22. Ashtari, S., Pourhoseingholi, M.A., Rostami, K., Aghdaei, H.A., Rostami-Nejad, M., Busani, L., Tavirani, M.R., and Zali, M.R. (2019). ‘Prevalence of Gluten-Related Disorders in Asia-Pacific Region: A Systematic Review’, *Journal of GastIrelandntestinal and Liver Diseases,* 28(1):95-105.
23. Association of European Coeliac Societies (AOECS) (2015). ‘1 in 100 people are estimated to suffer from coeliac disease in Europe’, Belgium. Available at: https://www.aoecs.org/
24. Association of UK Dietitians (BDA) (2015). Food Fact Sheet. Food allergies and intolerances. Available at: https://www.bda.uk.com/foodfacts/Allergy.pdf
25. Asthma and Allergy Foundation of America (AAFA) (2019). ‘Are Asthma and Allergies Disabilities?’. Available at: https://www.aafa.org/asthma-allergies-and-the-american-with-disabilities-act/
26. Bant, A., and Kruszewski, J. (2008). ‘Increased sensitization prevalence to common inhalant and food allergens in young adult Polish males’, *Annals of Agricultural and Environmental Medicine*, 15(1):21-27.
27. Batóg, P., Rencz, F., Péntek, M., Gulácsi, L., Filipiak, K. J., Rupel, V. P., Simon, J., Brodszky, V., Baji, P., Závada, J., Petrova, G., Rotar, A., and Golicki, D. (2018). ‘EQ-5D studies in cardiovascular diseases in eight Central and Eastern European countries: a systematic review of the literature’, *Kardiologia Polska*, 76(5), 860-870.
28. Bedolla-Pulido, T.R., Bedolla-Barajas, M., Morales-Romero, J., Bedolla-Pulido, T.I., Domínguez-García, M.V., Hernández-Colín, D.D., and Flores-Merino, M.V. (2019). ‘Self-reported hypersensitivity and allergy to foods amongst Mexican adolescents: Prevalence and associated factors’, *Allergologia et Immunopathologia*, 47(3), 246-253.
29. Benjamini, Y., and Hochberg, Y. (1995). Controlling the false discovery rate: a practical and powerful approach to multiple testing. J*ournal of the Royal Statistical Society* Series B, 57, 289–300. Available at: http://www.jstor.org/stable/2346101.
30. Ben-Shoshan, M., Harrington, D. W., Soller, L., Fragapane, J., Joseph, L., Pierre, Y. S., Godefroy, S. B., Elliott, S. J., & Clarke, A. E. (2012). Demographic predictors of peanut, tree nut, fish, shellfish, and sesame allergy in Canada. Journal of allergy, 2012, 858306.Ben-Shoshan, M., Harrington, D.W., Soller, L., Fragapane, J., Joseph, L., St Pierre, Y.,

31. Ben-Shoshan, M., Turnbull, E., Clarke, A. (2012). ‘Food Allergy: Temporal Trends and Determinants’. *Current Allergy and Asthma Reports,* 12:347-372

32. Benyamini, Y., and Idler, E.L. (1999). ‘Community studies reporting association between self-rated health and mortality – additional studies, 1995 to 1998’, Research on Aging, Vol. 21 No. 4, pp. 392-401.

33. Bergmann, K.C., Heinrich, J., and Niemann, H. (2016). ‘Current status of allergy prevalence in Germany’, Position paper of the Environmental Medicine Commission of the Robert Koch Institute, *Allergo Journal Int*ernational*,* 25:6–10.

34. Bilaver, L. A., Chadha, A. S., Doshi, P., O’Dwyer, L., and Gupta., R. S. (2019). ‘Economic burden of food allergy’, Annals of Allergy, Asthma & Immunology, 122(4), 373-380.

35. Bilaver, L. A., Chadha, A. S., Doshi, P., O’Dwyer, L., and Gupta. R. S. (2019). ‘Economic burden of food allergy’, Annals of Allergy, Asthma & Immunology, 122(4), 373-380.

36. Bilaver, L. A., Kester, K. M., Smith, B. M., and Gupta, R. S. (2016). ‘Socio-economic Disparities in the Economic Impact of Childhood Food Allergy’, *Pediatrics,* 137(5).

37. Bingöl, G., Altıntaş, D.U., Yılmaz, M., and Kendirli S.G. (2016). ‘Clinical Features of Food Allergy during the 1st Year of Life: The ADAPAR Birth Cohort Study’, *International Archives of Allergy and Immunology,* 169(3):171-180.

38. Birdi, G., Cooke, R., and Knibb, R. (2016). ‘Quality of Life, Stress, and Mental Health in Parents of Children with Parentally Diagnosed Food Allergy Compared to Medically Diagnosed and Healthy Controls’. *Journal of Allergy*, 2016, pp.1-7.

39. Black, J.L., and Orfila, C. (2011). ‘Impact of coeliac disease on dietary habits and quality of life’.*J. Hum. Nutr. Diet.*,24, 582–587.

40. Blok, B.M.F., Doriene van Ginkel, C., Roerdink, E.M., Kroeze, M.A., Stel, A.A., Meulen, G.N., and Dubois, A.E.J., (2011). ‘Extremely low prevalence of epinephrine auto-injectors in high-risk food-allergic adolescents in Dutch high schools’, *Pediatric Allergy,* 22(4):374-377.

41. Bollinger, M. E., Dahlquist, L. M., Mudd, K., Sonntag, C., Dillinger, L., and McKenna, K. (2006). 'The impact of food allergy on the daily activities of children and their families', *Annal of Allergy Asthma and Immunology,* 96, 415-21.

42. Bord Bia Consumer Insights Report, 2017. Retrieved from: https://www.bordbia.ie/globalassets/bordbia2020/industry/insights/consumer-insights/gluten-free-in-ireland-final-report-april-2017.pdf

43. Brazier, J., Ratcliffe, J., Salomon, J.A., and Tsuchiya, A. (2007). Measuring and valuing health benefits for economic evaluation. Oxford: Oxford University Press.

44. Brick, A., Normand, C., O'Hara, S. and Smith, S. (2015). Economic evaluation of palliative care in Ireland. Dublin, Ireland: Trinity College Dublin.
45. British National Formulary (BNF) (2020). British National Formulary - NICE. Available at: https://bnf.nice.org.uk/
46. Bublin, M., Dennstedt, S., Buchegger, M., Antonietta, M., Ciardiello, M., Bernardi, M.L., Tuppo, L., Harwanegg, C., Hafner, C., Ebner, C., Ballmer-Weber, B.K., Knulst, A., Hoffmann-Sommergruber, K., Radauer, C., Mari, A., and Breiteneder, H. (2011). 'The performance of a component-based allergen microarray for the diagnosis of kiwifruit allergy', *Clinical and Experimental Allergy,* 41(1), 129-136.
47. Bublin, M., Pfister, M., Radauer, C., Oberhuber, C., Bulley, S., DeWitt, Å, M., Lidholm, J., Reese, G., Vieths, S., Breiteneder, H., Hoffmann-Sommergruber, K., and Ballmer-Weber, B.K. (2010). 'Component-resolved diagnosis of kiwifruit allergy with purified natural and recombinant kiwifruit allergens', *Journal of Allergy and Clinical Immunology*, 125(3), 687-694.e1.
48. Burden, M., Mooney, P.D., Blanshard, R.J., White, W.L., Cambray-Deakin, D.R., and Sanders, D.S. (2015). 'Cost and availability of gluten-free food in the UK: In store and online'. *Postgrad. Med. J.*, 91, 622–626.
49. Burney, P., Summers, C., Chinn, S., Hooper, R., van Ree, R., and Lidholm, J. (2010). 'Prevalence and distribution of sensitization to foods in the European Community Respiratory Health Survey: a EuroPrevall analysis'*.* *Allergy*, 65 (9), 1182–1188.
50. Burney, P.G.J., Potts, J., Kummeling, I., Mills, E. N. C., Clausen, M., Dubakiene, R., Barreales, L., Fernandez-Perez, C., Fernandez-Rivas, M., Le, T., Knulst, A. C., Kowalski, M. L., Lidholm, J., Ballmer-Weber, B. K., Braun-Fahlander, C., Mustakov, T., Kralimarkova, T., Popov, T., Sakellariou, A., Papadopoulos, N. G., Versteeg, S. A., Zuidmeer, L., Akkerdaas, J. H., Hoffmann-Sommergruber, K., and van Ree, R. (2014). 'The prevalence and distribution of food sensitization in European adults', *Allergy*, 69(3), 365-371.
51. Caffarelli, C., Coscia, A., Ridolo, E., Dascola, C.P., Gelmett, C., Raggi, V., Volta, E., Vanell, M., and Dall'Aglio, P.P. (2011). 'Parents' estimate of FA prevalence and management in Italian school-aged children', *Pediatrics International,* 53(4):505-510.
52. Caio, G., Volta, U., Sapone, A., Leffler, D. A., De Giorgio, R., Catassi, C., and Fasano, A. (2019). 'Coeliac disease: a comprehensive current review'. *BMC Med*, 17, 142. Available at: https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-019-1380-z#citeas DOI: https://doi.org/10.1186/s12916-019-1380-z

53. Caio, G., Volta, U., Sapone, A., Leffler, D.A., De Giorgio, R., Catassi, C., and Fasano. A (2019). 'Coeliac disease: a comprehensive current review'. *BMC Med* 17:142.
54. Cantril, H. (1965). 'The Pattern of Human Concerns'. New Brunswick, NJ: Rutgers University Press.
55. Capacci, S., Leucci, A. C., and Mazzocchi, M. (2018). 'There is no such thing as a (gluten-) free lunch: Higher food prices and the cost for coeliac consumers', *Economics & Human Biology*, 30, 84-91.
56. Capuozzo, M., Ottaiano, A., Nava, E., Cascone, S., Cinque, C., Iaffaioli, R. V., Scognamiglio, C., Palumbo, E., and Capuozzo, M. (2013). 'Epidemiology and economic impact of coeliac disease in the South Vesuvian area of Naples: a survey'. *Frontiers in Public Health*, 1, 18. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3854951/pdf/fpubh-01-00018.pdf
57. Carehome.co.uk (2019). All Counties in the UK with Care Homes. Available at: https://www.carehome.co.uk/
58. Centers for Disease Control and Prevention, National Center for Health Statistics, (2013). 'Summary Health Statistics for U.S. Children: National Health Interview Survey, 2012', *Vital and Health Statistics*, (258):1-81. DHHS Publication No. 2014–1586, Hyattsville, Maryland.
59. Central Statistics Office (CSO) (2015), 'Census At School 2015'. Cork: Central Statistics Office. Available at: https://www.cso.ie/en/interactivezone/censusatschoolsreleases/censusatschool2015/
60. Central Statistics Office (CSO) (2015). CensusAtSchool 2015. Cork: Central Statistics Office. Available at: https://www.cso.ie/en/interactivezone/censusatschoolsreleases/censusatschool2015/
61. Central Statistics Office, (2020). Inflation indices 2020. Available at: https://www.cso.ie/en/statistics/prices/consumerpriceindex/
62. Cerecedo, I., Zamora, J., Fox, M., Voordouw, J., Plana, N., Rokicka, E., Fernandez-Rivas, M., Vázquez Cortés, S., Reche, M., Fiandor, A., Kowalski, M., Antonides, G., Mugford, M., Frewer, L. J., and de la Hoz, B. (2014). 'The impact of double-blind placebo-controlled food challenge (DBPCFC) on the socioeconomic cost of food allergy in Europe', *Journal of Investigational Allergology and Clinical Immunology*. 24(6), 418–424.
63. Choung, R.S., Ditah, I.C., Nadeau, A.M., Rubio-Tapia, A., Marietta, E.V., Brantner, T.L., Camilleri, M.J., Rajkumar, S.V., Landgren, O., Everhart, J.E., and Murray, J.A. (2015).

‘Trends and racial/ethnic disparities in gluten-sensitive problems in the United States: findings from the National Health and nutrition examination surveys from 1988 to 2012. *The American Journal of Gastroenterology'*. 110(3):455–61.

