The preferences of those with food allergies and/or intolerances when eating out (FS305013)

FINAL REPORT

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Executive Summary

On 13th December 2014, EU legislation was introduced requiring retailers of non-prepacked foodstuffs to provide customers with information relating to the presence of 14 specified allergens as ingredients in their products. The legislation affects information provision in restaurants, takeout facilities, and all other food outlets. Within the UK, this legislation is enforced by the Food Information Regulations (FIR) 2014. As EU member states have discretion as to the means through which allergen information is made available it is vital that the Food Standards Agency (FSA) understands the preferences that food allergic and intolerant individuals have for the provision of trusted information about non-prepacked foods in order to provide relevant guidance and recommendations to food businesses as to how to provide allergen information to consumers that will improve their satisfaction with, and confidence in, the information that they are provided with.

To this end, the FSA commissioned research to establish consumer preferences for information provision about allergens when eating out and to investigate the impact of the FIR on food allergic and intolerant adult consumers and on parents and caregivers of food allergic and intolerant children. The research had two parts: Part A was conducted between February 2014 and February 2015; data collection was completed prior to the implementation of the legislation in December 2014. The second stage of the project - Part B – was conducted in 2016 with the principal aim of assessing changes in the views and self-reported eating out practices of FA and FI consumers. This report presents the results of the completed project which covers both Part A and Part B.

There were two phases of empirical work.

- In depth qualitative research consisting of interviews and diaries with food allergic and intolerant individuals from across the UK to explore their information seeking practices and preferences around non-prepacked foods and how these changed, if at all, over the pre to post legislation period.
- A questionnaire survey to quantitatively characterise any changes over the pre and post legislation period in preferences for information provision and in quality of life.

This work was informed throughout by reviews of the relevant literature and ongoing engagement with key stakeholders - most particularly the Anaphylaxis Campaign, Coeliac UK and Allergy UK.

Overall the research indicates that there *have been improvements in the eating out experiences of those with a food allergy or intolerance since the implementation of the FIR legislation*. There was greater confidence to ask staff and an increase in the extent to which staff were seen as a resource for confident food choices. Starting from a very low base there was a slight increase in how adventurous people felt when they were eating out. Finally post legislation views about the inadequacy of menu information had softened – participants felt it was more adequate then than they did pre legislation. There were other measures where we saw some more specific changes – for example there was an increase in planning for those seeking to avoid more than two allergens, and parents who were seeking to support their children to avoid allergens were more satisfied post legislation that menus enabled confident food choices. The effect sizes are small; however, the small but significant results are consistently in the direction of improvement.

The research indicates that people seek and take a range of opportunities to find information to inform and improve their eating out experiences with a food allergy or intolerance. These start with looking for information online and occur at various points through to the arrival of the food at the table. Across all of these, overall *people had a preference for written information about the allergen content of food.* Both before and after the legislation they expressed a preference for allergen

information to be presented in a written/printed format to which they have easy, independent access. Post legislation people - mainly those seeking to avoid gluten - seemed more aware and to have had more experience with separate allergen specific menus. There was also greater appreciation of the possibility of using menus that detail the ingredients of all dishes as a supplement to the main menu of the venue – not as an alternative.

Although unquestionably people preferred their first line resource for making decisions about what to eat when they were eating out to be written, *the best eating out experiences involved knowledgeable and attentive staff*. The following were all interpreted as being likely to mean that the venue would provide a safe and enjoyable eating out experience: evidence of being known and of their allergy being known; of staff knowledge and awareness even when contacted ahead of time; of proactive staff with a willingness to adjust the dishes and of staff with a positive and engaged attitude, who dealt with difficulties in a positive manner and communicated well. Having said that there were a range of important reasons why *most people's primary reliance was not on what staff told them*. For many the mere act of asking carried with it an inherent risk of being seen as 'making a fuss', being embarrassed and carried added potential for misinformation and mistakes. *People read a range of subtle cues from staff and the broader 'body language' of the venue to* get a sense of how much they could be trusted to provide a safe eating out experience.

One of the most frequently encountered examples of written information after the legislation was the display of a sign asking people to ask staff and to make themselves known to staff if they had a food allergy or intolerance. Although some saw this as an improvement suggesting raised awareness and a willingness to respond to allergen enquiries, many saw it as *meaningless and that this was venues taking the easiest option available in order to comply with the letter of the law*. The responses of participants indicated that this very general 'please ask our staff' message may potentially be seen as another variant of 'may contain' labelling - that is that it is a box ticking exercise that is fulfilling the letter of the law but not its spirit.

After the legislation, in contrast to before, there was a clear sense of a lack of equity in the provision of information about different allergens. Although as we said above, overall the availability of allergen information was seen to have improved since implementation of the legislation, *after the legislation there was a perceived disparity in information provision for different allergens*. Information for those seeking to avoid gluten was perceived to be most the most widespread. Those seeking to avoid milk felt the provision for them was generally poor. They had less reliance on speaking to staff, considered allergen menus to have less potential as a source of information, and were less positive about invitations on the menu to speak to staff than those seeking to avoid either gluten or nuts.

Greater information about allergens did not necessarily mean that there were more options for what people seeking to avoid allergens could eat. Whilst consumers appreciated the increase in allergen information provision where available, for many increased information did not equate to greater choice or variety in the dishes that were safe for them to eat. They valued venues that provided allergen-free alternatives to dishes, but often felt that allergen information was designed to tell them what they 'could not' eat rather than informing them about the availability of viable alternatives.

