

An Investigation of Healthcare Supports for Those with Food Allergy in Ireland

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ABSTRACT

Introduction: In Ireland, around 5% of children and 3% adults have food allergy (134,000 people). This current paper describes a survey that was carried out on a subset of service-users with the aim of identifying whether there is a need for increased specialist medical services and/or for a funded charity such as Anaphylaxis Ireland, defunct since 2015.

Materials & Methods: These needs were assessed via an online survey using Google Forms. The survey was conducted from 17-27th February 2020. There were 31 questions in total, relating to topics such as symptoms, clinical wait times, satisfaction with care provided and demand for support services.

Results: There were 50 valid responses. Results showed that wait-times for referrals are shorter for privately referred patients (43% seen in 1 month) than public patients (20% seen in 1 month), most patients did not see a dietician (81.8%) and allergy management is generally effective (93% decrease in severe cases). Also, there is high demand for support services such as allergen-free food list (54.5% of respondents) and caterer's lists (54.5% of respondents).

Discussion: This is the first paper outlining food allergy care since 2015 in Ireland and the findings suggest the need for improved GP awareness of food allergy and filling consultant immunologist posts to reduce public wait times. Also, a funded support organisation should be reinstated to meet all the needs of food allergy patients.

KEYWORDS: food allergy, immunology, anaphylaxis, food allergen, dietetic service, Ireland

INTRODUCTION

Food allergy is an important public health issue that affects both children and adults and may be increasing in prevalence (Boyce *et al.*, 2010). In Ireland, statistics show that approximately 5% of children and 3% of adults suffer from food allergies (Irish Nutrition and Dietetic Institute (INDI), 2020). There has been a 615% increase in hospitalisations for anaphylaxis reported between 1992-2012 in the United Kingdom (Turner *et al.*, 2015). Food allergy has been defined as adverse reactions to food in which immunologic mechanisms have been demonstrated. This term therefore encompasses both immunoglobulin E (IgE)-mediated and non-IgE-mediated food allergies (Muraro *et al.*, 2014). This strict definition separates food allergy from food intolerance and hypersensitivity, metabolic conditions such as lactose intolerance, and coeliac disease (Hadley, 2006). Although any food may provoke a reaction, relatively few foods are responsible for most food allergic reactions, these include milk, egg, peanuts, tree nuts, fish, and shellfish (Sampson, 2003).

The clinical presentation of food allergy involves a large spectrum of symptoms including skin (urticaria, angioedema, atopic eczema), gastrointestinal (vomiting, abdominal pain, diarrhoea,

constipation), respiratory (rhinorrhoea, dyspnoea) and circulatory (cardiovascular collapse) (Muraro *et al.*, 2014). Both modifiable and non-modifiable early life risk-factors for food allergies have been identified, including male sex, ethnicity, genetics, allergen exposure (timing and route of exposure) and vitamin D insufficiency (Loh and Tang, 2018). The exact causative agent of food allergy development is unknown however, Platts-Mills (2015) argues changes in environment, hygiene and lifestyle have led to the increase in allergies in recent years. Improved hygiene, and the movement of children indoors means they are exposed to less antigens early in life, therefore they cannot be desensitised to those antigens. Consequently, this leads to exaggerated immune responses later in life in the form of allergies.

The current survey aimed to assess the provision of care for those with food allergies in Ireland and evaluate the strengths and weaknesses of the public healthcare system for the diagnosis and treatment of food allergy patients. The level of satisfaction with management and treatment options and any new approaches to treating food allergy patients were also examined. The respondents were asked to recommend any support services that may be helpful in managing their food allergy. The possible changes that may have occurred in the provision of care since the 2015 disbanding of Anaphylaxis Ireland were also interpreted, by comparing the satisfaction of food allergy patients who were diagnosed and treated prior to and after that year. The last paper on this topic in Ireland was published in 2014 (Conlon, *et al.*, 2014).

MATERIALS AND METHODS

Survey Population

The target population for this study was individuals with food allergies in Ireland. To include the full range of those with food allergies, populations of both adult and paediatric patients were surveyed. Parents answered the survey on behalf of their children if aged under 18 years. Respondents were selected by asking individuals in the community either verbally, via social media or posters if they have a food allergy or if they know someone with a food allergy. If they knew someone, they were asked to pass the survey link to that individual. The population was sourced from locations across Ireland.

Method of Conducting the Survey

Responses were taken from the 17th of February 2020 to the 27th of February 2020. An online survey platform (Google Forms) was used to construct the survey. There were 31 questions in total, relating to topics including symptoms, clinical wait times, satisfaction with care provided and need for support services (shown in **Appendix 1**). The surveys were answered anonymously.