64. Ciacci, C. and Zingone, F. (2015), ‘The Perceived Social Burden in Coeliac Disease’, *Diseases*, 3(2), 102–110. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5548237/pdf/diseases-03-00102.pdf
65. Cianferoni, A., and Votto, M. (2020). ‘COVID-19 and allergy: How to take care of allergic patients during a pandemic?’. *Pediatric Allergy and Immunology*, 31(S26), pp.96-101.
66. Citizens Information (2021). Drug Payment Scheme. Available at: https://www.citizensinformation.ie/en/health/drugs_and_medicines/drugs_payment_scheme.html
67. Clarke, A.E., Elliott, S.J., Pierre, Y.S., Soller, L., La Vieille, S., and Ben-Shoshan, M. (2020). 'Temporal trends in prevalence of food allergy in Canada'. *Journal of Allergy and Clinical Immunology: In Practice,* 8(4), 1428-1430.
68. Clover, A.F., Nevantaus, H., Macdougall, C.F., and Cant, A.J. (2005). ‘Severe food-allergic reactions in children across the UK and Ireland, 1998-2000’. *Acta Paediatrica*, 94:689-695.
69. Coeliac Disease Foundation (2019). What is Coeliac Disease? Available at: https://celiac.org/about-celiac-disease/what-is-celiac-disease/
70. Coeliac Society of Ireland (2014). Prevalence and diagnosis. Available at: https://www.coeliac.ie/join-now/professional/prevalence-and-diagnosis/
71. Coeliac Society of Ireland (2019). Dataset of 2,899 individuals reporting to have medically diagnosed coeliac disease in 2019.
72. Coeliac Society of Ireland (2021). About Coeliac Disease.
73. Coeliac UK (2019). About Coeliac Disease. Available at: https://www.coeliac.org.uk/coeliac-disease/about-coeliac-disease-and-dermatitis-herpetiformis/
74. Coeliac UK (2019). Coeliac Disease in Children. Available at: https://www.coeliac.org.uk/coeliac-disease/coeliac-disease-in-children/
75. Cohen, B. L., Noone, S., Munoz-Furlong, A., and Sicherer, S. H. (2004). 'Development of a questionnaire to measure quality of life in families with a child with food allergy', Journal of Allergy and Clinical Immunology, 114, 1159-1163.

76. Colver, A.F., Nevantaus, H., Macdougall, C.F., and Cant, A.J. (2015). ‘Severe food-allergic reactions in children across the UK and Ireland, 1998-2000’, Acta Paediatrica, 94(6):689-695.
77. Connolly, S., Gillespie, P., O’Shea, E., Cahill, S., and Pierce, M. (2014). Estimating the economic and social costs of dementia in Ireland. Dementia, 13, 5–22.
78. Cornelisse-Vermaat, J.R., Voordouw, J., Yiakoumaki, V., Theodoridis, G., and Frewer, L.J. (2008). ‘Food-allergic consumers’ labelling preferences: a cross-cultural comparison’. Eu J Public Health, 18:115-120.
79. Crevel, R. W., Ballmer-Weber, B. K., Holzhauser, T., Hourihane, J. O., Knulst, A. C., Mackie, A. R., Timmermans, F., and Taylor, S. L. (2008). 'Thresholds for food allergens and their value to different stakeholders', *European Journal of Allergy and Clinical Immunology,* 63, 597-609.
80. Crocker, H., Crispin, J., and Peters, M. (2018). ‘Quality of life in coeliac disease: qualitative interviews to develop candidate items for the Coeliac Disease Assessment Questionnaire’, *Dove Press*: Patient Related Outcome Measures, 9 211–220. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6038864/pdf/prom-9-211.pdf
81. Crocker, H., Jenkinson, C., and Peters, M. (2020). ‘Healthcare experiences and quality of life of adults with coeliac disease: a cross-sectional study’*. J Hum Nutr Diet*. 33, 741– 751.
82. Cummings, A. J., Knibb, R. C., King, R. M., and Lucas, J. S. (2010). ‘The psychosocial impact of food allergy and food hypersensitivity in children, adolescents and their families: a review’. *Allergy*. 65, 933–45.
83. Curtis, L., and Burns, A. (2019). *Unit Costs of Health and Social Care 2019,* Unit Costs of Health and Social Care. PSSRU, Kent, UK, 176 pp. ISBN 978-1-911353-10-2. Available at: https://www.pssru.ac.uk/project-pages/unit-costs/unit-costs-2019/
84. D'Auria E, Anania C, Cuomo B, Decimo F, Indirli GC, Mastrorilli V, Santoro A, Sartorio MUA, Veronelli E, Caffarelli C, Marseglia GL, Calvani M, Food Allergy Study Group TISOPAAIS. (2020), ‘COVID-19 and food allergy in children’. *Acta Biomed*. 11;91(2):204-206.
85. de Blok, B. M., Vlieg-Boerstra, B. J., Oude-Elberink, J. N., Duiverman, E. J., DunnGalvin, A., Hourihane, J. O., Cornelisse-Vermaat, J. R., Frewer, L., Mills, C., and Dubois, A. E. (2007). ‘A framework for measuring the social impact of food allergy across Europe: a EuroPrevall state of the art paper’. *Allergy.* 62(7), 733–737.
86. De Martinis, M., Sirufo, M.M., Viscido, A., and Ginaldi, L. (2019). ‘Food allergies and Ageing’. *International Journal of Molecular Sciences*, 20, 5580.

87. Dean, T., Venter, C., Pereira, B., Arshad, S.H., Grundy, J., Clayton, C.B., and Higgins, B., (2007). 'Patterns of sensitization to food and aeroallergens in the first 3 years of life', *Journal of Allergy and Clinical Immunology,* 120(5):1166-1171.
88. Department of Education (Northern Ireland) (2018). 'Guidance on the use of adrenaline auto-injectors (AAIs) in schools in Northern Ireland'. Available at: https://www.anaphylaxis.org.uk/wp-content/uploads/2018/10/Guidance-on-the-use-of-adrenaline-auto-injectors-AAIs-in-schools-in-Northern-Ireland.pdf
89. Department of Education (Northern Ireland) (2021). Department of Education Institution Search. Available at: http://apps.education-ni.gov.uk/appinstitutes/default.aspx.
90. Department of Education and Skills (2015). Data on Individual Schools.
91. Department of Health (England) (2017a). The Availability of Gluten-Free Foods on Prescription in Primary Care. Consultation on the Availability of Gluten-Free Foods on Prescription in Primary Care. Technical report. Department of Health (England).
92. Department of Health (England), (2017b). The Availability of Gluten-Free Foods on Prescription in Primary Care. Impact Assessment. Technical report. Department of Health (England).
93. Department of Health (Northern Ireland) (2019). National Health Service (NHS) Reference Costs 2018 to 2019, National Schedule of NHS Costs. Available at: https://improvement.nhs.uk/resources/national-cost-collection/#ncc1819.
94. Department of Health (Northern Ireland) (2019). Trust Reference Costs 2018/2019. Available at: https://www.health-ni.gov.uk/articles/trust-reference-costs
95. DiGiacomo, D. V., Tennyson, C. A., Green, P. H., and Demmer, R. T. (2013). 'Prevalence of gluten-free diet adherence among individuals without coeliac disease in the USA: Results from the continuous national health and nutrition examination survey 2009-2010'. *Journal of Gastroenterology*, 48, 921-925.
96. Dobru, D., Pascu, O., Tanţă, M., Gheorghe, C., Goldiş, A., Bălan, G., Olteanu, I., Fraticiu, A., Dumitru, E., Miuţescu, E., Mulder, C., and Podoleanu, S. (2003). 'The prevalence of coeliac disease at endoscopy units in Romania: routine biopsies during gastroscopy are mandatory (a multicentre study)', *Romanian Journal of Gastroenterology*, 12(2):97-100.
97. Dr. Schär Institute (2019). Epidemiology of Coeliac Disease. Available at: https://www.drschaer.com/uk/institute/a/prevalence-coeliac-disease
98. Du Toit, G., Foong, R., and Lack, G. (2016). 'Prevention of food allergy – Early dietary interventions'. *Allergology International*, 65(4), pp.370-377.

99. Dubakiene, R., Rudzeviciene, O., Butiene, I., Sezaite, I., Petronyte, M., Vaicekauskaite, D., and Zvirbliene, A., (2012). 'Studies on early allergic sensitization in the Lithuanian birth cohort', *The Scientific World Journal,* 909524.

100. DunnGalvin, A., Dubois, A.E., Flokstra-de Blok, B.M., and Hourihane, J.O.B. (2015). 'The effects of food allergy on quality of life'. *Chem Immunol Allergy*. 101, 235–252.

101. DunnGalvin, A., Hourihane, J., Frewer, L., Knibb, R., Oude Elberink, J., and Klinge, I. (2006). 'Incorporating a gender dimension in food allergy research: a review'. *European Journal of Allergy and Clinical Immunology* 61(11).1336-1343.

102. DunnGalvin, A., Roberts, G., Schnadt, S., Astley, S., Austin, M., Blom, W., Baumert, J., Chan, C., Crevel, R., Grimshaw, K., Kruizinga, A., Regent, L., Taylor, S., Walker, M., and Mills, E. (2019). 'Evidence-based approaches to the application of precautionary allergen labelling: Report from two iFAAM workshops'. *Clinical & Experimental Allergy*, 49(9), pp. 1191-1200.

103. DunnGalvin, A., Treneva, M., Pampura, A., Grebenko, A., Makatsori, M., and Munblit, D. (2020). 'Quality of life associated with maternal anxiety disorder in Russian children and adolescents with food allergy'. *Pediatric Allergy and Immunology*, 31(1), pp.78-84.

104. Education (Northern Ireland) (2019). Home. Available at: https://www.education-ni.gov.uk/.

105. Eggesbø, M., Botten, G., Halvorsen, R., and Magnus, P. (2001a). 'The prevalence of allergy to egg: a population-based study in young children', *Allergy*, 56(5):403-411.

106. Eggesbø, M., Botten, G., Halvorsen, R., and Magnus, P. (2001b). 'The prevalence of CMA/CMPI in young children: The validity of parentally perceived reactions in a population-based study', *Allergy,* 56(5):393-402.

107. Eggesbø, M., Botten, G., Stigum, H., Nafstad, P., and Magnus, P. (2003c). 'Is delivery by caesarean section a risk factor for FA?' *Journal of Allergy and Clinical Immunology*, 112(2):420-426.

108. Eller, E., Kjaer, H.F., Host, A., Andersen, K.E., and Bindslev-Jensen, C. (2009). 'FA and food sensitization in early childhood: Results from the DARC cohort', *Allergy*, 64(7):1023-1029.

109. European Academy of Allergy and Clinical Immunology (2014). EAACI food allergy and anaphylaxis guidelines: diagnosis and management of food allergy, *Allergy*. 69(8):1008-25.

110. European Academy of Allergy and Clinical Immunology (2015). Food Allergy and Anaphylaxis Public Declaration. Zurich, Switzerland. Available at: http://www.anaphylaxisireland.ie/wp-content/uploads/2013/04/FoodAllergyAnaphylaxisPublicDeclarationCombined-1.pdf

111. European Commission (1997). Food Science and Techniques, Reports of the Scientific Committee for Food (37th series): Adverse reactions to food and food ingredients. Available at: https://ec.europa.eu/food/sites/food/files/safety/docs/sci-com_scf_reports_37.pdf

112. European Food Information Council (EUFIC) (2013). Food Allergens – Allergic Reaction to Food. Available at: https://www.eufic.org/en/healthy-living/article/food-allergens

113. European Food Safety Authority (EFSA) (2014). 'NDA Panel (EFSA Panel on Dietetic Products, Nutrition and Allergies), Scientific Opinion on the evaluation of allergenic foods and food ingredients for labelling purposes', *European Food Safety Authority Journal*, 12(11):3894,286.

114. European Union (2011). REGULATION (EU) No. 1169/2011 of The European Parliament and of The Council Of 25 October 2011 on the provision of food information to consumers.

115. EuroQol Group (1990). 'EuroQol – a new facility for the measurement of health-related quality of life'. Health Policy 16:199–208.

116. EuroQol Group (2021). EuroQol Website. Available at: www.euroqol.org

117. Exchange-Rates.Org (2019). British Pounds (GBP) to Euros (EUR) exchange rate for October 18, 2019. Available at: https://www.exchange-rates.org/Rate/GBP/EUR/10-18-2019

118. Exchange-rates.org (2019). US Dollar Exchange Rates for 2019 Euro. Available at: https://www.exchange-rates.org/HistoricalRates/E/USD/7-26-2019

119. Falcão, H., Lunet, N., Lopes, C., and Barros, H, (2004). 'Food hypersensitivity in Portuguese adults', *European Journal of Clinical Nutrition*, 58(12):1621-1625.

120. Fasano A. (2003), 'Coeliac disease: how to handle a clinical chameleon'. *New England Journal of Medicine*. 348:2568–70.