Table of Contents

Acknowledgements
Executive Summary
Report overview
Introduction
Phase 01: Rapid Evidence Assessment9
Phase 02: Information seeking practices and information provision preferences: a qualitative approach
Phase 03: Information seeking practices and information provision preferences: A quantitative approach
Phase 04: Dissemination and knowledge exchange16
Implications and Recommendations16
THE PREFERENCES OF THOSE WITH FOOD ALLERGIES AND/OR INTOLERANCES WHEN EATING OUT 18
Introduction
Research Aims21
Phase 01: Rapid Evidence Assessment
Classification of venues22
Factors affecting venue choice23
Factors affecting food choice23
The service encounter24
Information provision25
Phase 02: Information seeking practices and information provision preferences: a qualitative
approach
Interviews:
Participants
Procedure
Analysis
Findings
Strategies for venue and food selection
The menu as an information resource
Overview of the role of the written information in food choice
Symbol-based and abbreviated indicators of allergen content in menus
Supplementary allergen reference source42
Separate allergen free menu44

Accessing and providing allergen related information online	45
Signs and notices	47
Interpretation of signs/statements on the menu: Please engage with staff	49
Staff as information resources	51
Reticence about relying on staff	51
Post legislation increased confidence to ask	53
Staff signals that warrant confidence	54
Post legislation improvement	59
The legislation and its impact on food allergic / intolerant consumers	61
Raising awareness	63
Permission to ask	64
Freedom to be more adventurous	64
Allergen cross-contamination, food preparation and ingredient substitution	66
Similarities and differences between groups	68
The role of parents	68
Early signs of allergic response as an early warning system	69
Restricted diets and identification with wider groups	70
5	
Differences between those avoiding different allergens	
	72
Differences between those avoiding different allergens Phase 03: Information seeking practices and information provision preferences: a quar approach	72 ntitative 74
Differences between those avoiding different allergens Phase 03: Information seeking practices and information provision preferences: a quar approach Research objectives	72 ntitative 74 74
Differences between those avoiding different allergens Phase 03: Information seeking practices and information provision preferences: a quar approach	72 ntitative 74 74
Differences between those avoiding different allergens Phase 03: Information seeking practices and information provision preferences: a quar approach Research objectives	72 ntitative 74 74 74
Differences between those avoiding different allergens Phase 03: Information seeking practices and information provision preferences: a quar approach Research objectives Methods	72 ntitative 74 74 74 74
Differences between those avoiding different allergens Phase 03: Information seeking practices and information provision preferences: a quarapproach Research objectives Methods Design:	72 ntitative 74 74 74 74 74
Differences between those avoiding different allergens Phase 03: Information seeking practices and information provision preferences: a quarapproach Research objectives Methods Design: Participants: Ethical Considerations: Materials:	72 ntitative 74 74 74 74 74 74 75 75
Differences between those avoiding different allergens Phase 03: Information seeking practices and information provision preferences: a quarapproach Research objectives Methods Design: Participants: Ethical Considerations:	72 ntitative 74 74 74 74 74 74 75 75
Differences between those avoiding different allergens Phase 03: Information seeking practices and information provision preferences: a quarapproach Research objectives Methods Design: Participants: Ethical Considerations: Materials: Data Analysis Results	72 ntitative 74 74 74 74 74 74 75 75 75 75 77 79
Differences between those avoiding different allergens Phase 03: Information seeking practices and information provision preferences: a quarapproach Research objectives Methods Design: Participants: Ethical Considerations: Materials: Data Analysis Results Profile of participants	72 ntitative 74 74 74 74 74 74 75 75 75 75 75 77 79 79
Differences between those avoiding different allergens Phase 03: Information seeking practices and information provision preferences: a quarapproach Research objectives Methods Design: Participants: Ethical Considerations: Materials: Data Analysis Results	72 ntitative 74 74 74 74 74 74 75 75 75 75 75 77 79 79
Differences between those avoiding different allergens Phase 03: Information seeking practices and information provision preferences: a quarapproach Research objectives Methods Design: Participants: Ethical Considerations: Materials: Data Analysis Results Profile of participants	72 ntitative 74 74 74 74 74 74 75 75 75 77 79 79 79
Differences between those avoiding different allergens Phase 03: Information seeking practices and information provision preferences: a quarapproach Research objectives	72 ntitative 74 74 74 74 74 74 75 75 75 75 75 79 79
Differences between those avoiding different allergens	72 ntitative 74 74 74 74 74 74 75 75 75 75 79 79

Imp	plications and recommendations	.98
	The legislation	.97
	Familiarity	.97
	The role of verbal information	.96
	The role of written information	.96

Report overview

Introduction

On 13th December 2014, EU legislation was introduced requiring retailers of non-prepacked foodstuffs to provide customers with information relating to the presence of any of the 14 specified allergens (peanuts, tree nuts, milk, soya, mustard, lupin, eggs, fish, molluscs, crustaceans, cereals containing gluten, sesame seeds, celery and sulphur dioxide (at levels above 10mg/kg, or 10 mg/litre) as ingredients in their products. The legislation affects information provision in restaurants, takeout facilities, and all other food outlets. All of those seeking to avoid foods containing any of the 14 listed allergens are, in principle, affected by the EU Food Information for Consumers Regulation (No. 1169/2011) (EU FIC). Within the UK, this legislation is enforced by the Food Information Regulations 2014 (FIR).