Data Analysis

Data analysis was conducted using Microsoft Excel and Google Sheets. The representation of the general population among the survey population was determined using the Census 2016 data (Central Statistics Office Census, 2016) and Prevalence Data (Irish Food Allergy Network Allergy, 2016). The Top 14 Allergens based on Regulation (EU) No 1169/2011 of the European Parliament (2011) on food labelling were used to identify “rare allergies” in this survey. The complete set of data was divided into four subgroups: the general population, paediatric patients, rare allergens and finally, severity subdivisions (mild, moderate, and severe). Responses were considered valid if the subject consented to participation, is resident in Ireland and stated specifically they had a food allergy. Symptoms and patient experiences were used as validation of self-reported allergy severity.

RESULTS

There were 50 valid responses from 56 submissions. Six submissions were excluded as the respondents were either coeliac or not resident in the Republic of Ireland. Of the valid responses, 70% (n=35) of respondents were female and 30% (n=15) were male. Of the respondents, 76% (n= 38) were over 18 and 24% (n = 12) were parents of under 18 paediatric patients, answering on behalf of their child.

Regarding self-reported severity, 28% were mild (n=14), 42% were moderate (n=21) and 30% were severe (n=15). Survey respondents were asked to describe their medical experiences of food allergy and the prevalence of these experiences was examined across the range of food allergy severity presented in Table 1.

Table 1: Validation of Self-Reporting of Allergies by Comparison of Experiences of each Severity Group

Parameter of Severity	Mild Patients	Moderate Patients	Severe Patients
Anaphylactic shock	0%	5%	9%
Hospitalisation from allergy	0%	5%	50%
Adrenaline auto-injector (Epipen) carriage	0%	19%	64%

The number of respondents who reported allergy to each of the common allergens was noted and prevalence of that allergy among the respondents was calculated and can be seen in figure 1. This prevalence was compared with the prevalence of allergens among the severe cohort of patients. Some individuals had more than one allergy (n=23). Peanuts, other nuts, molluscs, and crustaceans represented some of the most common allergens.

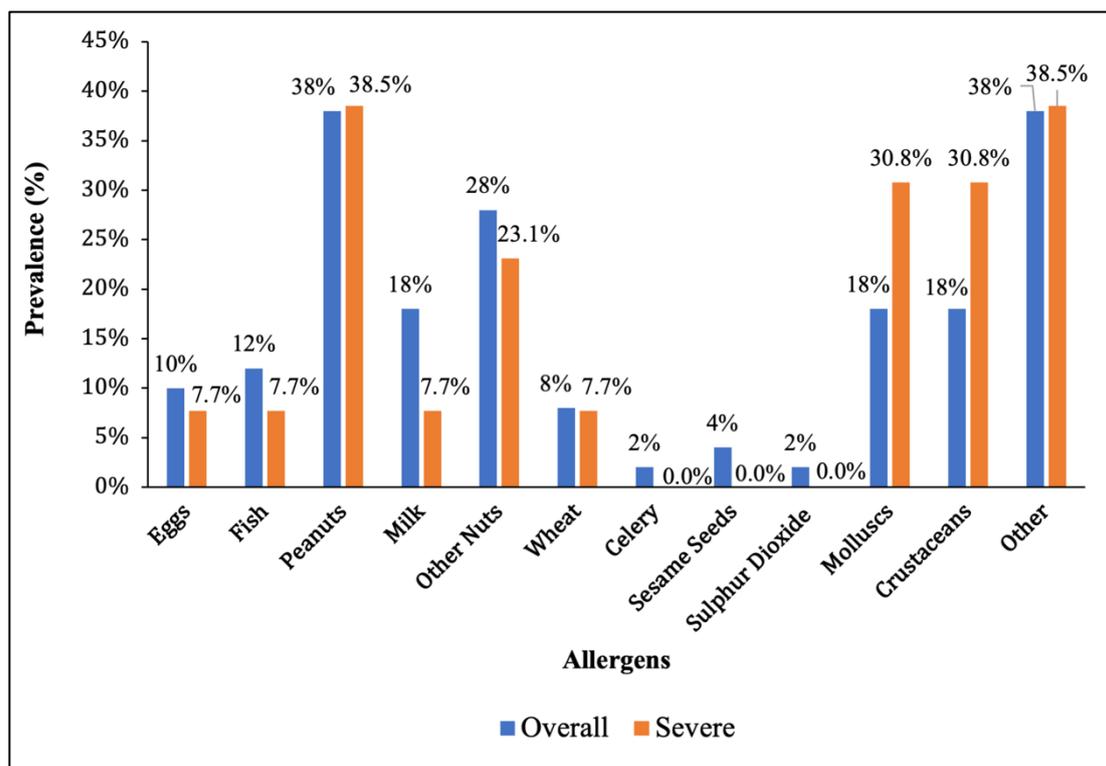


Figure 1: Frequency of Reported Food Allergens in Respondents

The respondents reported who they considered their primary care provider for their allergy and the frequency of these providers among this population was calculated. 12% (n=6) of respondents reported more than one individual as their predominate carer. Most respondents had care provided by General Practitioners. Of the total respondents 26% (n=13) had used complementary or alternative treatments for their food allergy outside of mainstream healthcare provider

The predominant healthcare provider for paediatric patients (n =12) were as follows: 58% an immunologist, 35% a GP and 7% did not state whether they had a healthcare provider.