121. Fasano, A., and Catassi, C . (2012). Clinical practice. 'Coeliac disease'. *New England Journal of Medicine,* 367:2419-26.

122. Fasano, A., and Catassi, C. (2005). 'Coeliac disease in children', *Best Practice and Research Clinical Gastroenterology,* 19(3):467-78.

123. Flabbee, J., Petit, N., Jay, N., Guénard, L., Codreanu, F., Mazeyrat, R., Kanny, G., and Moneret-Vautrin, D. A. (2008). 'The economic costs of severe anaphylaxis in France: an inquiry carried out by the Allergy Vigilance Network', *Allergy*, 63: 360–365.

124. Flokstra-de Blok, B. M., van der Meulen, G. N., DunnGalvin, A., Vlieg-Boerstra, B. J., Oude Elberink, J. N., Duiverman, E. J., Hourihane, J. O., and Dubois, A. E. (2009). 'Development and validation of the food allergy quality of life questionnaire—adult form'. *Allergy*. 64(8), 1209 1217.
125. Flokstra-de Blok, B.M., Dubois, A. E., Vlieg-Boerstra, B. J., Oude Elberink, J. N., Raat, H., DunnGalvin. A., Hourihane, J.O., and Duiverman, E. J. (2010). 'Health-related quality of life of food allergic patients: comparison with the general population and other diseases', *Allergy*, 65(2), 238-244.
126. Fong, A., Katelaris, C., and Wainstein, B. (2017). 'Bullying and quality of life in children and adolescents with food allergy'. *Journal of Paediatrics and Child Health*, 53(7), pp.630-635.
127. Food Safety Authority of Ireland (2017). 'Audit Report, Targeted Audit of Allergen Information on Non-Prepacked Food'. Available at: https://www.fsai.ie/uploadedFiles/Enforcement_and_Audit/Audit/Reports/Targeted_Audit_Allergen_Info_Non-Pre-Packed_Food.pdf
128. Food Safety Authority of Ireland (FSAI) (2015). Food hypersensitivity, food allergy and intolerance. Available at: https://www.fsai.ie/Foodhypersensitivityfoodallergyandintolerance
129. Food Safety Authority of Ireland (FSAI) (2016). Correct allergen labelling. Available at: https://www.fsai.ie/uploadedFiles/News_Centre/Newsletters/Newsletters_Listing/FSAI%20News%20October%202016_10%20(Final%202).pdf
130. Food Safety Authority of Ireland (FSAI), (2011). 'Monitoring and Surveillance Series Food Allergens and Labelling Survey'. Dublin, Ireland. Available at: https://www.fsai.ie/resources_publications/allergen_labelling_2011.html.html
131. Food Standards Agency, (2002). 'May contain' labelling - the consumer's perspective. UK: Food Standards Agency.
132. Ford E., Mannino, D.M., Homa, D.M., Gwynn, C., Redd, S.C., Moriarity, D.G., and Mokdad, A. (2003). 'Self-reported asthma and health-related quality of life'. *Chest,* 123:119-127.
133. Fox, A.T., Sasieni, P., Toit, G., Syed, H., and Lack, G. (2009). 'Household peanut consumption as a risk factor for the development of peanut allergy', *Journal of Allergy and Clinical Immunology*, 123(2):417-423.
134. Fox, M., Mugford, M., Voordouw, J., Cornelisse-Vermaat, J., Antonides, G., de la Hoz Caballer, B., Cerecedo, I., Zamora, J., Rokicka, E., Jewczak, M., Clark, A. B., Kowalski, M. L., Papadopoulos, N., Knulst, A. C., Seneviratne, S., Belohlavkova, S., Asero, R., de Blay,

F., Purohit, A., Clausen, M., Flokstra-de Blok, B., Dubois, A. E., Fernandez-Rivas, M., Burney, P., Frewer, L. J., and Mill, C. E. N. (2013). 'Health sector costs of self-reported food allergy in Europe: a patient-based cost of illness study', *European Journal of Public Health*, 23(5), 757–762. doi:10.1093/eurpub/ckt010.

135. Fox, M., Mugford, M., Voordouw, J., Cornelisse-Vermaat, J., Antonides, G., de la Hoz Caballer, B., Cerecedo, I., Zamora, J., Rokicka, E., Jewczak, M., Clark, A. B., Kowalski, M. L., Papadopoulos, N., Knulst, A. C., Seneviratne, S., Belohlavkova, S., Asero, R., de Blay, F., Purohit, A., Clausen, M., Flokstra de Blok, B., Dubois, A. E., Fernandez-Rivas, M., Burney, P., Frewer, L. J. & Mill, C, E. N. (2013). 'Health sector costs of self-reported food allergy in Europe: a patient-based cost of illness study', *European Journal of Public Health*, 23(5), 757–762. doi:10.1093/eurpub/ckt010.
136. Fox, M., Voordouw, J., Mugford, M., Cornelisse, J., Antonides, G., and Frewer, L. (2009). 'Social and Economic Costs of Food Allergies in Europe: Development of a Questionnaire to Measure Costs and Health Utility', *Health Services Research*, 44(5p1):1662-1678.
137. Frongia, O., Bellomo, A.R., Di Giorgio, G., Fiumalbi, C., Frizza, J., Maresca, C., Mari, M., Tominz, R., Binkin, N., Perra, A., Bella, A., and Atti, M. C. D. (2005). 'Intolleranze e allergie alimentari nella prima infanzia' (Food allergies and intolerance in infants and children), *Medico e Bambino*, 24:533-538.
138. Fry, L., Madden, A.M., and Fallaize, R. (2018). 'An investigation into the nutritional composition and cost of gluten-free versus regular food products in the UK'. *J. Hum. Nutr. Diet. 31*, 108–120. https://onlinelibrary.wiley.com/doi/epdf/10.1111/jhn.12502
139. FSAI (2019). Report of the Scientific Committee of the Food Safety Authority of Ireland. Information required for the risk assessment of undeclared food allergens in Ireland. Dublin, Ireland. Available at: https://www.fsai.ie/WorkArea/DownloadAsset.aspx?id=17186
140. Fueyo-Díaz, R., Magallón-Botaya, R., Masluk, B., Palacios-Navarro, G., Asensio-Martínez, A., Gascón-Santos, S., Olivan-Blázquez, B., and Sebastián-Domingo, J. J. (2019). 'Prevalence of coeliac disease in primary care: the need for its own code', *BMC Health Services Research*, 19(1):578.
141. Gannon, B., O'Shea, E., and Hudson, E. (2008). Economic Consequences of Falls and Fractures among Older People. *Irish Medical Journal*. 101. 170-3.
142. Gatti, S., Lionetti, E., Balanzoni, L., Verma, A.K., Galeazzi, T., Gesuita, R., Scattolo, N., Cinquetti, M., Fasano, A., and Catassi, C. (2020). 'Increased Prevalence of Coeliac Disease in School-age Children in Italy', *Clinical Gastroenterology and Hepatology,* 18(3), 596-603.

143. Gelincik, A., Buyukozturk, S., Gul, H., Isik, E., Issever, H., Ozseker, F., Colakoğlu, B., Dal, M., Ayvaz, O., Güngör, G., and Akkor, A. (2008). 'Confirmed prevalence of FA and non-allergic food hypersensitivity in a Mediterranean population', *Clinical & Experimental Allergy*, 38(8):1333-1341.

144. Ghisoni, M., Wilson, C., Morgan, K., Edwards, B., Simon, N., Langley, E., Rees, H., Wells, A., Tyson, P., Thomas, P., Meudell, A., Kitt, F., Mitchell, B., Bowen, A., and Celia, J. (2017). 'Priority setting in research: user-led mental health research'. *Research Involvement and Engagement*, 3(1).

145. Godefroy, S.B., Elliott, S.J., and Clarke, A.E. (2010). 'A population-based study on peanut, tree nut, fish, shellfish, and sesame allergy prevalence in Canada'. *Journal of Allergy and Clinical Immunology,* 125 (6), 1327–1335.

146. Gonçalves, L.C.P., Guimarães, T.C.P., Silva, R.M., Cheik, M.F.A., Nápolis, A.C.D.R., Silva, G.B.E., and Segundo, G.R.S. (2016). 'Prevalence of food allergy in infants and pre-schoolers in Brazil', *Allergologia et Immunopathologia*, 44(6), 497-503.

147. Goossens, N. J., Flokstra-de Blok, B. M., van der Meulen, G.N., Arnlind, M. H., Asero, R., Barreales, L., Burney, P., Cerecedo, I., Clausen, M., Fernandéz-Rivas, M., Frewer, L., de la Hoz Caballer, B., Jansson, S.A., Jedrzejczak-Czechowicz, M., Knulst, A. C., Kowalski, M. L., Papadopoulos, N. G., Purohit, A., Rokicka, E., Starosta, P., Vásquez-Cortés, S., Duiverman, E. J., and Dubois, A. E. (2014). 'Health-related quality of life in food-allergic adults from eight European countries'. *Annals of Allergy, Asthma and Immunology,* 113(1), 63–68 (e1).

148. Government of Republic of Ireland (2019). The Minimum Wage in Ireland 2019. Available at: https://www.gov.ie/en/publication/b7da27-the-minimum-wage-in-ireland-2019/

149. Government of UK (2019). National Minimum Wage and National Living Wage rates. Available at: https://www.gov.uk/national-minimum-wage-rates

150. Greenhawt, M. (2016). 'Food allergy quality of life and living with food allergy'. *Current Opinion in Allergy & Clinical Immunology*, 16(3), pp.284-290.

151. Growing Up in Ireland (GUI) (2008). The Growing Up in Ireland study from the Economic & Social Research Institute (ERSI): Child Cohort (9 years) and Infant Cohort (9 months). Available at: https://www.growingup.ie/about-growing-up-in-ireland/

152. Gruefeldova, J., Domijan K., and Walsh, C. (2019). A Study of Food Safety Knowledge, Practice and Training among food handlers in Ireland. *Journal of Food Control,* 105, 131-140.

153. Grundy, J., Matthews, S., Bateman, B., Dean, T., and Arshad, S.H. (2002). 'Rising prevalence of allergy to peanut in children: Data from 2 sequential cohorts'*, The Journal of Allergy and Clinical Immunology*, 110(5):784-789.
154. Gujral, N., Freeman, H.J., and Thomson, A.B.R. (2012). 'Coeliac disease: Prevalence, diagnosis, pathogenesis and treatment', *World Journal of Gastroenterology*, 18(42), 6036-6059.
155. Gupta, R., Holdford, D., Bilaver, L., Dyer, A., Holl, J.L., and Meltzer, D. (2013). The economic impact of childhood food allergy in the United States. *JAMA Paediat*rics, 167, 1026-31
156. Gupta, R.S., Springston, E.E., Warrier, M.R., Smith, B., Kumar, R., Pongracic, J., and Holl, J.L. (2011). 'The prevalence, severity and distribution of childhood food allergy in the United States', *Official Journal of the American Academy of pediactrics.*
157. Gupta, R.S., Warren, C.M., Smith, B.M., Blumenstock, J.A., Jiang, J., Davis, M.M., and Nade, K.C. (2018). 'The Public Health Impact of Parent-Reported Childhood Food Allergies in the United States', *Pediatrics,* 142(6), e20181235.
158. Gupta, R.S., Warren, C.M., Smith, B.M., Jiang, J., Blumenstock, J.A., Davis, M.M., Schleimer, R.P., and Nadeau, K.C. (2019). 'Prevalence and Severity of Food Allergies Among US Adults', *The Journal of American Medical Association Network Open*, 2(1), e185630.
159. Hanci, O., and Jeanes, Y.M. (2019). 'Are gluten-free food staples accessible to all patients with coeliac disease?', *Frontline Gastroenterology*, 10:222–228.
160. Hanly, P., Céilleachair, A. Ó., Skally, M., O'Leary, E., Kapur, K., Fitzpatrick, P., Staines, A., and Sharp, L. (2013). How much does it cost to care for survivors of colorectal cancer? Caregiver's time, travel and out-of-pocket costs. *Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer*, *21*(9), 2583–2592.
161. Health Information and Quality Authority (2019). Guidelines for the economic evaluation of health technologies in Ireland. Dublin, Ireland.
162. Health Service Executive (HSE) (2018). Coeliac disease. Available at: https://www.hse.ie/eng/health/az/c/coeliac-disease/
163. Health Service Executive (HSE) (2013). A national model of care for Paediatric Healthcare Services in Ireland. Available at: https://www.hse.ie/eng/services/publications/clinical-strategy-and-programmes/paediatric-allergy.pdf

164. Health Service Executive (HSE) (2019). HSE Pay scales. Available at: https://www.hse.ie/eng/staff/resources/hr-circulars/hr-circular-027-2019-appendix-2-1st-september-2019-consolidated-payscales-final-pdf.pdf

165. Hefle, S. L., Furlong, T. J., Niemann, L., Lemon-Mule, H., Sicherer, S., and Taylor, S. L. (2007). 'Consumer attitudes and risks associated with packaged foods having advisory labelling regarding the presence of peanuts', *Journal of Allergy and Clinical Immunology,* 120,171- 6.