EU member states have discretion as to the means through which allergen information is made available – for example this could be orally by a member of staff, using a label, or on a menu or a chalk board. It is thus vital that the Food Standards Agency (FSA) understand the preferences that food allergic and intolerant individuals have for the provision of trusted information about nonprepacked foods, the role that different information sources have in allowing food allergic and food intolerant individuals to assess risk, and to make informed choices about where they eat and what they eat. Over two years have now passed since the FIR became law and thus it is also important that the FSA are aware of any changes over this time in people's experiences of eating out and in the ease, confidence and satisfaction with which people can make choices and what food to eat and where. It is also important to understand whether there have been any changes in the quality of life of food allergic and intolerant individuals.

In line with this, the FSA funded a project to investigate the impact of the legislation on food allergic and intolerant adult consumers and on parents and caregivers of food allergic (FA) and food intolerant (FI) children and adolescents under 18 years of age. The project had two parts; Part A was conducted between February 2014 and February 2015; data collection was completed prior to the implementation of the legislation in December 2014. The second stage of the project - Part B – was conducted in 2016 with the principal aim of assessing changes in the views and self-reported eating out practices of FA and FI consumers. This report presents the results of the completed project which covers both Part A and Part B¹.

The results of this project are relevant to the review of the implementation and resources provided for the allergen information requirements under the EUFIC. Findings can guide how food businesses provide allergen information to consumers; to improve their satisfaction with, and confidence in the information that they are provided with.

The project had four main objectives which were addressed in both Part A (pre legislation) and Part B (post legislation):

- To conduct a rapid evidence assessment to assist with defining the structure and content of the qualitative and quantitative work in particular to inform decisions about inclusion criteria for participants for this work and how to recruit them.
- To understand the preferences for information provision that food allergic and intolerant consumers have relating to the 14 allergenic ingredients when buying and eating foods that are non-prepacked, and to examine how these preferences have changed since implementation of the FIR.

¹ The standalone Part A report produced in March 2015 is available as a separate document

- To identify if there have been any changes in the quality of life for food allergic and intolerant consumers since the implementation of FIR and, if there are, to assess if any changes are attributable to changed information seeking practices and preferences.
- To review project findings and to derive implications for practice, communication and information provision

Both Part A (pre legislation) and Part B (post legislation) had four corresponding phases:

- Phase 01: Characterising developments in the peer reviewed and grey literature regarding the purchase and consumption of non-prepacked food by food allergic and food intolerant individuals
- Phase 02: In depth qualitative research consisting of interviews and diaries with food allergic and intolerant individuals from across the UK to explore their information seeking practices and preferences around non-prepacked foods and how these changed, if at all, over the pre to post legislation period.
- Phase 03: A questionnaire survey to quantitatively characterise any changes over the pre and post legislation period in preferences for information provision and in quality of life. Returning participants were supplemented with new participants in the Part B survey and additional questions about the role of support groups and social media in providing support around eating out practices were addressed.
- Phase 04: Conducting workshops to understand the views of key stakeholders around the ongoing implementation of the FIR regulations.

In this report we describe each of these phases in turn bringing together the findings from Part A (pre legislation) and Part B (post legislation). Following a discussion of the results the final section will outline the implications and recommendations of the research.

Phase 01: Rapid Evidence Assessment

In Part A, a rapid evidence assessment was conducted in order to identify the main issues affecting choices when eating out – for those that do and do not have adverse reactions to food.

The rapid evidence assessment conducted prior to the implementation of the legislation was conducted in order to identify the main issues affecting choices when eating out – for those that do and do not have adverse reactions to food. Most studies address the choices available to, and made by, the *non-allergic* consumer. Very limited evidence was found relating to the food choices of allergic and intolerant consumers. Such evidence as there is suggests that their need to avoid allergens is often the primary driving force in food and venue choice. There is a lack of any coherent vocabulary for *eating out venues*. There is a paucity of evidence around the factors affecting venue choice for consumers with a food allergy or intolerance although it is important to consider a range of general drivers of venue choice (such as location and price) as well as those specifically related to allergen management. Within venues, food choice for food allergic and intolerant individuals is subject to informal if not explicit risk assessments. Greater understanding is needed about how these risk assessments operate as well as about what is required (including nature of information) required to make less risky food choices. The service encounter seems to have particular significance for those with food allergy and intolerance in terms of making confident food choices.

In relation to information provision around prepacked food it is clear that consumers in general, as well as those seeking to avoid allergens, wish to have information about the product, e.g. ingredients, nutritional content, provenance of the food. However, little is known about information provision requirements and preferences in eating out settings – an increased understanding of this is vital in relation to the requirements of the new FIR legislation.

Part of the intention behind the FIR legislation is that those who have adverse reactions to any of the 14 allergens will be invited to speak to staff in order let them know their requirements. Engaging with staff is crucial to the service encounter. However, conversations with staff can also be associated with stigma and embarrassment for the allergic or intolerant consumer.

Taken together, the importance of the service encounter alongside sub optimal staff knowledge and awareness sets a challenging background for the continued implementation of the legislation and the potentially vital role that consumers might reasonably expect that staff will play in providing information about allergens in food.