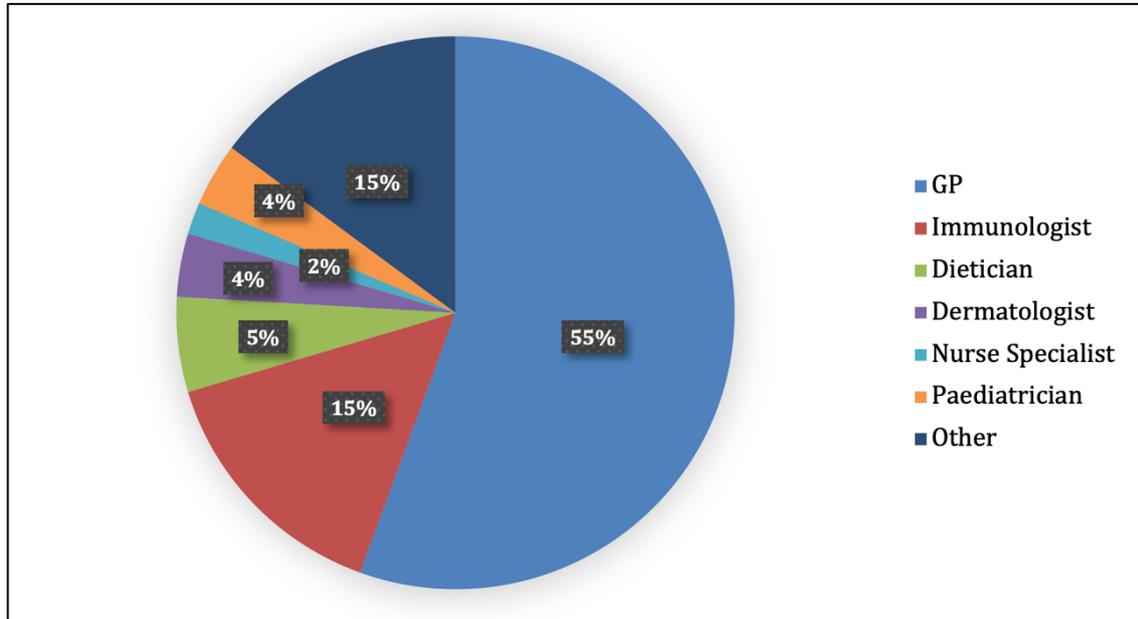


Figure 2: Predominant Health Care Provider for People with Food Allergies in Ireland.

Immunologist Referrals

Of the 50 responses, 60% (n=30) individuals were not referred to an immunologist. There were 13 respondents who had been referred in the past five years. The remainder (n=7) did not answer the question. Table 2 shows the wait time in months to see an immunologist for; patients referred through the private versus public system and paediatric versus adult populations. Half of paediatric patients were referred privately, 43% were referred publicly and 7% had no referrals

Wait times were also investigated dependent on allergy severity, and in those who have a close relative with food allergy versus those who do not. One patient referred privately who did not answer the wait-time question. One patient who answered that they were waiting 4-6 months did not answer whether they had a family history of food allergy.

Table 2: Wait Time (in months) to see an Immunologist

Wait Time (months)**	Private (n=7)*	Public (n=5)	Paediatric (n=7)	Adult (n=6)	Mild (n=1)	Moderate (n=4)	Severe (n=8)	Close Relative (n=2)	No Close Relative (n=10)
1	3	1	3	2	0	2	3	1	4
2-3	3	1	1	3	1	1	2	1	3
4-6	1	0	1	0	0	0	1	0	0
7-11	0	2	1	1	0	1	1	0	2
12+	0	1	1	0	0	0	1	0	1

* One patient referred privately did not answer the wait-time question.

** One patient who answered that they were waiting 4-6 months did not answer whether they had a family history of food allergy.

Dietician Referrals

A total of 84% (n=42) of respondents had not been referred to a dietician. Of those who had (n =8), three quarters were seen within a month (n=6) and the remainder were seen in two-three months (n=2). Of these individuals, 75% (n=6) reported having adequate information on their allergy and the supports available to them. In contrast, 52% (n=17) of those who had not seen a dietician reported having adequate information.

Efficacy of Food Allergy Treatment

As seen below, the number of respondents in each severity bracket was noted before treatment of their allergy and was compared with the proportion of severity after treatment. Note the decrease in severe cases and increase of mild cases after treatment.