166. Hertzen, L.V., Makela M.J., Petays, T., Jousilahti, P., Kosunen, T.U., Laatikainen, T., Vartiainen, E., and Haahtela, T. (2006). 'Growing disparities in atopy between the Finns and the Russians: A comparison of 2 generations', *The Journal of Allergy and Clinical Immunology*, 117(1):151-157.

167. HIPE 1 (Hospital Inpatient Enquiry), Information Management Unit (IMU), Hospital Inpatient Enquiry (HIPE) database, Republic of Ireland. Discharges with a principal diagnosis of ICD-9-CM 995.60 - 995.69.

168. HIPE 2 (Hospital Inpatient Enquiry), Information Management Unit (IMU), Hospital Inpatient Enquiry (HIPE) database, Republic of Ireland. Discharges with a principal diagnosis of ICD-10, T780.

169. HM Revenue & Customs (2019). Travel - mileage and fuel rates and allowances. Available at: https://www.gov.uk/government/publications/rates-and-allowances-travel-mileage-and-fuel-allowances/travel-mileage-and-fuel-rates-and-allowances.

170. Ho, M.H.K., Lee, S.L., Wong, W.H.S., Ip, P., and Lau, Y.L. (2012). 'Prevalence of self-reported food allergy in Hong Kong Children and teens – a population survey', *Asian Pacific Journal of Allergy Immunology,* 30(4):275-284.

171. Hospital In-Patient Enquiry (2018). HIPE data requests. Dublin, Ireland.

172. Høst, A., Halken, S., Jacobsen, H.P., Christensen, A.E., Herskind, A.M., and Plesner, K. (2002). 'Clinical course of cow's milk protein allergy/intolerance and atopic diseases in childhood', *Paediatric Allergy and Immunology*, 13(15):23-28.

173. Hourihane, J.O., Aiken, R., Briggs, R., Gudgeon, L.A., Grimshaw, K.E.C., DunnGalvin, A., and Roberts, S.R. (2007). 'The impact of government advice to pregnant mothers regarding peanut avoidance on the prevalence of peanut allergy in United Kingdom children at school entry'*, The Journal of Allergy and Clinical Immunology,* 119(5):1197-1202.

174. Hsicherer, S., Muñoz-Furlong, A., and Sampson, H.A. (2003). 'Prevalence of peanut and tree nut allergy in the United States determined by means of a random digit dial

telephone survey: A 5-year follow-up study', *Journal of Allergy and Clinical Immunology*, 112(6):1203-1207.

175. https://nhi.ie/find-a-nursing-home/
176. https://www.anaphylaxis.org.uk/wp-content/uploads/2018/10/Guidance-on-the-use-of-adrenaline-auto-injectors-AAIs-in-schools-in-Northern-Ireland.pdf
177. https://www.education.ie/en/Publications/Statistics/Data-on-Individual-Schools/
178. Institute of Food Research (IFR) (2006). Memorandum by the Institute of Food Research (IFR). Available at: https://publications.parliament.uk/pa/ld200607/ldselect/ldsctech/166/7031509.htm
179. Irish College of General Practitioners (ICGP) (2015). Irish College of General Practitioners Quick Reference Guide (ICGP QRG), Diagnosis and management of adult coeliac disease. Available at: https://www.icgp.ie/go/library/catalogue/item/B082AC8D-CC52-79BF-05E5445183224121
180. Irish Food Allergy Network (IFAN) (2017). Schools. Available at: http://ifan.ie/childcare-schools/
181. Irish Food Allergy Network (IFAN) (2019). Food allergy in summary. Available at: http://ifan.ie/food-allergy-in-summary/summary/
182. Irish Health (2016). Food intolerance often confused with allergies. Available at: http://www.irishhealth.com/article.html?id=25258
183. Irish Health (2018a). Coeliac disease – a personal perspective. Available at: http://www.irishhealth.com/article.html?id=818
184. Irish Health (2018b). Coeliac disease – more common than you think. Available at: http://www.irishhealth.com/article.html?id=6904
185. Irish Nurses and Midwives Organisation (INMO) (2010). 'Eliminating misery of CMPA', *WIN*, 18(9): 49-51.
186. Irish Nutrition and Dietetic Institute (INDI) (2019b). Coeliac disease and the gluten-free diet. Available at: https://www.indi.ie/news/281-coeliac-disease-and-the-gluten-free-diet.html
187. Irish Nutrition and Dietetics Institute (INDI) (2019). Food allergies and intolerances. Available at: https://www.indi.ie/diseases,-allergies-and-medical-conditions/food-allergy-and-intolerance/383-food-allergies-and-intolerances-factsheet.html
188. Isolauri, E., Huurre, A., Salminen, S., and Impivaara, O. (2004). 'The allergy epidemic extends beyond the past few decades', *Clinical and Experimental Allergy*, 34(7):1007-1010.

189. Jansson S.A., Protudjer, J.L., Arnlind Heibert, M., Bengtsson, U., Kallström-Bengtsson, I., Marklund, B., Middelveld, R.J., Rentzos, G., Sundqvist, A.C., Akerström, J., Ostblom, E., Dahlén, S.E., and Ahlstedt, S. (2014). Socio-economic evaluation of well characterized allergy to staple foods in adults. *European Journal of Allergy and Clinical Immunology*, 69,1241-7.

190. Jansson, S.A., Heibert-Arnlind, M., Middelveld, R., Bengtsson, U. J., Sundqvist, AC., Kallström-Bengtsson, I., Marklund, B., Rentzos, G., Åkerström, J., Östblom, E., Dahlén, S.E., and Ahlstedt, S. (2013). 'Health-related quality of life, assessed with a disease-specific questionnaire, in Swedish adults suffering from well-diagnosed food allergy to staple foods', *Clinical and Translational Allergy*, 3:21.

191. Jansson, S.A., Östblom, E., Protudjer, J., Arnlind, M. H., Bengtsson, U., Källström-Bengtsson, I., Marklund, B., Middelveld, R., Rentzos, G., Sundqvist, A.C., Åkerström, J., Dahlén, S.E., and Ahlstedt, S. (2015). 'Health-related quality of life in children and adolescents allergic to staple foods'. *Clinical and Translational Allergy*, 5 (Suppl 3):O23.

192. Johansson, S.G., Hourihane, J.O., Bousquet, J., Bruijnzeel-Koomen, C., Dreborg, S., Haahtela, T., Kowalski, M.L., Mygind, N., Ring, J., van Cauwenberge, P., van Hage-Hamsten, M., Wüthrich, B. (2001). EAACI (the European Academy of Allergology and Clinical Immunology) nomenclature task force. 'A revised nomenclature for allergy. An EAACI position statement from the EAACI nomenclature task force'. *Allergy*.56(9):813-24.

193. Johansson, S.G.O., Nopp, A., Florvaag, E., Lundahl, J., Soderstrom, T., Guttormsen, A.B., Hervig, T., Lundberg, M., Oman, H., and Hage, M.V. (2005). 'High prevalence of IgE antibodies among blood donors in Sweden and Norway*', Allergy,* 60(10):1312-1315.

194. Johnston, S.D., Watson, R.G., McMillan, S.A., Sloan, J., and Love, A.H.G. (1997). 'Prevalence of coeliac disease in Northern Ireland', *Lancet,* 350(9088),1370.

195. Jones, K. (2013). 'Success for a novel approach to priority setting in South Australian public dental clinics', *Australian Dental Journal*, 58: 378–383.

196. Julge, K., Vasar, M., and Bjorksten, B. (2001). 'Development of allergy and IgE antibodies during the first five years of life in Estonian children', *Clinical and Experimental Allergy*, 31(12):1854-1861.

197. Kahneman, D., Diener, E., and Schwarz N. (1999). Foundations of Hedonic Psychology: Scientific Perspectives on Enjoyment and Suffering. New York: Russell Sage Foundation.

198. Kamdar, T.A., Peterson, S., Lau, C.H., Saltoun, C.A., Gupta, R.S., and Bryce, P.J. (2015). ‘Prevalence and characteristics of adult-onset food allergy’. *Journal of Allergy and Clinical Immunology: In Practice,* 3 (1), 114–115 e111.

199. Kanny, G., Moneret-Vautrin, D.A., Flabbee, J., Beaudouin, E., Morisset, M., and Thevenin, F. (2001). ‘Population study of FA in France’, *Journal of Allergy and Clinical Immunology,* 108(1):133-140.

200. Kaya, A., Erkoçoğlu, M., Civelek, E., Çakır, B., and Kocabaş, C.N. (2013). ‘Prevalence of confirmed IgE-mediated food allergy among adolescents in Turkey’, *Paediatric Allergy and Immunology*, 24(5):456-462.

201. Kelleher, M. M., Dunn-Galvin, A., Gray, C., Murray, D. M., Kiely, M., Kenny, L., McLean, W. H. I., Irvine, A. A., and Hourihan, J. O. (2016). ‘Skin barrier impairment at birth predicts food allergy at 2 years of age’, *Journal of Allergy and Clinical Immunology*, 137(4):1111-1116.e8.

202. Kim, M., Lee, J.Y., Jeon, H.Y., Yang, H.K., Lee, K.J., Han, Y., Kim, Y.H., Kim, J., abd Ahn, K. (2017). ‘Prevalence of Immediate-Type Food Allergy in Korean Schoolchildren in 2015: A Nationwide, Population-based Study’*, Allergy, Asthma and Immunology Research,* 9(5):410-416.

203. Kinsey, L., Burden, S.T., and Bannerman, E. (2008). ‘A dietary survey to determine if patients with coeliac disease are meeting current healthy eating guidelines and how their diet compares to that of the British general population’. Eur. *J. Clin. Nutr.* 62, 1333–1342.

204. Kratzer, W., Kibele, M., Akinli, A., Porzner, M., Boehm, B.O., Koenig, W., Oeztuerk, S., Mason, R.A., Mao, R., and Haenle, M.H. (2013). ‘Prevalence of coeliac disease in Germany: A prospective follow-up study’, *World Journal Gastroenterol*, 19(17): 2612–2620.

205. Krause, T.G., Koch, A., Poulsen, L.K., Kristensen, B., Olsen, O.R., and Melbye, M. (2002). ‘Atopic sensitization among children in an Arctic environment’, *Clinical and Experimental Allergy*, 32(3):367-372.

206. Kristinsdottir, H., Clausen, M., Ragnarsdottir, H.S., Halldorsdottir, I.H., McBride, D., Beyer, K., and Sigurdardóttir, S.T. (2011). ‘Algengifaeduofnaemishjaislenskumbornum a fyrstaari’ (Prevalence of FA in Icelandic infants during first year of life), *Laeknabladid,* 97(1):11-18.

207. Kucukosmanoglu, E., Yazi, D., Yesil, O., Akkoc, T., Gezer, M., Bakirci, N., Bahceciler, N.N., and Barlan, I.B. (2008). ‘Prevalence of egg sensitization in Turkish infants based on skin prick test’, *Allergologia Et Immunopathologia*, 36(3):141-144.

208. Kurukulaaratchy, R.J., Matthews, S., and Arshad, S.H. (2005). 'Defining childhood atopic phenotypes to investigate the association of atopic sensitization with allergic disease', *Allergy*, 60(10):1280-1286.

209. Kvenshagen, B., Halvorsen, R., and Jacobsen, M. (2009). 'Is there an increased frequency of food allergy in children delivered by caesarean section compared to those delivered vaginally*?*', *Acta Pædiatrica*, 98(2):324-327.

210. Lack, G., Fox, D., Northstone, K., and Golding, J. (2003). 'Factors Associated with the Development of Peanut Allergy in Childhood', The *New England Journal of Medicine*, 348(11):977-985.