Studies have focused on food providers (noting variability in how they provide information), as well as on consumers who relied on a range of formal and informal information sources though this was not specifically in the eating out context.

Two studies in the grey literature have sought to evaluate the impact of the FIR legislation reporting an increase in awareness of the legislation amongst the general public and in those affiliated to an allergy support group. Greater visibility of signposting about allergen provision was noted as well as increased confidence in asking staff, though post legislation a majority of respondents were noting issues with a lack of staff knowledge and understanding. It is notable that these studies were cross sectional – that is with different people answering questions pre and post legislation. The focus of both the qualitative and quantitative work to be reported here is on longitudinal data, that is, where people who gave their views before the legislation come back post legislation. This allows for a much clearer characterisation of what, if anything, has changed and why.

Phase 02: Information seeking practices and information provision preferences: a qualitative approach

The qualitative work was designed to understand the strategies that food intolerant and food allergic individuals use in order to manage the purchase and consumption of non-prepacked foods in eating out environments. It also considers the views of parents/carers that are responsible for managing the consumption of non-prepacked foods for children. Individuals with medically diagnosed food allergy and food intolerance as well as those with self-diagnosed food intolerance were included.

In Part A pre legislation, 75 participants took part in in-depth interviews and 47 diaries were completed. In Part B post legislation, 57 of these participants returned to the study: 56 were interviewed of whom 26 also completed diaries. All participants who ate out sometimes, and were allergic or intolerant to, and seeking to avoid, one of the 14 allergens covered by the legislation were eligible for inclusion. Participants seeking only to avoid allergens outside the 14 were not included.

The interview schedule both pre and post legislation encouraged reflection on current practice and preferences with regard to purchasing and consuming non-prepacked food as well as understanding preferences for, and trust in, information sources and channels. Pre legislation hopes and expectations of the legislation were explored in the pre legislation interviews. Post legislation participants were asked to reflect on their perceptions of the legislation.

Both pre and post legislation participants were invited to keep a diary relating to their eating out observations in order to complement the more decontextualised reflections of the interview with comments on particular instances of seeking or encountering allergen information in eating out environments and when purchasing non-prepacked foods for home consumption. Participants had the choice of completing a paper diary or providing written observations electronically and/or as an audio diary. Participants were also encouraged to submit photos as part of their diary, including photos of the venue; signs or menus including allergen information; the meal itself; or any other information that participants deemed relevant.

The data from both the interviews and the diaries were analysed using framework analysis.

Results

Insights from the pre and post legislation research are integrated and presented in 5 main sections. First, strategies for venue and food selection that are independent of information provided about food that is either written down or delivered by staff. Second, written information provided by eating out venues; this is mainly about menus but includes insights about written information online, symbols, separate menus catering for different allergies, and about the increasingly common signs that invite consumers to speak to staff if they have requirements related to allergens. The third section is about information from staff and outlines the range of signals that consumers attend to in seeking to discern the trustworthiness of staff as well as characterising the ways in which consumers value information provision by staff. Next, the fourth section deals with views about the legislation and its impact. Finally, the fifth section considers differences between groups – with a particular focus on how the post legislation period has seen an accentuation of differences between those that are seeking to avoid particular allergens.

Strategies for venue and food selection

Participants used heuristics ('rules of thumb') for assessing risk in selecting venues and dishes that were often independent from any information that was provided. When selecting eating out venues, participants consistently emphasised their preference for familiar and regularly attended eating establishments. The preference for familiar venues was largely based on levels of trust and confidence gained over repeated visits with no associated side-effects. Cues provided by one environment were transferred to another and thus the standardisation afforded by retail chains in the context of unfamiliar places was valued. In the absence of familiarity, other cues are used to assess risk and to maximise the likelihood of a safe and enjoyable eating experience. Indicators that the food was fresh, that the place was clean and hygienic, where there was the possibility of constructing a meal from simple basic ingredients all served to increase the possibilities for confident eating out. Conversely, complex meals, unclear food processing practices in pre-prepared dishes led to the venue being less positively regarded. Indicators of institutional care and vigilance were well regarded though the bottom line was often that eating out was a risky affair. Ultimately, participants were accustomed to weighing the balance of risk, and the requirements of vigilance (taking care) and compromise (playing it safe) in their eating out selections.

The menu as an information resource

Overall, both pre and post legislation, participants tended to prefer to access information about allergens through written information. Within this, participants used the menu as their primary source of written information although other written resources were also accessed. Participants emphasised the merits of written information and menus were scrutinised frequently to access information online, in window displays, and at the table prior to food ordering. Post legislation, participants made more extensive use of information and menus available online. In situ, menus containing symbol/abbreviation-based warning systems were the preferred source of allergen information and participants advocated that these be delivered in a 'universal' format to simplify understanding. The need for greater detail in menus was emphasised as a means of maximising consumer choice and trust. Separate menus containing dishes that are free from specific allergens were appreciated by some; though these were not available for the majority of allergens. Some participants reported being provided with a detailed master list of ingredients/allergens by staff which took many forms. Although this provided some reassurance, some were concerned that such sources were being used as an alternative to the menu. These information resources were considered useful as supplementary once an initial selection had been made. Depending on their size and complexity, it was felt that the guidance of staff in negotiating them might be helpful. Signs inviting customers to

make staff aware of food allergies and intolerances were widespread and were appreciated by some as evidence of increased allergen awareness despite their poor placement on occasion. Others were negative and sceptical about these invitations to 'ask staff about the allergen content of foods', seeing them as locating more responsibility with the consumer and lessening the responsibly of the venue.