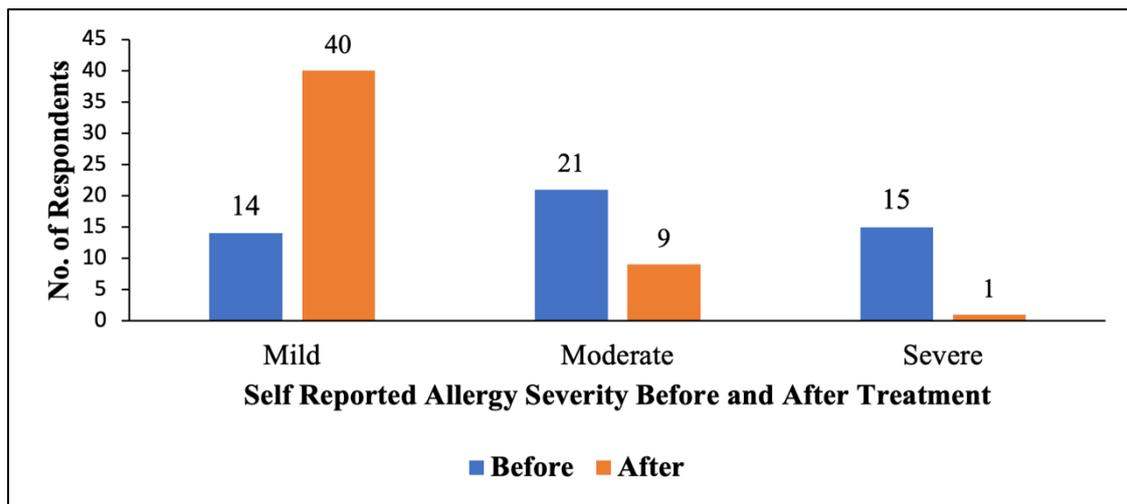


Figure 3: Change in Severity of Food Allergies Before and After Treatment

Table 3 compares the satisfaction with diagnosis and treatment among patient diagnosed prior to 2015 and subsequently.

Table 3: Level of Satisfaction with Allergy Diagnosis/Treatment in Long-Term and Short-Term Patients*

Time Since Diagnosis*	Satisfied	Dissatisfied
Short-term	57%	43%
Long-term	74%	26%

*Long term is defined as a diagnosis as prior to 2015 and short term since 2015.

Respondents (n=43) were asked to list the methods by which they had been tested for their food allergy. 20 respondents were tested by more than one method. Blood tests, followed by skin-prick tests and allergen exclusion were the most common testing methods see figure 4.

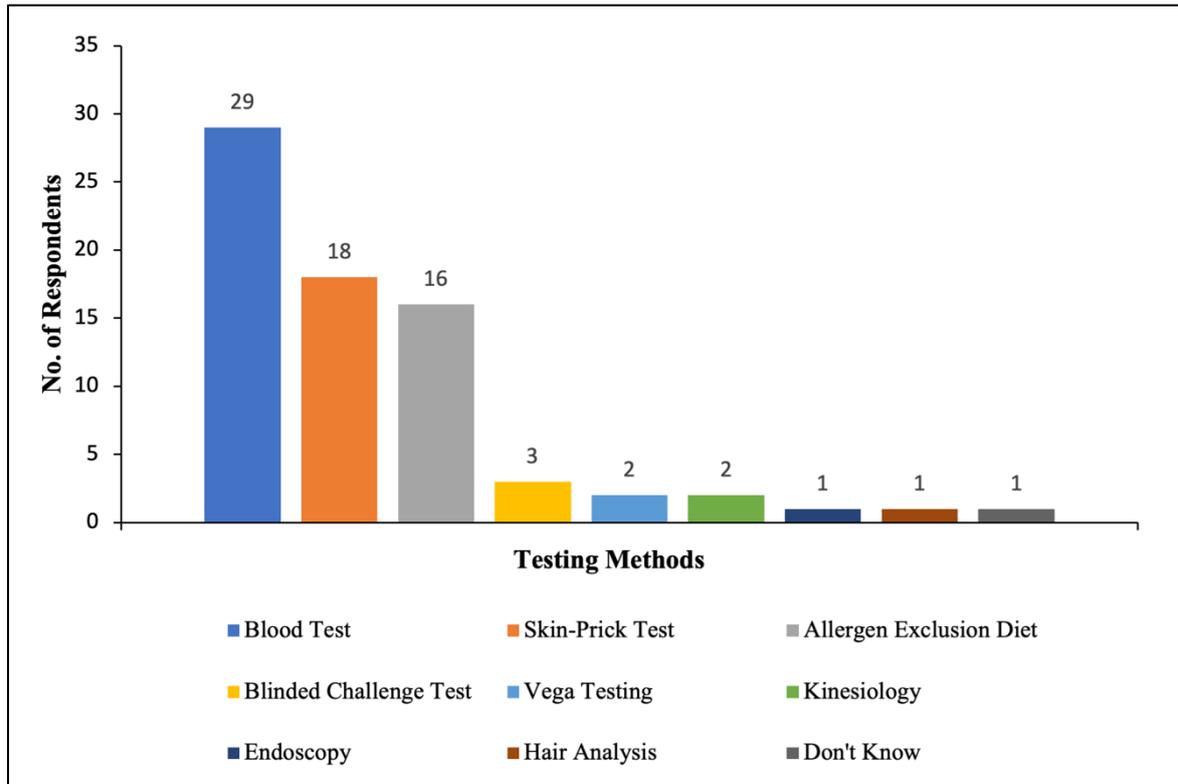


Figure 4: Number of Respondents Who Underwent Each Form of Food Allergy Testing

Respondents (n=48) were asked to list the methods they had used to manage their food allergy. The total number of people who used each method is seen in figure 5. Nineteen respondents had used more than one management method. Allergen exclusion was the most common management strategy.