211. Le, T., Bublin, M., Breiteneder, H., Fernández-Rivas, M., Asero, R., Ballmer-Weber, B., Barreales, L., Bures, P., Belohlavkova, S., de Blay, F., Clausen, M., Dubakiene, R., Gislason, D., van Hoffen, E., Jedrzejczak-Czechowicz, M., Kowalski, M., Kralimarkova, T., Lidholm, J., DeWitt, Å., Mills, C., Papadopoulos, N., Popov, T., Purohit, A., van Ree, R., Seneviratne, S., Sinaniotis, A., Summers, C., Vázquez-Cortés, S., Vieths, S., Vogel, L., Hoffmann-Sommergruber, K., and Knulst, A. C. (2013). Kiwifruit allergy across Europe: Clinical manifestation and IgE recognition patterns to kiwifruit allergens. *Journal of Allergy and Clinical Immunology*, 131(1), pp.164-171.

212. Lee, A. R., Wolf, R.L., Lebwohl, B., Ciaccio, E.J., and Green, P.H.R. (2019). 'Persistent Economic Burden of the Gluten-Free Diet', *Nutrients*, 11, 399*.*

213. Lee, A.H., Kim, K.E., Lee, K.E., Kim, S.H., Wang, T.W., Kim, K.W., and Kwak, T.K. (2013). 'Prevalence of food allergy and perceptions on food allergen labelling in school foodservice among Korean students', *Allergy, Asthma and Respiratory Disease,* 1:227–234.

214. Lee, A.R., Ng, D.L., Zivin, J., and Green, P.H.R (2007). 'Economic burden of a gluten-free diet'. *J Hum Nutr Diet*, 20(5):423-30.

215. Leja, M., Shums, Z., Nikitina-Zake, L., Gavars, M., Kikuste, I., Milo, J., Daugule, I., Pahomova, J., Pirags, V., Dzerve, V., Klovins, J., Erglis, A., and Norman, G.L. (2015). 'Prevalence estimation of coeliac disease in the general adult population of Latvia using serology and HLA genotyping', *United European Gastroenterol Journal,* 3(2): 190–199.

216. Leonard, M. M., Sapone, A., Catassi, C., and Fasano, A. (2017). 'Coeliac Disease and Noncoeliac Gluten Sensitivity: A Review', JAMA, 318(7),647-656.

217. Leung, T.F., Yung, E., Wong, Y.S., Lam, C., and Wong, G. (2009). 'Parent-reported adverse food reactions in Hong Kong Chinese pre-schoolers: epidemiology, clinical

spectrum and risk factors', *Journal of Paediatric Allergy and Immunology,* 20(4):339-346.

218. Lionetti, E., Gatti, S., Pulvirenti, A., and Catassi, C. (2015). 'Coeliac disease from a global perspective', *Best Practice and Research Clinical Gastroenterology*, 29(3), 365-379.

219. Long, K.H., Rubio-Tapia, A., Wagie, A.E., Melton III, L.J., Lahr, B.D., Van Dyke, C.T., and Murray, J. A. (2010). 'The economics of coeliac disease: a population-based study', *Alimentary Pharmacology and Therapeutics,* 32(2), 261-269.

220. Lowney, A.C., Myles, H.T., Bristowe, K., Lowney, E. L., Shepherd, K., Murphy, M., O'Brien, T., Casserly, L., McQuillan, R., Plant, W.D., Conlon, P.J., Vinen, C., Eustace, J.A., and Murtagh, F.E.M. (2015). Understanding What Influences the Health-Related Quality of Life of Hemodialysis Patients: A Collaborative Study in England and Ireland. *Journal of Pain and Symptoms Management,* 50,778-786.

221. Lucas, J.S., Grimshaw, K.E., Collins, K., Warner, J.O., and Hourihane, J.O. (2004). 'Kiwi fruit is a significant allergen and is associated with differing patterns of reactivity in children and adults', *Clinical and Experimental Allergy*, 34 (2004), pp. 1115-1121.

222. Lyons S. A., Clausen, M., Knulst, A.C., Ballmer-Weber, B. K., Fernandez-Rivas, M., Barreales, L., Bieli, C., Dubakiene, R., Fernandez-Perez, C., Jedrzejczak-Czechowicz, M., Kowalski, M.L., Kralimarkova, T., Kummeling, I., Mustakov, T.B., Papadopoulos, N.G., Popov, T.A., Xepapadaki, P., Welsing, P.M.J. Potts, J., Mills, E.N.C., van Ree, R., Burney, P., and Le, T.M. (2020). 'Prevalence of Food Sensitization and Food Allergy in Children Across Europe', *Journal of Allergy and Clinical Immunology: In Practice*, 8(8)2736-2746, e9. Available at: https://www.jaci-inpractice.org/article/S2213-2198(20)30371-8/fulltext

223. Lyons S. A., Knulst, A.C., Peter G.J., Burney, P.G.J., Fernández-Rivas, M., Ballmer-Weber, B.K., Barreales, L., Bieli, C., Clausen, M., Dubakiene, R., Fernández-Perez, C., Jedrzejczak-Czechowicz, M., Kowalski, M., Kummeling, I., Mustakov, T.B., van Os-Medendorp, H., Papadopoulos, N.G., Popov, T.A., Potts, J., Xepapadaki, P., Welsing, P., Mills, E.N., van Ree, R., and Le, T.M. (2020a). 'Predictors of Food Sensitization in Children and Adults Across Europe'. *Journal of Allergy and Clinical Immunology: In Practice*, 8(9):2074-3083, e2.

224. Lyons, S.A., Burney, P.G.J., Ballmer-Weber, B.K., Clausen, M., Dubakiene, R., Fernandez-Perez, C., Fernandez-Riva, M., Fernandez-Perez, C., Fritsche, P., Jedrzejczak-Czechowicz, M.L., Kowalski, M., and Kralimarkova, T. (2019). 'Food Allergy in Adults:

Substantial Variation in Prevalence and Causative Foods Across Europe', *The Journal of Allergy and Clinical Immunology: In Practice,* 7(6):1920-1928.e11.

225. MacCulloch, K., and Rashid, M. (2014). 'Factors affecting adherence to a gluten-free diet in children with celiac disease'. *Paediatr. Child Health*, 19, 305.

226. MacGiobuin, S., Stitt, V., Philbin, D., Higgins, B., McGuire, G., O'Regan, A. M., and Kelly, M. (2017). 'Food Allergy Emergencies in Children – To what extent are Early Years Services prepared? A cross sectional Survey'*. Irish Medical Journal* 8;110(7):600.

227. Mack, D., Chan, E., Shaker, M., Abrams, E., Wang, J., Fleischer, D., Hanna, M. and Greenhawt, M. (2020). 'Novel Approaches to Food Allergy Management During COVID-19 Inspire Long-Term Change'. *The Journal of Allergy and Clinical Immunology: In Practice*, 8(9), pp. 2851-2857.

228. MacKenzie, H. Roberts, G., van Laar, D., Dean, T. (2010). 'Teenagers' experiences of living with food hypersensitivity: a qualitative study', *Pediatr Allergy Immunol,* 21 (Pt 1), 595-602.

229. Mahabir, S., Gaffney, C., Costello, M., Villeneuve, J., and Moylett, E. (2013). 'Are primary schools in the west of Ireland prepared to respond to food allergy emergencies among children aged 5 to 12 years?' British Society for Allergy and Clinical Immunology Abstracts of the 2013 Annual Meeting. *Clinical & Experimental Allergy*, 43:1428–1472.

230. Majkowska-Wojciechowska, B., Wardzynska, A., Luczynska, M., Kowalski, M.K., Makowska, J., and Kowalski, M.L. (2009). 'Food hypersensitivity in the population of school children in Lodz - Results of the "EuroPrevall" surveys', *Alergia Astma Immunologi*, 14:35-44.

231. Makharia, G.K., Verma, A.K., Amarchand, R., Bhatnagar, S., Das, P., Goswami, A., Bhatia, V., Ahuja, V., Gupta, S.D., and Anand K. (2011). 'Prevalence of celiac disease in the northern part of India: a community-based study', *Journal of Gastroenterology and Hepatology,* 26(5):894-900.

232. Marklund, B., Ahlstedt, S., and Nordström, G. (2004). 'Health-related quality of life among adolescents with allergy-like conditions: with emphasis on food hypersensitivity', *Health Qual Life Outcomes*, 2:65.

233. Marrugo, J., Hernández, L., and Villalba, V. (2008). 'Prevalence of self-reported food allergy in Cartagena (Colombia) population', *Journal of Allergologia et Immunopathologia*, 36(6):320-324.

234. Martínez-Martinez, M. I., Alegre-Martínez, A., García-Ibánez, J., and Cauli, O. (2019). 'Quality of Life in People with Coeliac Disease: Psychological and Socio-

Economic Aspects'. *Endocrine, Metabolic & Immune Disorders - Drug Targets*, 19(2), 116 - 120. Available at: http://www.eurekaselect.com/163964/article?trendmd-shared=3

235. Matricardi, P.M., Bockelbrink, A., Beyer, K., Keil, T., Niggemann, B., Gruber, C., Wahn, U., and Lau, S., (2008). 'Primary versus secondary immunoglobulin E sensitization to soy and wheat in the Multi-Centre Allergy Study cohort', *Clinical and Experimental Allergy,* 38(3):493-500.

236. Mattila, L., Kilpeläinen, M., Terho, E. O., Koskenvuo, M., Helenius, H., and Kalimo, K. (2003). 'Food hypersensitivity among Finnish university students: association with atopic diseases', *Clinical & Experimental Allergy*, 33(5), 600-606.

237. McBride, D., Keil, T., Grabenhenrich, L., Dubakiene, R., Drasutiene, G., Fiocchi, A., Dahdah, L., Sprikkelman, A.B., Schoemaker, A. A., Roberts, G., Grimshaw, K., Kowalski, M. L., Stanczyk-Przyluska, A., Sigurdardottir, S., Clausen, M., Papadopoulos, N. G., Mitsias, D., Rosenfeld, L., Reche, M., Pascual, C., Reich, A., Hourihane, J., Wahn, U., Mills, E. N. C., Mackie, A, and Beyer, K. (2012). 'The EuroPrevall birth cohort study on food allergy: baseline characteristics of 12,000 new-borns and their families from nine European countries'. *Pediatr Allergy Immunol*. 23: 230–239.

238. McClain, S., Bowman, C., Fernandez-Rivas, M., Ladics, G. S., and Ree, R. (2014). 'Allergic sensitization: food- and protein-related factors', *Clinical and Translational Allergy,* 4(1), pp. 11.

239. McGowan, E.C., and Keet, C.A. (2013). 'Prevalence of self-reported food allergy in the National Health and Nutrition Examination Survey (NHANES) 2007-2010', *Journal of Allergy and Clinical Immunology*, 132 (5), 1216-1219.e5.

240. McWilliam, V., Peters, R., Tang, M.L.K., Dharmage, S., Ponsonby, A.L., Gurrin, L., Perrett, K., Koplin, J., and Allen, K.J. (2019). 'Patterns of tree nut sensitization and allergy in the first 6 years of life in a population-based cohort', *Journal of Allergy and Clinical Immunology,* 143(2):644-650.e5.

241. Miles, S., Fordham, R., Mills, C., Valovirta, E., and Mugford, M. (2005). 'A framework for measuring costs to society of IgE-mediated food allergy', *European Journal of Allergy and Clinical Immunology,* 60, 996- 1003.

242. Miller, G., Coffield, E., Leroy, Z., and Wallin, R. (2016). 'Prevalence and Costs of Five Chronic Conditions in Children', *J Sch Nurs.*, 32(5): 357–364.

243. Møller, A. H., Erntoft, S., Vinding, G. R., and Jemec, G., BE (2015). 'A systematic literature review to compare quality of life in psoriasis with other chronic diseases using EQ-5D-derived utility values', *Patient Related Outcome Measures*, 6, 167–177.

244. Moonesinghe, H., Mackenzie, H., Venter, C., Kilburn, S., Turner, P., Weir, K., and Dean, T. (2016). 'Prevalence of fish and shellfish allergy: A systematic review', *Annals of Allergy, Asthma and Immunology,* 117(3), 264-272,e4.

245. Mossakowska, M., Pawlinska-Chmara, R., and Broczek, K.M. (2008). 'Asthma, allergy, and respiratory symptoms in centenarians living in Poland', *Journal of Physiology and Pharmacology*, 59 Suppl 6:483-489.