Staff as information sources

In familiar venues, participants valued the reliability of established relationships with staff and the levels of knowledge and care associated with 'safe' eating out environments. Where these relationships were not yet established, there were a range of signals from staff that were used to infer trustworthiness. Evidence of being recognised and of their allergy/intolerance being understood, of staff knowledge and awareness when contacted ahead of time as well as within the venue at the time of eating, of proactive, engaged staff who dealt with difficulties in a positive manner and communicated well, and who were willing to adapt dishes, were all interpreted as being likely to mean that the venue would provide a safe and enjoyable eating out experience.

Fundamentally, although participants appreciated the need to ask questions of staff, and valued these social interactions when helpful, for many, the mere act of asking carried with it an inherent risk of being seen as 'making a fuss', and the additional potential for misinformation and mistakes. Where information was judged to be satisfactory, participants' feelings of 'drawing attention' and being seen as 'different' were reduced, and their levels of control and freedom in their food choices enhanced.

Post legislation, participants felt that there was greater awareness of the needs of FA/FI customers. This normalised the eating out experience of participants to some degree and made them feel more included, particularly where staff were seen to be proactive in volunteering information or accommodating customer's needs. Overall, although post legislation, participants continued to express a preference for written information as the baseline expectation, for many, greater staff awareness, coupled with the 'permission' to ask questions afforded by the legislation, made participants more willing to engage with, and trust staff as an information resource.

The legislation and its impact on food allergic / intolerant consumers

Pre legislation, participants were generally positive about any legislation which would be likely to enhance information provision and reduce risk when eating out. In principle, participants believed that the legislation would 'normalise' their food allergy / intolerance conditions. This in turn would result in greater freedom to try new venues and foods. Participants also believed that the legislation would empower them to seek information, and to expect constructive and knowledgeable responses from staff in return. However, the fact that issues of allergen cross-contamination, food preparation and ingredient substitution were not covered in the legislation was a cause for concern which had the potential to restrict some participants' new-found freedoms. Overwhelmingly, participants believed that delivery of the legislation should be conveyed in written form, and preferably on the menu, in order to maximise levels of consumer control and independence in selecting their food choices.

The greater allergen awareness exhibited by food providers and staff post legislation, had improved many FA/FI customers' eating out experiences. For many, this was also translated into greater freedom and choice when eating out although this depended on the allergen which participants avoided. In the absence of adaptation of meals or provision of alternative ingredients, more information did not necessarily equate to greater choice for participants. The risk of allergen cross-contamination limited choices and was still a cause for concern for many. In line with pre legislation findings, participants preferred allergen information to be delivered in written form or using recognised symbols although greater awareness on the part of staff made participants more amenable to the potential for their input in order to ensure a safe eating out experience.

Similarities and differences between groups

Analysis of the pre legislation interviews revealed few differences between participant groups in relation to the core themes of information seeking and preferences, use of information resources, and views regarding the new legislation. However, there were some minor differences; parents emphasised the need to spare their child disappointment when eating out; through taking a 'taste test' certain allergic participants identified some reliance on an early warning reaction which alerted them to unsafe foods. Sometimes there was a perceived under-representation of information resources for those with particular allergies/intolerances which created distance between the experience of their own allergy or intolerance and how they perceived the experiences of others. For example milk allergic/intolerant participants perceived an improvement in awareness, choice, or improvement relating to the eating out experiences of others compared to them. Coeliac and gluten intolerant participants observed that although a fashion for 'gluten free' diets had provided them with greater choice, there was also a risk that their gluten avoidance was seen as a 'fad' and not taken as seriously as it merited

Phase 03: Information seeking practices and information provision preferences: A quantitative approach

The quantitative work addressed several aims, most of which sought to establish if there was any evidence for impact of the FIR. Specifically the aims were to characterise:

1. Eating out behaviours and any changes in these evident in the pre to post legislation period.

2. Preferences in respect of current eating out practices and any changes in the pre to post legislation period.

3. Satisfaction with, and confidence in, information provision about allergens and whether this changed in the pre to post legislation period.

4. Preferences for information provision and any changes in these in the pre to post legislation period.

5. Quality of life and any changes in quality of life between pre and post legislation.

Participants in the online survey were aged 18-65 years who ate out of the home and reported a food allergy or food intolerance or cared for a child with a food allergy or food intolerance to one of the 14 allergens.

874 participants took part in the pre legislation survey. Eighty six percent (751) of whom were female, with an even spread of age. 518 (59%) were adults and 356 (41%) were parents. Six hundred and one (69%) respondents reported symptoms of food allergy (FA), and 273 (31%) symptoms of food intolerance (FI). FA participants were most likely to avoid peanuts (378; 63%) or tree nuts (353; 59%) whilst FI participants were most likely to avoid cereals containing gluten (192; 70%) or milk (110; 40%).