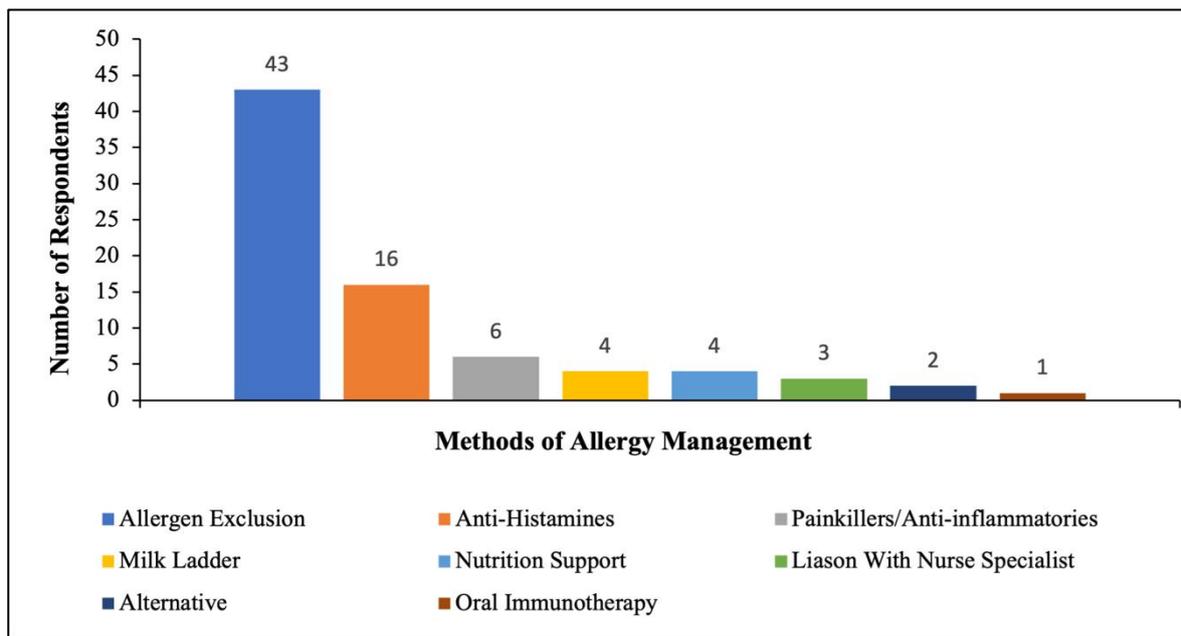


Figure 5: Number of Respondents Who Used Each Method of Food Allergy Management

The self-reporting efficacy of convention versus alternative treatments is seen in table 4 showing that the efficacy of convention methods is reported as better than alternative medicines.

Table 4: Self-Reported Efficacy of Conventional versus Alternative Treatment of Food Allergy*

Medical Pathway for Allergy Treatment	Average Self-Reported Efficacy (1-10 scale)
Conventional Medicine	8.1/10
Alternative Medicine	5.8/10

*Efficacy scale 1-10, where 1 is completely ineffective and 10 is extremely effective

Beneficial Changes Recommended by those with Food Allergies

Adult respondents were asked to list what services they felt would be most effective/necessary to support their food allergy care, the frequency of requests for each service was calculated. This was compared with the frequency of services requested by parents of children with food allergies to assess if their needs differ when compared to the adult population. Most parents wanted separate food preparation areas and issuing of a parental guide. Adult respondents wanted caterer's lists and updated food lists for their allergen.