246. Muller, H.L. (1996). 'Diagnosis and treatment of insect sensitivity'. *J Asthma Res,* 3:331–3.

247. Multiple Sclerosis Society (MSS) (2015). 'Societal Cost of Multiple Sclerosis in Ireland 2015'. Ireland. Available at: https://www.ms-society.ie/sites/default/files/201906/MS%20Ireland%20%20Societal%20Cost%20of%20MS%20in%20Ireland%202015cc.pdf

248. Munblit, D., Perkin, M., Palmer, D., Allen, K., and Boyle, R. (2020). 'Assessment of Evidence About Common Infant Symptoms and Cow's Milk Allergy'. *JAMA Paediatrics*, 174(6), 599-608.

249. Mustalahti, K., Catassi, C., Reunanen, A., Fabiani, E., Heier, M., McMillan, S., Murray, L., Metzger, M.H., Gasparin, M., Bravi, E., and Mäki, M. (2010). Coeliac EU Cluster, Project Epidemiology. The prevalence of coeliac disease in Europe: results of a centralized, international mass screening project', *Annals of Medicine,* 42(8):587-595.

250. Mylotte, M., Mitchell, B.E., McCarthy, C.F., and McNicholl, B. (1973). 'Incidence of coeliac disease in the West of Ireland', *British Medical Journal,* 1(5855):703-5.

251. National Institute for Health and Care Excellence (NICE) (2015). Coeliac disease: recognition, assessment and management. Technical report. National Institute for Health and Care Excellence.

252. Nicolaou, N., Poorafshar, M., Murray, C., Simpson, A., Winell, H., Kerry, G., Harlin, A., Woodcock, A., Ahlstedt, S., and Custovic, A. (2010). 'Allergy or tolerance in children sensitized to peanut: prevalence and differentiation using component-resolved diagnostics', *Journal of Allergy and Clinical Immunology,* 125(1):191-197.

253. Niggemann, B., Schmitz, R., and Schlaud, M. (2011). 'The high prevalence of peanut sensitization in childhood is due to cross-reactivity to pollen', *Allergy,* 66(7):980-981.

254. Nursing Home Ireland (2019). Find a Nursing Home.

255. Nwaru, B.I., Hickstein, L., Panesar, S.S., Muraro, A., Werfel, T., Cardona, V., Dubois, A.E., Halken, S., Hoffmann-Sommergruber, K., Poulsen, L.K., Roberts, G., Ree, R.V., Vlieg-Boerstra, B.J., and Sheikh, A. (2014). EAACI Food Allergy Anaphylaxis Guidelines

Group. ‘The epidemiology of food allergy in Europe: a systematic review and meta-analysis’, *Allergy*, 69(1), 62-75.

256. Ohlund, K., Olsson, C., Hernell, O., and Ohlund, I. (2010). ‘Dietary shortcomings in children on a gluten-free diet.’ *J. Hum. Nutr. Diet.*, 23, 294–300.

257. Ontiveros, N., Valdez-Meza, E.E, Vergara-Jiménez, M.J., Canizalez-Román, A., Borzutzky, A., and Cabrera-Chávez, F. (2016). ‘Parent-reported prevalence of food allergy in Mexican schoolchildren: A population-based study’, *Allergologia et Immunopathologia,* 44(6):563-570.

258. Orhan, F., Karakas, T., Cakir, M., Aksoy, A., Baki, A., and Gedik, Y., (2009). ‘Prevalence of immunoglobulin E-mediated FA in 6- to 9-year-old urban schoolchildren in the eastern Black Sea region of Turkey’, *Clinical and Experimental Allergy*, 39(7):1027-1035.

259. Osborne, N.J., Koplin, J.J., Martin, P. E., Gurrin, L. C., Lowe, A.J., Matheson, M. C., Ponsonby, A.L., Wake, M., Tang, M. L., Dharmage, S. C., and Allen, K. J. (2011). ‘Prevalence of challenge-proven IgE-mediated food allergy using population-based sampling and predetermined challenge criteria in infants’*, Journal of Allergy and Clinical Immunology*, 127(3):668-676.

260. Ostblom, E., Lilja, G., Ahlstedt, S., Hage, M.V., and Wickman, M. (2008). ‘Patterns of quantitative food-specific IgE-antibodies and reported food hypersensitivity in 4-year-old children’, *Allergy,* 63(4):418-424.

261. Ostblom, E., Lilja, G., Pershagen, G., Hage, M.V., and Wickman, M. (2008). ‘Phenotypes of food hypersensitivity and development of allergic diseases during the first 8 years of life’, *Clinical and Experimental Allergy*, 38(8):1325-1332.

262. Ostblom, E., Wickman, M., Hage, M.V., and Lilja, G., (2008). ‘Reported symptoms of food hypersensitivity and sensitization to common foods in 4-year-old children’, *Acta Paediatrica,* 97(1):85-90.

263. Osterballe, M., Hansen, T.K., Mortz, C.G., Host, A., and Bindslev-Jensen, C. (2005). ‘The prevalence of food hypersensitivity in an unselected population of children and adults’, *Paediatric Allergy and Immunology*, 16(7):567-573.

264. Osterballe, M., Mortz, C.G., Hansen, T.K., Andersen, K.E., and Bindslev-Jensen, C. (2009). ‘The prevalence of food hypersensitivity in young adults’, *Paediatric Allergy and Immunology*, 20(7):686-692.

265. Panagiotou, S. and Kontogianni, M.D. (2017). ‘The economic burden of gluten-free products and gluten-free diet: a cost estimation analysis in Greece’, *Journal of Human Nutrition and Dietetics*, 30(6), 746–752.

266. Patel, D. A., Holdford, D. A., Edwards, E., and Carroll, N. V. (2011). 'Estimating the economic burden of food-induced allergic reactions and anaphylaxis in the United States', *Journal of Allergy and Clinical Immunology*, 128(1), 110–15. e5.

267. Penard-Morand, C., Raherison, C., Kopferschmitt, C., Caillaud, D., Lavaud, F., Charpin, D., and Bousquet, J. (2005). 'Prevalence of FA and its relationship to asthma and allergic rhinitis in schoolchildren', *Allergy*, 60(9):1165-1171.

268. Peniamina, R. L., Bremer, P., Conner, T. S., and Mirosa, M. (2014). 'Understanding the Needs of Food-Allergic Adults', *Qualitative Health Research*, 24(7), 933-945.

269. Pereira, B., Venter, C., Grundy, J., Clayton, C.B., Arshad, S.H., and Dean, T. (2005). 'Prevalence of sensitization to food allergens, reported adverse reaction to foods, food avoidance, and food hypersensitivity among teenagers', *Journal of Allergy and Clinical Immunology*, 116(4):884-892.

270. Perkin, M.R., Logan, K., Tseng, A., Raji, B., Avis, S., Peacock, J., Brough, H., Marrs, T., Radulovic, S., Craven, J., Flohr, C., and Lack, G. (2016). 'Randomized Trial of Introduction of Allergenic Foods in Breast-Fed Infants', *The New England Journal of Medicine*, 374(18):1733-1743.

271. Peters, R.L., Koplin, J.J., Gurrin, L.C., Dharmage, S.C., Wake, M., Ponsonby, A.L., Tang, M.L.K., Lowe, A.J., Matheson, M., Dwyer, T., and Allen, K.J. (2017). 'The prevalence of food allergy and other allergic diseases in early childhood in a population-based study: Health Nuts age 4-year follow-up', *Journal of Allergy and Clinical Immunology*, 140(1), 145-153.

272. Picarelli, A., Di Tola, M., Borghini, R., Isonne, C., Donato, G., De Vitis, I., and Frieri, G. (2014). 'The High Medical Cost of Coeliac Disease Missed Diagnosis: Is it Cheaper to Suspect it in Time?'. *Internal Medicine*. 4(3), 155. Available at: https://www.longdom.org/open-access/the-high-medical-cost-of-celiac-disease-missed-diagnosis-is-it-cheaper-to-suspect-it-in-time-2165-8048.1000155.pdf

273. Posnett, J., and Jan, S. (1996). 'Indirect cost in economic evaluation: The opportunity cost of unpaid inputs', *Health Economics*, 5(1), 13 -23.

274. Praag Van, B.M.S., and Ferrer-I-Carbonell, A. (2004). Happiness Quantified: A Satisfaction Calculus Approach, Oxford University Press, Oxford.

275. Prescott, S.L., Pawankar, R., Allen, K.J., Campbell, D.E., Sinn, J.K.H., Fiocchi, A., Ebisawa, M., Sampson, H.A., Beyer, K., and Lee, B.W. (2013). 'A global survey of changing patterns of food allergy burden in children', *World Allergy Organization Journal*, 6(1):21.

276. Prevolnik, R. V., Divjak, M., Zrubka, Z., Rencz, F., Gulácsi, L., Golicki, D., Mirowska-Guzel, D., Simon, J., Brodszky, V., Baji, P., Závada, J., Petrova, G., Rotar, A., and Péntek, M. (2019). 'EQ-5D studies in nervous system diseases in eight Central and East European countries: a systematic literature review', *European Journal of Health Economics,* 20 (Suppl 1), 109-117.

277. Price, T., and Howard, R. (2017). Coeliac Disease in Later Life: An Interpretive Phenomenological Analysis, *International Journal of Coeliac Disease*. 5(4), 140-149.

278. Primeau, M. N., Kagan, R., Joseph, L., Lim, H., Dufresne, C., Duffy, C., Prhcal, D. and Clarke, A. (2000). 'The psychological burden of peanut allergy as perceived by adults with peanut allergy and the parents of peanut-allergic children', *Clinical and Experimental Allergy,* 30, 1135-43.

279. Protudjer, J.L.P., Jansson S.A., Heibert-Arnlind M., Bengtsson U., Kallström-Bengtsson, I., Marklund, B., Middelveld, R., Rentzos G., Sundqvist, A.C., Åkerström, J., Östblom, E., Dahlén, S.E., Ahlstedt, S. (2015). 'Household costs associated with objectively diagnosed allergy to staple foods in children and adolescents.' *Journal of Allergy and Clinical Immunology Practice.* 3, 68-75

280. Protudjer, J.L.P, Jansson, S.A., Middelveld, R., Östblom, E., Dahlén, S.E., Heibert-Arnlind, M., Bengtsson, U., Kallström-Bengtsson, I., Marklund, B., Rentzos, G., Sundqvist, A.C., Åkerström, J., and Ahlstedt, S. (2016). 'Impaired health-related quality of life in adolescents with allergy to staple foods', *Clinical and Translational Allergy*, 6 (37).

281. Protudjer, J.L.P., Golding, M., Salisbury, M., Abrams, E. and Roos, L. (2021). 'High anxiety and health-related quality of life in families with children with food allergy during coronavirus disease 2019'. *Annals of Allergy, Asthma and Immunology*, 126(1), pp.83-88.e1.

282. Protudjer, J.L.P., Jansson, S., Östblom, E., Arnlind, M., Bengtsson, U., Dahlén, S., Kallström-Bengtsson, I., Marklund, B., Middelveld, R., Rentzos, G., Sundqvist, A., Åkerström, J. and Ahlstedt, S. (2015b). 'Health-related quality of life in children with objectively diagnosed staple food allergy assessed with a disease-specific questionnaire'. *Acta Paediatrica*, 104(10), pp.1047-1054.

283. Pyrhonen, K., Hiltunen, L., Kaila, M., Nayha, S., and Laara, E. (2011). 'Heredity of food allergies in an unselected child population: An epidemiological survey from Finland', *Paediatric Allergy and Immunology*, 22:124-132.

284. Pyrhonen, K., Nayha, S., Kaila, M., Hiltunen, L., and Laara, E., (2009). ‘Occurrence of parent-reported food hypersensitivities and food allergies among children aged 1-4 years’, *Paediatric Allergy and Immunology*, 20(4):328-338.

285. Pyziak, K., and Kamer, B. (2011). ‘Natural history of IgE-dependent FA diagnosed in children during the rest three years of life’, *Advances in Medical Sciences,* 56(1):48-55.

286. Quaranta, L., Riva, I., Gerardi, C., Oddone, F., Floriano, I., and Konstas, A. G. P. (2016). ‘Quality of Life in Glaucoma: A Review of the Literature’, *Advances in Therapy*, 33(6), 959-981.

287. Rance, F., Grandmottet, X., and Grandjean, H. (2005). ‘Prevalence and main characteristics of schoolchildren diagnosed with food allergies in France’, *Clinical and Experimental Allergy*, 35(2):167-172.

288. Reese, I., Holzhauser, T., Schnadt, S., Dölle, S., Kleine-Tebbe, J., Raithel, M., Worm, M., Zuberbier, T., and Vieths, S. (2015). ‘Allergen and allergy risk assessment, allergen management, and gaps in the European Food Information Regulation (FIR)’. *Allergo Journal International*, 24(6), pp.180-184.