In the post legislation survey, 188 participants took part who had also taken part in the pre legislation survey – we will refer to these as the 'returners'. One hundred and sixty one (86%) were female, with an even spread of age. One hundred and eight (58%) were adults and 80 (42%) were parents. One hundred and twenty nine (69%) respondents reported symptoms of food allergy (FA), and 59 (31%) symptoms of food intolerance (FI). FA participants were most likely to avoid peanuts (86; 67%) or tree nuts (82; 64%) whilst FI participants were most likely to avoid cereals containing gluten (33; 56%) or milk (25; 42%).

Additionally, 204 new participants were recruited to take part in the post legislation survey. One hundred and seventy six (86%) were female, with an even spread of age. One hundred and four (51%)

were adults and 100 (49%) were parents. One hundred and seventeen (57%) respondents reported symptoms of food allergy (FA), and 87 (43%) symptoms of food intolerance (FI). FA participants were most likely to avoid peanuts (41; 47%) or tree nuts (42; 36%) whilst FI participants were most likely to avoid milk (42; 48%) or cereals containing gluten (41; 47%).

Participants were asked about how positive they felt about eating out, how adventurous they were in eating out; their preparation for eating out; how much they relied on speaking to staff when eating out; their satisfaction with written and with verbal information; their preferences for information from staff and from menus; preferences for using symbols and ingredients lists on the menu. Measures of Health Related Quality of Life relating to food allergy and food intolerance were also included.

As well as socio-demographic variables, various indicators of allergic status were collected including allergen induced symptoms, time since diagnosis, source of diagnosis, speed of reaction onset, and severity of reaction.

Mixed analyses of variance were conducted in order to explore whether there had been any changes in each of these eating out factors and in HRQL over time. Change over time was assessed by comparing differences in pre versus post legislation responses, and the impact of other key variables (for example: adult/child age, time since diagnosis) were considered between groups.

We also explored the possibility of differences between those that were avoiding different allergens.

Results^{2 3 4}

There were no significant differences in the characteristics of participants who returned to complete the post legislation survey and those who did not return after the pre legislation survey. There were a few small differences between those who returned to the post legislation survey and the new participants. Therefore these (and other) factors were accounted for in subsequent analyses of 'returning' participants to check if they explained any differences found.

Looking across all eating out venues, there was no change in the mean frequency of participants' eating out behaviours between pre and post legislation (Pre M= 1.10, SD= .60; Post M= 1.14, SD= .62 p> .05).

Both pre and post legislation, 'Adults' reported eating out more frequently (Pre/Post M= 1.26) than 'parents' (Pre/Post M= 0.92).

There was evidence of changes over time (Pre to Post) which indicated greater positivity in information seeking behaviours and preferences. There were significant increases in 'Confidence in asking staff', 'Adequacy of menu information', 'Staff as a resource for confident food choices', and 'Adventurousness'. For parents, there was evidence of improvement in ratings of the 'Menu as a resource for confident food choices'. The effect sizes are small, however, the small but significant results are consistent across the factors and in the same direction.

- > There was a significant increase in 'confidence in asking staff' between the pre legislation and post legislation surveys (Pre M= 3.32, Post M= 4.00, p= .006, η_p^2 = .06).
- > There was a small but significant difference with more positive views about staff as a resource for confident food choices (Pre M= 3.31, Post M= 3.51, p= .014, η_p^2 = .05) post legislation

² M= Mean participant score

³ p= significance level (ps<.05 indicate significant differences between groups)

 $^{^4}$ Effect sizes $(\eta_p{}^2)$ are reported. Effect sizes of .2 are small, .5 are moderate and .8 are large.

- > There was no overall significant difference between participant ratings pre and post legislation. For participants reporting avoidance of more than two allergens, there was a significant increase in 'Planning' between Pre (M= 3.37) and Post (M= 3.55) (p= .013, η_p^2 = .051).
- > Parents were more satisfied post legislation that menus enabled confident food choices (Pre M= 2.68, Post M= 2.99) (p = .023; η_p^2 = .043).
- > Participants post legislation had slightly softened their views about the inadequacy of menu information they felt it was more adequate then than they did pre legislation (Pre M = 1.51, Post M= 1.74, p= .013, η_p^2 = .05).
- > There was a small but significant increase in adventurousness in participant eating out practices between pre and post legislation (Pre M= 1.35, Post M= 1.53, p =.004, η_p^2 = .07) though it is important to note that the overall level remains very low between 1 and 2 on a 7 point scale ranging from 0 to 6.

Both pre and post legislation, participants were asked to indicate which information sources they thought were the three most reliable sources to help make decisions about food choices. They were also asked to select the one source they considered least reliable.

- A conversation with the chef remains the source selected in the top 3 most reliable sources both pre and post legislation though there is a drop of 10% in participants awarding this reliability rating post legislation
- The reverse picture is shown in selection of the website menu listing all ingredients this too was rated a highly reliable source by over half of the participants both before and after the legislation. However, there is an increase of almost 10% post legislation.
- In line with this, there was also a rise in participants' reliability ratings for the printed menu in the post legislation survey – around 13% more people rated it as a top source of reliable information.
- Conversations with the manager are no longer a top 3 reliable source post legislation though this decrease is small. In line with the general picture that written information is considered more reliable than personal communication with staff, conversations with serving staff were considered in the top 2 most unreliable sources both pre and post legislation with an increase in people taking this view post legislation.
- It is notable that the least reliable source continues to be the blackboard menu. Whether the temporary nature of 'blackboard' information or the potential for limitations in the detail provided, might have motivated participants to judge this resource as particularly unreliable is unclear.