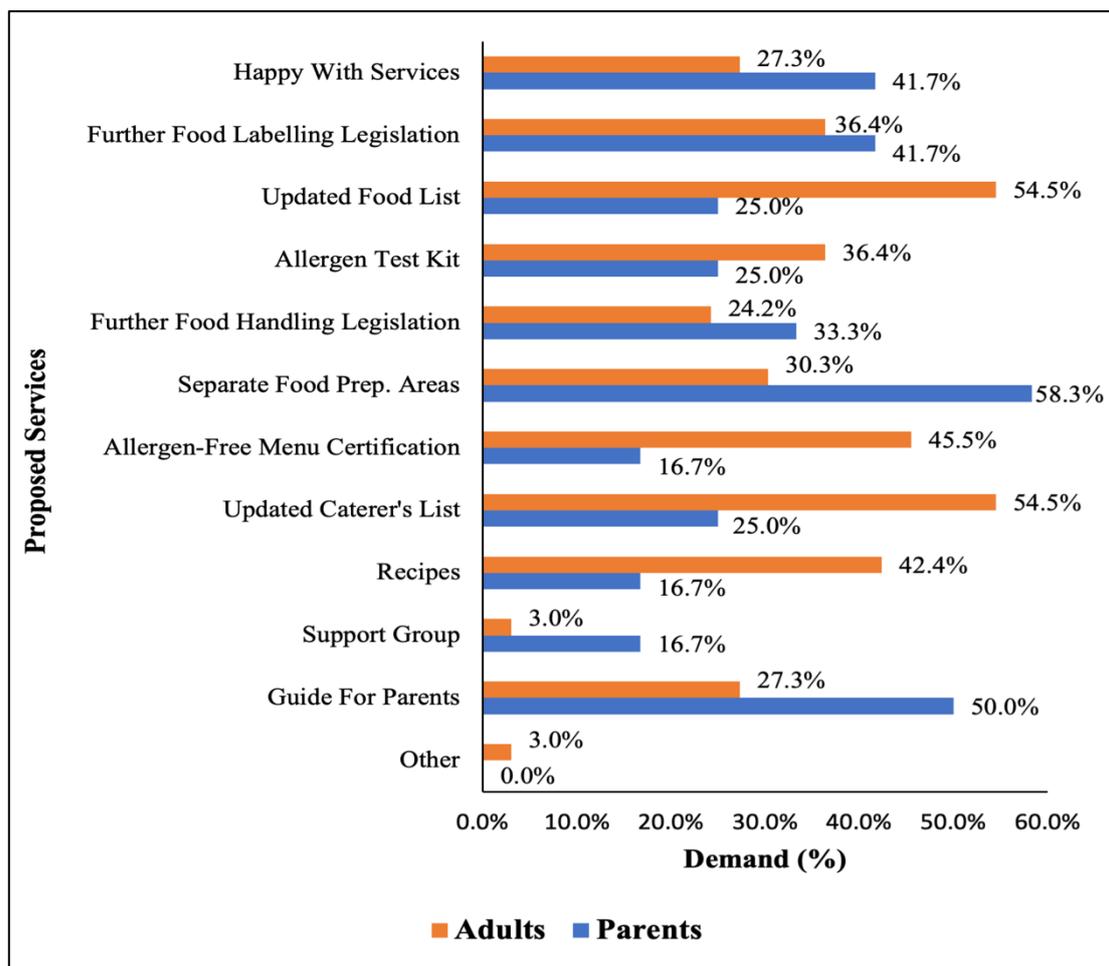


Figure 6: Suggested Needs for a Variety of Support Services Presented as a Percentage of Adult Respondents and Parent Respondents

DISCUSSION

The purpose of this study was to survey people with food allergies and assess the care they received in Ireland since the last published study by Conlon *et al.*, (2014), which covered allergies in general, rather than food allergies specifically. With the closure of the only Irish food allergy support organisation Anaphylaxis Ireland in 2016 (Anaphylaxis Ireland, 2020), it may be beneficial to analyse the gaps in support post-diagnosis for food allergy patients. It is reported that approximately 3% of adults and 5% of children in Ireland have food allergies (IFAN, 2020). Of a given population 5% is taken as a representative sample, therefore the 50 subjects of this survey represent 1000 individuals with food allergies.

The most common foods that respondents were allergic to are shown in Figure 1. In Ireland these are peanut/other nuts, cow's milk, fish, and egg allergies, which together account for 90% of food allergies globally (Żukiewicz-Sobczka *et al.*, 2013). In this survey, 80% of respondents reported having at least one of these allergies. Some people had an allergy to a foodstuff that fell outside the EU list of major food allergens (Annex II to Regulation 1169/2011 (FIC), 2011). These foods were collectively termed rare allergens and included strawberry, kiwi, yeast, and others. As the responses to this survey were gathered anonymously, allergy symptoms and experiences of the respondents were self-reported. One key area of self-reporting was the severity of an individual's allergy. As a measure of validation of this self-reporting Table 1 compares the frequency of symptoms and experiences of patients which is used as evidence to accept the three sub-divisions of mild, moderate, and severe in further analysis. As Table 1 shows, there was an increase in prevalence of all parameters measured in self-reported severe patients relative to moderate and mild patients. Anaphylaxis is used as a measure of severity as it represents a life-threatening, systemic hypersensitivity (Reber, *et al.* 2017). Hospitalisation for an allergic reaction often occurs due to anaphylactic shock (Banerji, *et al.* 2011). The most substantial difference between mild and severe patients was adrenaline auto-injector carriage (used in anaphylactic emergencies), this serves as a strong indicator of allergy severity.