289. Rencz, F., Gulácsi, L., Drummond, M., Golicki, D., Prevolnik, R. V., Simon, J., Stolk, E.A., Brodszky, V., Baji, P., Závada, J., Petrova, G., Rotar, A., and Péntek, M. (2016). ‘EQ-5D in Central and Eastern Europe: 2000-2015’, *Quality of Life Research*, 25(11), 2693-2710.

290. Rewers, M. (2005). ‘Epidemiology of coeliac disease: What are the prevalence, incidence, and progression of coeliac disease?’, *Gastroenterology*, 128(4):47–51.

291. Roberts, G., Peckitt, C., Northstone, K., Strachan, D., Lack, G., Henderson, J., Golding, J., and ALSPAC Study Team (2005). ‘Relationship between aeroallergen and food allergen sensitization in childhood’, *Clinical and Experimental Allergy,* 35(7):933-940.

292. Roehr, C.C., Edenharter, G., Reimann, S., Ehlers, I., Worm, M., Zuberbier, T., and Niggemann, B. (2004). ‘Food allergy and non-allergic food hypersensitivity in children and adolescents’, *Clinical and Experimental Allergy,* 34(10):1534-1541.

293. Roma, E., Roubani, A., Kolia, E., Panayiotou, J., Zellos, A., and Syriopoulou, V.P. (2010). ‘Dietary compliance and life style of children with coeliac disease’. J*. Hum. Nutr. Diet,* 23, 176–182.

294. Rona, R.J., Keil, T., Summers, C., Gislason, D., Zuidmeer, L., Sodergren, E., Sigurdardottir, S.T., Lindner, T., Goldhahn, K., Dahlstrom, J., McBride, D., and Madsen, C. (2007). ‘The prevalence of food allergy: A meta-analysis’, *Journal of Allergy and Clinical Immunology,* 120(3):638–646.

295. Ronchetti, R., Jesenak, M., Trubacova, D., Pohanka, V., and Villa, M.P. (2008). 'Epidemiology of atopy patch tests with food and inhalant allergens in an unselected population of children', *Paediatric Allergy and Immunology,* 19(7):599-604.

296. Rubio-Tapia, A., Ludvigsson, J.F., Brantner, T.L., Murray, J.A., and Everhart, J.E. (2012). 'The prevalence of coeliac disease in the United States', *American Journal of Gastroenterol,* 107(10):1538-1544.

297. *Safe*food (2013a). 'Dining out: The challenge for those with a Food Allergy or Food Intolerance, Evaluation Results: Republic of Ireland'. Available at: https://www.safefood.net/getmedia/62903d02-8532-4659-a7e6-59ba365ec00f/Final-report-IRELAND-Jan2015.aspx?ext=.pdf

298. *Safe*food (2013b). 'Dining out: The challenge for those with a Food Allergy or Food Intolerance, Evaluation Results: Northern Ireland'. Available at: https://www.safefood.net/getmedia/3f1e9d08-a448-47c9-bfbb-0305513ef6b7/Final-report-NI-Jan2015.aspx?ext=.pdf

299. Safe*f*ood (2016). Presentation: Living with food allergy and intolerance in Ireland. Available at: http://www.safefood.eu/SafeFood/media/SafeFoodLibrary/Documents/Professional/LivingwithFAFIinIrelandRuthCharles.pdf

300. Safi, M.A. (2018). 'Prevalence of Coeliac disease in Saudi Arabia: Meta-analysis.*' Global Vaccines and Immunology, 3(1):1-6.*

301. Sandin, A., Annus, T., Bjorksten, B., Nilsson, L., Riikjarv, M.A., Hage-Hamsten, M.V., and Braback, L. (2005). 'Prevalence of self-reported FA and IgE antibodies to food allergens in Swedish and Estonian schoolchildren', *European Journal of Clinical Nutrition,* 59(3):399-403.

302. Sasaki, M., Koplin, J.J., Dharmage, S.C., Field, M.J., Sawyer, S.M., McWilliam, V., Peters, R.L., Gurrin, L.C., Vuillermin, P.J., Douglass, J., Pezic, A., Brewerton, M., Tang, M.L., Patton, G.C., and Allen, K.J. (2018). 'Prevalence of clinic-defined food allergy in early adolescence: The School Nuts study', *Journal of Allergy and Clinical Immunology*, 141(1): 391-398.

303. Savvateeva, L.V., Erdes, S.I., Antishin, A.S., and Zamyatnin, A.A. (2017). 'Overview of Coeliac Disease in Russia: Regional Data and Estimated Prevalence', *Journal of Immunology Research,* Volume 2314813.

304. Schafer, T., Bohler, E., Ruhdorfer, S., Weigl, L., Wessner, D., Heinrich, J., Filipiak, B., Wichmann, H.E., and Ring, J. (2001). 'Epidemiology of FA/food intolerance in adults: Associations with other manifestations of atopy', *Allergy*, 56(12):1172-1179.

305. Schnabel, E., Sausenthaler, S., Schaaf, B., Schafer, T., Lehmann, I., Behrendt, H., Herbath, O., Borte, M., Kramer, U., Berg, A.V., Wichmann, H.E., Heinrich, J., and LISA Study Group (2010). 'Prospective association between food sensitization and FA: Results of the LISA birth cohort study', *Clinical and Experimental Allergy*, 40(3):450-457.

306. Schoemaker, A.A., Sprikkelman, A.B., Grimshaw, K.E., Roberts, G., Grabenhenrich, L., Rosenfeld, L., Siegert, S., Dubakiene, R., Rudzeviciene, O., Reche, M., Fiandor, A., Papadopoulos, N.G., Malamitsi-Puchner, A., Fiocchi, A., Dahdah, L., Sigurdardottir, S.T., Clausen, M., Stańczyk-Przyłuska A., Zeman, K., Mills, E.N., McBride, D., Keil, T., and Beyer, K. (2015). 'Incidence and natural history of challenge-proven cow's milk allergy in European children - EuroPrevall birth cohort', *Journal of Allergy and Clinical Immunology*, 70(8):963-72.

307. Scott, L.A., Berni, T.R., Berni, E.R., De Vries, J., and Currie, C.J. (2019). 'Evaluation of the healthcare resource use and the related financial costs of managing peanut allergy in the United Kingdom', Expert Review of Clinical Immunology, 15(8):889-896.

308. See, J. A., Kaukinen, K., Makharia, G. K., Gibson, P. R., Murray, J.A. (2015). 'Practical insights into gluten-free diets', *Nat Rev Gastroenterol Hepatol.* 12(10), 580–591. Available at: https://www.nature.com/articles/nrgastro.2015.156

309. Shah, S., Akbari, M., Vanga, R., Kelly, C. P., Hansen, J., Theethira, T., Tariq, S., Dennis, M., and Leffler, D. A. (2014). 'Patient perception of treatment burden is high in coeliac disease compared with other common conditions'. *Am J Gastroenterol.* 109(9), 1304 –1311. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4159418/pdf/nihms585846.pdf

310. Shaker, M., Schwartz, J., and Ferguson, M. (2017). 'An update on the impact of food allergy on anxiety and quality of life'. *Current Opinion in Paediatrics*, 29(4), pp.497-502.

311. Sicherer, S. H., Noone, S. A., and Munoz-Furlong, A. (2001). 'The impact of childhood food allergy on quality of life', *Annals of Allergy, Asthma & Immunology,* 87, 461-4.

312. Sicherer, S.H., Muñoz-Furlong, A., and Sampson, H.A. (2004). 'Prevalence of seafood allergy in the United States determined by a random telephone survey', *Journal of Allergy and Clinical Immunology,* 114(1):159-165.

313. Sicherer, S.H., Muñoz-Furlong, A., Godbold, J.H., snd Sampson, H.A. (2010). 'US prevalence of self-reported peanut, tree nut, and sesame allergy: 11-year follow-up', *Journal of Allergy and Clinical Immunology,* 125(6):1322-1326.

314. Sicherer, S.H., Noone, S.A., & Muñoz-Furlong, A. (2001). 'The impact of childhood food allergy on quality of life'. *Ann Allergy Asthma Immunol.* 87(6), 461-464.

315. Simons, E., Balshaw, R., Lefebvre, D.L., Dai, D., Turvey, S.E., Moraes T.J., Piushkumar, J., Sears, M.R., Subbarao, P., and Becker, A.B. (2020). 'Timing of Introduction, Sensitization, and Allergy to Highly Allergenic Foods at Age 3 Years in a General-Population Canadian Cohort', *The Journal of Allergy and Clinical Immunology: In Practice,* 8(1):166-175.

316. Singh, N. S. (2018). (Unpublished manuscript) Prevalence of food allergy among young adults in the Republic of Ireland with regard to clinical background of the disease and quality of life. Thesis, Master of Science in Food Safety Management, Dublin, Dublin Institute of Technology. Available at: https://www.worldallergy.org/UserFiles/file/WhiteBook2-2013-v8.pdf

317. Singh, P., Arora, A., Strand, T.A., Leffler, D.A., Catassi, C., Green, P.H., Kelly, C.P., Ahuja, V., and Makharia, G. K. (2018). 'Global Prevalence of Coeliac Disease: Systematic Review and Meta-analysis'. *Clinical Gastroenterology and Hepatology*, 16:823-836. Available at: https://celiac.org/main/wp-content/uploads/2018/06/Global-prevalence-of-celiac-disease_GGH_2018.pdf

318. Singh, P., Arora, S., Singh, A., Strand, T.A., and Makharia, G.K. (2016). 'Prevalence of coeliac disease in Asia: A systematic review and meta-analysis', *Journal of Gastroenterol Hepatology*, 31(6):1095-101.

319. Soller, L., Ben-Shoshan, M., Harrington, D.W., Fragapane, J., Lawrence, J., Pierre, Y., Godefroy, S.B., Vieille, S.L., Elliott, S.J., and Clarke, A.E. (2012). 'Overall prevalence of self-reported food allergy in Canada', *Journal of Allergy and Clinical Immunology,* 130(4): 986-988.

320. Sommer, I., Mackenzie, H., Venter, C., and Dean, T. (2014). 'An exploratory investigation of food choice behavior of teenagers with and without food allergies'. *Annals of Allergy Asthma Immunology,* 112, 446–52.

321. Soost, S., Leynaert, B., Almqvist, C., Edenharter, G., Zuberbier, T., and Worm, M. (2009). 'Risk factors of adverse reactions to food in German adults', *Clinical and Experimental Allergy,* 39(7):1036-1044.

322. Sverker, A., Hensing, G., and Hallert, C. (2015). 'Controlled by food' - lived experiences of coeliac disease. *J Hum Nutr Diet*, 18(3), 171–180. Available at: https://onlinelibrary.wiley.com/doi/epdf/10.1111/j.1365-277X.2005.00591.x

323.Tariq, S.M., Stevens, M., Matthews, S., Ridout, S., Twiselton, R., and Hide, D. W. (1996). Cohort study of peanut and tree nut sensitisation by age of 4 years. BMJ, 313(7056):514-7.

324. Tariq, S.M., Matthews, S.M., Hakim, E.A., and Arshad, S.H. (2000). 'Egg allergy in infancy predicts respiratory allergic disease by 4 years of age', *Paediatric Allergy and Immunology*, 11(3):162-167.

325. Tariq, S.M., Stevens, M., Matthews, S., Ridout, S., Twiselton, R., and Hide, D. W. (1996). 'Cohort study of peanut and tree nut sensitisation by age of 4 years', *British Medical Journal*, 313(7056):514-517.

326. Taylor, S.L., and Baumert, J.L. (2020). 'Food allergies, sensitivities, and intolerances', in Marriott, B.P., Birt, D.F., Stallings, V.A. and Yates, A.A. (eds), Present Knowledge in Nutrition, Clinical and Applied Topics in Nutrition 11th ed, Vol.2, Academic Press, pp. 535-548.

327. Technological University Dublin (2019). Self-reported food allergy data from registered students in TU Dublin (19,929 students) attending the academic year of 2018-2019.

328. Thalayasingam, M., and Lee, B.W. (2015). 'Fish and shellfish allergy', *Chemical Immunology and Allergy*, 101:152-61.

329. The European Academy of Allergy and Clinical Immunology (EAACI) (2015). 'Advocacy Manifesto, Tackling the Allergy Crisis in Europe - Concerted Policy Action Needed'. Brussels, Belgium. Available at: https://www.eaaci.org/documents/EAACI_Advocacy_Manifesto.pdf

330. The EuroQol Group (1990). EuroQol - a new facility for the measurement of health-related quality of life, *Health Policy*, 16(3):199-208.