There were no significant improvements in the Health Related Quality of Life measures post legislation. Adults and parents both showed a decrease in scores, indicating an improvement in quality of life, but the changes are not statistically significant.

Based on the findings of the qualitative work, we hypothesised that there would be differences in perceptions of information provision between those seeking to avoid different key allergen groups ('Cereals containing gluten', 'Nuts' [peanuts and tree nuts⁵], and 'Milk') pre and post legislation. There were no differences between allergen groups pre legislation but there were significant post legislation differences on several measures.

⁵ 'Peanuts' and 'Tree nuts' were combined in a single 'Nuts' category for the purposes of 'key allergen groups' comparisons only

- Participants avoiding nuts (M= 3.79) had a greater reliance on speaking to staff than those avoiding gluten (M= 3.26, p= .019) and those avoiding milk (M= 3.15, p= .003).
- Participants avoiding nuts (M= 3.93, p= .007) and those avoiding gluten (M= 4.11, p= .001) both considered allergen menus to have greater potential as a source of information than those avoiding milk (M= 3.49).
- Those avoiding nuts (M= 4.67) were more positive about statements on the menu inviting customers with allergies and intolerances to ask about dishes than those avoiding milk (M= 4.33, p= .016).
- Post hoc analysis bordered on significant (p= .056) suggesting that those avoiding nuts (M= 4.60) were more positive about the sign inviting customers with allergies and intolerances to ask about dishes than are those avoiding milk (M= 4.29).

Phase 04: Dissemination and knowledge exchange

As part of the dissemination strategy for the project and in order to consolidate a robust set of recommendations, at the end of both Phases 1 and 2, workshops were held with a range of key stakeholders from local authorities, food businesses, support groups and representatives from industry bodies. These events provided an opportunity to refine the implications of the research, in particular exploring whether possible recommendations are considered practicable and how their feasibility might be increased.

Delegates provided valuable input structured around presentations of project findings. A range of useful reflections and observations were made in discussion. An evaluation was conducted at both events and indicated that the workshop and the content of the research were well received by practitioners.

Further project dissemination will take place through peer reviewed publications that are in preparation. One paper from Phase 1 has been published⁶ and two others are under review. Opportunities will be sought for further dissemination and knowledge exchange in order to ensure that the work obtains maximum impact.

Implications and Recommendations

- 1) Written information provided by the venue and increasingly available in multiple locations is generally likely to be trusted it is therefore vital that it is trustworthy.
- 2) A lack of questions and queries about allergens should not be read as a lack of demand for, or interest in, information about allergens. It might also indicate a lack of trust and confidence in the venue or uncertainty about what is best to ask and to whom.
- 3) When customers ask staff questions about allergens, they will take notice of more than the words that are given in reply. Signals about the competence of the venue to cater for their allergy or intolerance will be read from the care, interest and expertise that staff demonstrate. Staff training should take this into account.

⁶ Begen, F. M., et al. (2016). "Consumer Preferences for Written and Oral Information about Allergens When Eating Out." <u>PloS one</u> **11**(5)

- 4) The venue website is a key early source of information about the venue and provides an early opportunity for the venue to demonstrate care, interest and expertise in catering for customers with a food allergy or intolerance.
- 5) Venues should recognise the increasing reliance of many on digital sources of information and ensure that where possible Wi-Fi is available, that details of allergens in particular dishes are on line, and that the website is optimized for mobile devices.
- 6) When eating out, the information seeking journey of customers seeking to avoid allergens ranges from the early online search or phone call through to the scrutiny of ingredients at the table. Strategies for providing both written and verbal information should be designed accordingly.
- 7) Consider how allergen information in the main menu can be comprehensive yet simple and clear. Separate menus relating to different allergens are valued and welcome. Allergen reference sources that provide supplementary information about all the ingredients in a dish are also valued. The availability of these other options should be signaled in the basic menu and staff should be able to engage with customers about the detail of these if required.
- 8) Seek to identify ways in which the venue can actively and visibly signal that staff are attentive to the requirements of those that wish to avoid allergens. It should be made clear that those with a food allergy or intolerance have an invitation to ask questions and that these will be clearly, confidently and correctly answered in a timely manner.
- 9) There is considerable value in proactive information provision relevant to allergens. For example, when the server first goes to a table, as part of the opening dialogue diners might be invited to let the server know if they have particular preferences or requirements around allergens.
- 10) Consumers value the provision of relevant alternatives where suitable meals are not available. Similarly, being able to mix and match simple components of a meal in order to build one's own meal from identified ingredients is also valued.
- 11) Recognise that when returning to a venue in which they have eaten a particular dish before customers often assume that the meal ingredients are the same. They may assume this similarity too when eating in different branches of the same chain. Chains of venues need to bear this in mind either in terms of ensuring consistency or signaling to customers that consistency cannot be guaranteed.
- 12) Customers wanted to see consistency in universal symbols for the presence or absence of allergens in menus or other information sources in the UK and across Europe. Clarity and consistency was also required in whether the symbol indicates the presence or absence of the allergen.
- 13) There are risks to the credibility of those responsible for enacting the legislation and potential for a growth in scepticism or cynicism on the part of those with food allergy or intolerance if information provision about allergens is not meaningfully and sustainably implemented.
- 14) Increased menu options particularly for those seeking to avoid cereals containing gluten or nuts are welcome. Increased provision of options for customers with different requirements especially those seeking to avoid milk are required.
- 15) Though not covered by the legislation it is important to recognise ongoing consumer concerns about cross contamination when eating out. Associated may contain statements are generally considered to be unhelpful when seeking to manage a food allergy or intolerance.