An important aspect of allergy care in Ireland is the healthcare professional that manages diagnosis and treatment of that allergy. Of respondents, most were under a general practitioner's (GPs) care, with more complex cases referred to a specialist consultant immunologist as shown in Figure 2. Other practitioners consulted were dieticians and dermatologists. Testing for food allergy via blood test was reported by 67.4% of respondents (Figure 4). This is typically performed in GP practices. The GP will also note clinical and family history to diagnose the allergy (National Institute for Health Care and Excellence (NICE), 2011). Skin-prick tests were carried out in the diagnosis of 41.9% of those surveyed (Figure 4), which is usually conducted by dermatology outpatient departments (Purcell, 2019). Instances in which a GP may refer to an immunologist include where there is anaphylaxis or severe delayed reactions, faltering growth in young children or non-response to allergen exclusion (NICE, 2011).

When considering consultant immunologist referral wait-times, only those referred since 2015 were included, to allow appraisal since the publication of Conlon *et al.* in 2014 where they found there was an increasing demand for specialist public allergy services across Ireland. In this survey, 60% of individuals were not referred to an immunologist/allergist. As shown in Table 2, the wait times for private patients were shorter than for public referrals. National statistics on waiting times for public hospitals show that 742 people are currently (February 2020) on a waiting list to see an immunology consultant, a third of which have been waiting over 18 months (Outpatient by Specialty as at 27/02/2020, 2020). This represents a 7% increase since February 2015 (Outpatient by Specialty as at 26/02/2015, 2015). The key cause for the recent surge is both the lack of filled consultant vacancies and the rapid increase in referrals for allergic diseases, marking allergy as a “*major unmet need across the health service*” (Purcell, 2019). One consultant noted there are now only “*four and a half consultants in the country*” (Doyle, 2019). Previous studies detailing the effect of waiting times for outpatient services on the patient include a risk of physical deterioration, and higher levels of anxiety, uncertainty, and powerlessness whilst anticipating a disease outcome (Fogarty and Cronin, 2008). Paediatric patients were seen faster than their adult counterparts as shown on Table 2. Paediatric services may be better

resourced because there are more children with allergies (5%) in contrast with adults (1-2%) (Food Safety Authority of Ireland (FSAI), 2020).

Due to anaphylactic reaction risk, severe patients tend to be fast-tracked for immunology referrals (Purcell, 2019). Table 2 shows that a larger proportion of severe patients were seen within 1 month, however this trend was not observed in mild or moderate groups. In Table 2, those with a relative with food allergy were seen at an expedited rate, as family history is a significant clinical presentation of food allergy (The Royal College of Paediatrics and Child Health, 2011). It should be noted sample size was small for this parameter, so further study is needed. To help improve wait-times for allergy patients, the health service could encourage the recruitment of more consultant immunologists through in-house training initiatives and advertisement abroad to attract these specialists (Aronson, 2011). It was noted by Harding, *et al.* (2016) that a triage system reduced waiting lists by 40% compared to short-term investment (Kenis, 2006). Most patients reported their GP as their primary healthcare provider (Table 2). This may represent a lack of holistic care, with only 16% of respondents referred to a dietician in the past 5 years, and one respondent referred to a clinical nurse specialist.

It was found waiting times to see a dietician (from 2015 to 2020) were much shorter than that for the immunologist. Three-quarters of patients were seen within a month and the remainder in two-three months. As most (84%) respondents were not referred to a dietician, it is important to note the benefit reported by those who did. Of those who saw a dietician 75% felt they had adequate information on their allergen and support services available to them. In contrast, 52% of those not referred felt well-informed. An allergy patient is less likely to develop nutritional deficiencies due to allergen exclusion under the guidance of a registered dietician (Aronson, 2011). Under the guidance of dieticians, reintroduction of certain allergens (e.g. cow's milk, egg) has accelerated the rate at which infants grow out of their allergy (Brożek *et al.*, 2012; Dang *et al.*, 2016; Irish Food Allergy Network, 2020). Despite increased patient awareness and other benefits, dietetics is an underutilised service by healthcare-providers, and presents a valuable opportunity for more effective food allergy care

One successful aspect of food allergy care appears to lie in the management and treatment techniques used in the Irish health service. There is a distinct decline in those who self-report as severe and moderate after management (Figure 3). Mild cases greatly increased after treatment, encompassing 80% of respondents. The self-reported efficacy of conventional treatments in this survey was 8.1/10 (Table 4). In contrast, those patients using alternative/complementary treatments rated it 5.8/10. As no cure for food allergies exists, the standard and most basic management strategy is allergen avoidance (Lanser, *et al.* 2015). Of respondents, 87.5% practised allergen exclusion, while 33.3% used antihistamines (Figure 5). While theoretically allergen exclusion should result in lack of allergic reactions, this is often not the case due to contamination and mislabelling or risk-taking with allergens by patients (Sampson, *et al.* 2006). Allergy exclusion also carries psychological burdens and stress (Primeau, 2000). The patients who were diagnosed prior to 2015 were defined as long-term patients and those after 2015 were short-term patients. Most patients diagnosed prior to 2015 were satisfied with their diagnosis and current management strategy. However, those diagnosed in recent years are substantially less satisfied (Table 3). This may be attributed to the extended waiting times more recently or a lack of support services for those with allergies, for example the disbanding of Anaphylaxis Ireland (Figure 6). Other reasons for dissatisfaction reported were insufficient testing for those with multiple allergens and wrong tests being ordered (total IgE rather than specific-IgE), supporting the need for GP awareness of allergy. These, in combination with the challenges of allergen exclusion, suggests a need for newer, more effective forms of therapy for food allergies in Irish healthcare.