331. The EuroQol Group (2004). 'Measuring Self-Reported Population Health: An International Perspective based on EQ-5D'. Available at: https://euroqol.org/wp-content/uploads/2016/10/Measuring_Self-Reported_Population_Health_-_An_International_Perspective_based_on_EQ-5D.pdf

332.The Irish Times (2018a). 'Childhood allergies: 'We could see our little girl slipping away', The Irish Times, Ireland. Available at: https://www.irishtimes.com/life-and-style/health-family/childhood-allergies-we-could-see-our-little-girl-slipping-away-1.3338946

333.The Irish Times (2018b). 'New drug could save children from violent reactions to peanuts', The Irish Times, Ireland. Available at: https://www.irishtimes.com/news/health/new-drug-could-save-children-from-violent-reactions-to-peanuts-1.3702093.

334. The Lancet (2011). ‘Guidance on food allergy in children’. *The Lancet, Editorial.* 377(9767): 691.

335. Thompson, T. (1999). ‘Thiamin, riboflavin, and niacin contents of the gluten-free diet: Is there cause for concern?’, *J. Am. Diet. Assoc.* 99, 858–862.

336. Thompson, T. (2000). ‘Folate, iron, and dietary fibre contents of the gluten-free diet’. *J. Am. Diet. Assoc.* 100, 1389–1396.

337. Toit, G.D., Katz, Y., Sasieni, P., Mesher, D., Maleki, S.J., Fisher, H.R., Fox, A.T., Turcanu, V., Amir, T., Zadik-Mnuhin, G., Cohen, A., Livne, I., and Lack, G. (2008). ‘Early consumption of peanuts in infancy is associated with a low prevalence of peanut allergy’, *Journal of Allergy and Clinical Immunology,* 122(5):984-991.

338. Ben-Shoshan, M., Harrington, D.W., Soller, L., Fragapane, J., Joseph, L., St. Pierre, Y., Godefroy, S.B., Elliott, S.J., Clarke, A.E. (2010). A population-based study on tree nut, fish, shellfish, and sesame allergy prevalence in Canada’. *Journal of Allergy and Clinical Immunology,* 125 (6), 1327–1335.

339. TUSLA (2019). Register of Early Years Services by County. Available at: https://www.tusla.ie/services/preschool-services/list-of-pre-school-services-by-county/

340. U.S. Food and Drug Administration (FDA) (2008). ‘Approaches to establish thresholds for major food allergens and for gluten in foods’, *Journal of Food Protection*, 71(5):1043 – 1088.

341. UK Government and Parliament (2017). ‘Archived Petition: Public areas & Food places to have Epi Pens for food allergies’. Available at: https://petition.parliament.uk/archived/petitions/258291.

342. University of Portsmouth (2013). ‘Literature searches and reviews related to the prevalence of food allergy in Europe’, *EFSA supporting publication,* 506, 343.

343. Vasar, M., Julge, K., and Bjorksten, B. (2000). ‘Development of atopic sensitization and allergic diseases in early childhood’, *Acta Paediatriica*, 89(5):523-527.

344. Venter, C., Arshad, S.H., Grundy, J., Pereira, B., Clayton, C.B., Voigt, K., Higgins, B., and Dean, T. (2010). ‘Time trends in the prevalence of peanut allergy: Three cohorts of children from the same geographical location in the UK’, *Allergy,* 65(1):103-108.

345. Venter, C., Pereira, B., Grundy, J., Clayton, C.B., Arshad, S.H., Dean, T. (2006). ‘Prevalence of sensitization reported and objectively assessed food hypersensitivity amongst six-year-old children: A population-based study’, *Paediatric Allergy and Immunology*, 17(5):356-363.

346. Venter, C., Pereira, B., Grundy, J., Clayton, C.B., Roberts, G., Higgins, B., and Dean, T., (2006). 'Incidence of parentally reported and clinically diagnosed food hypersensitivity in the first year of life', The *Journal of Allergy and Clinical Immunology,* 117(5):1118-1124.

347. Venter, C., Pereira, B., Voigt, K., Grundy, J., Clayton, C.B., Higgins, B., Arshad, S.H., and Dean, T. (2008). 'Prevalence and cumulative incidence of food hypersensitivity in the first 3 years of life', *Allergy,* 63(3):354-359.

348. Violato M., Gray A., Papanicolas I., and Ouellet M. (2012). 'Resource Use and Costs Associated with Coeliac disease before and after Diagnosis in 3,646 Cases: Results of a UK Primary Care Database Analysis'. *PLOS ONE*, 7(7), e41308. Available at: https://journals.plos.org/plosone/article/file?id=10.1371/journal.pone.0041308&type=printable

349. Volta, U., Caio, G., Stanghellini, V., De Giorgio, R. (2014). 'The changing clinical profile of coeliac disease: a 15-year experience (1998-2012) in an Italian referral centre'. *BMC Gastroenterology*. 14:194.

350. Volta, U., and De Giorgio, R. (2012). 'New understanding of gluten sensitivity.' Nature Reviews. *Gastroenterology & Hepatology*, 9(5), 295e299.

351. Volta, U., and Villanacci, V. (2011). 'Coeliac disease: Diagnostic criteria in progress'. *Cellular & Molecular Immunology*, 8, 96e, 102.

352. Voordouw, J., Antonides, G., Fox, M., Cerecedo, I., Zamora, J., de la Hoz Caballer, B., Rokicka, E., Cornelisse-Vermaat, J.R., Jewczak, M., Starosta, P., Kowalski, M., Jędrzejczak-Czechowicz, M., Vázquez-Cortes, S., Cano-Escudero, S., Flokstra-De Blok, B.M.J., Dubois, A.E.J., Mugford, M., and Lynn J. Frewer, L. J. (2016). 'The Direct and Indirect Costs Associated with Food Hypersensitivity in Households: A Study In the Netherlands, Poland, And Spain' *Applied Studies in Agribusiness and Commerce,* 10, No. 2-3, 107-118.

353. Voordouw, J., Cornelisse-Vermaat, J.R., Yiakoumaki, V., Theodoridis, G., Chryssochoidis, G., and Frewer, L.J. (2009). 'Food allergic consumers' preferences for labelling practices: a qualitative study in a real shopping environment', *International Journal of Consumer Studies*, 33(1), 94-102.

354. Voordouw, J., Fox, M., Cornelisse-Vermaat, J., Antonides, G., Mugford, M., and Frewer, L. (2010). 'Household costs associated with food allergy: an exploratory study', *British Food Journal*, 112(11), 1205-1215.

355. Wagner, G., Berger, G., Sinnreich, U., Grylli, V., Schober, E., Huber, W.D., and Karwautz, A. (2008). ‘Quality of life in adolescents with treated coeliac disease: Influence of compliance and age at diagnosis’. *J. Pediatr. Gastroenterol. Nutr.* 47, 555–561.

356. Walkner, M., Warren, C., and Gupta, R. (2015). ‘Quality of Life in Food Allergy Patients and Their Families’. *Paediatric Clinics of North America*, 62(6), pp.1453-1461.

357. Wang, H., Warren, C., Gupta, R., and Davis, C. (2020). ‘Prevalence and Characteristics of Shellfish Allergy in the Paediatric Population of the United States’. *Journal of Allergy and Clinical Immunology: In Practice,* 8(4),1359-1370.

358. Waserman, S., Bégin, P., and Watson, W. (2018). ‘IgE-mediated food allergy’, *Allergy, Asthma & Clinical Immunology,* 14(55).

359. West, J., Fleming, K.M., Tata, L.J., Card, T.R. and Crooks, C.J. (2014). Incidence and Prevalence of Coeliac Disease and Dermatitis Herpetiformis in the UK Over Two Decades: Population-Based Study in *American Journal of Gastroenterology*, 109:757–768. Available at: https://journals.lww.com/ajg/Fulltext/2014/05000/Incidence_and_Prevalence_of_Celiac_Disease_and.22.aspx

360. West, J., Fleming, K.M., Tata, L.J., Card, T.R., and Crooks, C.J. (2014). ‘Incidence and Prevalence of Coeliac Disease and Dermatitis Herpetiformis in the UK Over Two Decades: Population-Based Study’, *The American Journal of Gastroenterology,* 109: 757-767.

361. Whitaker, J. K., West, J., Holmes, G. K., and Logan, R. F. (2009). ‘Patient perceptions of the burden of coeliac disease and its treatment in the UK’. *Alimentary Pharmacology & Therapeutics*, 29(10), 1131–1136. Available at: https://onlinelibrary.wiley.com/doi/epdf/10.1111/j.1365-2036.2009.03983.x

362. WHOQOL Group (1993). Study protocol for the World Health Organization project to develop a Quality of Life assessment instrument (WHOQOL), *Quality of Life Research*, 2(2), 153 – 159. Doi: https://doi.org/10.1007/BF00435734

363. Wild, D., Robins, G.G., Burley, V.J., and Howdle, P.D. (2010). ‘Evidence of high sugar intake, and low fibre and mineral intake, in the gluten-free diet’. *Alimentary Pharmacology & Therapeutics*. 32, 573–581.

364. Wilson, E.C.F., Peacock, S.T., and Ruta, D. (2009). ‘Priority Setting In Practice: What Is The Best Way To Compare Costs And Benefits?’, *Health Economics*, 18: 467–478.

365. Woods, R.K., Abramson, M., Bailey, M., and Walters, E.H. (2001). ‘International prevalences of reported food allergies and intolerances. Comparisons arising from

the European community respiratory health survey (ECRHS) 1991-1994', *European Journal of Clinical Nutrition,* 55(4):298-304.

366. World Health Organization (1948). Constitution of the World Health Organisation, WHO Basic Documents. Geneva.
367. World Health Organization (1997). WHOQOL Measuring quality of life. Geneva. Available at: https://www.who.int/mental_health/media/en/68.pdf
368. World Health Organization (2013). The WAO White Book on Allergy. Available at: https://www.worldallergy.org/UserFiles/file/WhiteBook2-2013-v8.pdf
369. World Health Organization (2006). Food allergies - Summary note. Available at: https://www.who.int/foodsafety/fs_management/No_03_allergy_June06_en.pdf
370. Xepapdaki, P., Fiocchi, A., Grabenhenrich, L., Roberts, G., Grimshaw, K.E.C., Fiandor, A., Larco, J.I., Sigurdardottir, S., Clausen, M., Papadopoulos, N.G., Dahdah, L., Mackie, A., Sprikkelman, A.B., Schoemaker, A.A., Dubakiene, R., Butiene, I., Kowalski, M.L., Zeman, K., Gavrilli, S., Keil, T., and Beyer, K. (2016). 'Incidence and natural history of hen's egg allergy in the first 2 years of life - The EuroPrevall birth cohort study', *Journal of Allery and Clinical Immunology*, 71(3): 350-357.
371. Zrubka, Z., Rencz, F., Závada, J., Golicki, D., Rupel, V.P., Simon, J., Brodszky, V., Baji, P., Petrova, G., Rotar, A., Gulácsi, L., and Péntek, M. (2017). 'EQ-5D studies in musculoskeletal and connective tissue diseases in eight Central and Eastern European countries: a systematic literature review and meta-analysis', *Rheumatology International*, 37(12), 1957-1977.
372. Zuberbier, T., Edenharter, G., Worm, M., Ehlers, I., Reimann, S., Hantke, T., Roehr, C.C., Bergmann, K.E., and Niggemann, B. (2004). 'Prevalence of adverse reactions to food in Germany - A population study', Allergy*,* 59(3):338-345.
373. Zuidmeer, L., Goldhahn, K., Rona, R.J., Gislason, D., Madsen, C., Summers, C., Sodergren, E., Dahlstrom, J., Lindner, T., Sigurdardottir, S.T., McBride, D., and Keil, T. (2008). 'The prevalence of plant food allergies: A systematic review', *Journal of Allergy and Clinical Immunology,* 121(5):1210-1218.

safefood

7 Eastgate Avenue, Eastgate, Little Island, Co.Cork, T45 RX01
7 Ascall an Gheata Thoir, An tOiléan Beag, Co. Chorcaí, T45 RX01
7 Aistyett Avenue, Aistyett, Wee Isle, Co. Cork, T45 RX01

Tel +353 (0)21 230 4100

Email: info@***safefood***.net

@***safefood***_net

@***safefood***_net

Helpline
ROI 0818 40 4567 **NI** 0800 085 1683

safefood