One promising new option is allergen immunotherapy, which one child from the current survey had undergone. This involved exposing the patient to increasing increments of their allergen with the aim of eventual desensitisation to the allergen (Licari, *et al.*, 2019). Some trials have shown up to 90% desensitisation, however there is a moderate risk of serious systemic allergic reaction, and thus require scrupulous adherence to maintenance doses (Nurmatov, *et al.* 2017; Nucera *et al.*, 2018; Licari, *et al.*, 2019; Chu *et al.*, 2019). Anti-cytokine therapies, gene therapy, probiotics and anti-IgE therapies may have applications in treating food allergies in the future (Kishida, *et al.* 2007; Licari, *et al.* 2019). These

treatments would not only act as effective management of food allergies but also remove the burden of allergen exclusion on Irish patients. Further research and development of these therapies could yield beneficial results for the care for allergies nationally and internationally.

With the rise of paediatric allergy cases worldwide, the care of children with food allergies presents unique challenges such as parental training and anxiety, nutritional insufficiencies and maintaining long-term management plans that change over a lifetime (The Royal College of Paediatrics and Child Health, 2011). According to the HSE (2013), paediatric allergy care was underdeveloped in Ireland, with most children not seeing an allergy specialist. Based on the current survey, most paediatric patients (58%) now see an immunologist which may represent an improvement in the provision of food allergy care for paediatrics since 2013. Half of paediatric patients were referred privately. Parents may have chosen the private referral route due to a faster diagnosis than the public route. Increased staff recruitment/specialist training in immunology and improved integration of the discipline into general practice will work to enhance the care provided to paediatric patients in Ireland.

The final component of food allergy care is post-diagnosis supports that improve the quality of life of a patient. The demand for a wide variety of services is shown in Figure 6. The adult cohort was less satisfied (27%) with current support services when compared with the parent population (42%). This coupled with the longer waiting times discussed above may indicate that adult food allergy care is not as effective or well-managed as paediatric care.

Of respondents, 36% recommended further legislation on food labelling and 42% of respondents recommended an updated list of products that are allergen-free. This suggests need for a funded entity in Ireland which maintains a food list in the same manner as the Coeliac Society of Ireland (2020), which is updated throughout the year. There is currently a high risk of allergen contamination in restaurants (36% had an allergic reaction while eating out). A combination of better food labelling and distribution of user-friendly, portable allergen test kits would reduce the incidence of contamination reactions (Ross, *et al.* 2018). An example is the smartphone-based microplate reader developed by Fu, *et al.* (2016), which involves spectrophotometric analysis using the phone camera.

Besides labelling, some respondents (Figure 6) believed that food handling legislation should be changed. Under EU law, there are no specific regulations for handling of allergenic foodstuffs (Annex II to Regulation 1169/2011, 2011). A possible change in catering facilities includes separate preparation areas for allergen-free food (supported by 26% of respondents). A beneficial change recommended by 40% of respondents (Figure 6) was improved allergen-free menu certification, in a similar vein to the Coeliac Society of Ireland (2020)'s "*Gluten-Free Promise*" campaign. Similarly, an updated list of caterers reviewed for allergen-awareness was supported by 44% of respondents in the current survey. It was found that 17% of parents supported the establishment of a food allergy support group. Support groups can aid the child in developing self-sufficiency (e.g. adrenaline auto-injector tutorials) which can reduce parental burden (Sharma, *et al.* 2012). There currently exists a parental guide provided by IFAN (2018) to help parents manage their child's allergy as 50% (see Figure 6) of parents wanted a parental guide, this suggests a need for increased awareness of such guides among parents. Overall, the current demand for services such as these highlights the gap in food allergy care in Ireland left by Anaphylaxis Ireland.

One of the limitations of the study was the small sample size ($n=50$) which is not representative of the whole Irish population, also most respondents came from Cork ($n=31$). A more thorough distribution of the survey nationally with a greater sample size would address this limitation and provide more representative data. Due to the methods used to distribute the surveys, such as via college email, the older population were not represented as well as the younger population.

In conclusion, a notable strength in Irish allergy care is the effectiveness of the treatment strategies currently available. Faster wait times indicate that paediatric immunology appears better resourced than the adult counterpart. The 50% rise in Irish cases and 700% increase in hospitalisations in the past decade highlights food allergy as a serious and urgent public health issue (Cahill, 2020). Necessary

changes include a decrease in wait-times because they currently put public patients at risk and increasing the role of the dietician for a holistic approach. Better GP and public awareness of food allergies, as well as improved legislation for food labelling/handling are also needed. Reinstatement of Anaphylaxis Ireland is recommended to lobby for these services and fill the gaps seen in patient support in this country.

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