THE PREFERENCES OF THOSE WITH FOOD ALLERGIES AND/OR INTOLERANCES WHEN EATING OUT

Introduction

On 13th December 2014, EU legislation was introduced requiring retailers of non-prepacked foodstuffs to provide customers with information relating to the presence of 14 allergens (peanuts, tree nuts, milk, soya, mustard, lupin, eggs, fish, molluscs, crustaceans, cereals containing gluten, sesame seeds, celery and sulphur dioxide (at levels above 10mg/kg, or 10 mg/litre) when used as ingredients in their products. The legislation is applicable across the UK and will impact on information provision in restaurants, take-outs, and other food outlets. Everyone avoiding foods containing any of the 14 listed allergens is, in principle, affected by the EU FIC.

'Non-prepacked foods' refers to foods that are sold loose. This occurs in both retail and catering environments. For example in supermarkets, goods sold loose from a delicatessen or the in-store bakery would fall into this category. Meals served in a restaurant or a takeaway would also come into this category. Although not defined in legislation, 'non-prepacked foods' includes food prepacked for direct sale (i.e. generally foods that have been packed on the same premises where they are being sold).

This FSA funded project investigates the likely impact of the legislation on food allergic (FA) and food intolerant (FI) adult consumers and on parents of food allergic and intolerant children and adolescents. The results of this study will inform the implementation of the new allergen information requirements under the EU Food Information for Consumers Regulation (No. 1169/2011) (EU FIC). Within the UK this will be enforced by The Food Information Regulations 2014 (FIR).

EU member states have discretion as to the means through which allergen information is made available – for example this could be orally by a member of staff, using a label, on a menu or a chalk board. It is thus vital that the Food Standards Agency (FSA) and the food industry understands the preferences that food allergic and intolerant individuals have for the provision of trusted information about non-prepacked foods, the role that different information sources have in allowing FA and FI individuals to assess risk, and to make informed choices about where they eat and what they eat. Over two years have now passed since the FIR became law and thus it is also important that the FSA are aware of any changes over this time in people's experiences of eating out and in the ease, confidence and satisfaction with which people can make choices about what food to eat and where. It is also important to understand whether there have been any changes in the quality of life of food allergic and intolerant individuals.

In line with this, the FSA funded a project to investigate the impact of the legislation on FA and FI adult consumers and on parents and caregivers of FA and FI children and adolescents under 18 years of age. The project had two parts; Part A was conducted between February 2014 and February 2015; data collection was completed prior to the implementation of the legislation in December 2014. The second stage of the project - Part B – was conducted in 2016 with the principal aim of assessing changes in the views and self-reported eating out practices of FA and FI consumers. This report presents the results of the completed project which covers both Part A and Part B⁷.

The results of this project are relevant to the review of the implementation and resources provided for the allergen information requirements under the EUFIC. Findings can guide how food businesses

⁷ The standalone Part A report produced in March 2015 is available as a separate document

provide allergen information to consumers; to improve their satisfaction with, and confidence in the information that they are provided with.

Reactions to allergens

Adverse reactions describe any unpleasant consequences following ingestion of a food, e.g. food poisoning and food aversions. Food hypersensitivities are reproducible reactions. If the reaction has an underlying immunological cause it is termed allergy⁸. Allergies can be further divided into IgE mediated and non-IgE mediated allergy although there can be some mixed presentations. Accurate characterisation of non-immune food intolerance is difficult, even in specialist NHS services, because of a lack of biomarkers. IgE mediated reactions usually occur rapidly following allergen exposure. Symptoms can range from mild/ moderate (e.g. urticarial rash, mild angioedema, rhinitis, diarrhoea and vomiting), to life threatening (bronchoconstriction, laryngeal oedema, cardiovascular collapse). The responsible allergen can usually be identified by measuring specific IgE levels in blood or by skin prick tests.

Non-IgE mediated allergy is less well defined and is more difficult to diagnose because there are no non-invasive biomarkers. Recognised symptoms are usually confined to the skin or gut, and usually occur some hours following ingestion of the food. Symptoms can range from mild/ moderate (colic, reflux, bloating, constipation) to severe (severe persistent vomiting or diarrhoea, significant blood in stool, faltering growth). Food protein-induced enterocolitis syndrome (FPIES) is an example of non-IgE mediated allergy whilst atopic dermatitis includes features of IgE mediated and non-IgE mediated allergy.

The underlying mechanisms for food intolerance are poorly understood with the exception of enzyme deficiencies, most commonly lactose intolerance. Many patients labelled as intolerant to a food are likely to have immune-mediated disease which cannot be diagnosed by non-invasive tests. Coeliac disease is an autoimmune condition triggered by an abnormal response to gluten. Coeliac disease has a clear diagnostic pathway and can be referred to as having an intolerance to gluten (food intolerance).

It is likely that individuals will behave differently depending on the implications of eating the food allergen, for example, the consequences for an individual at immediate risk of anaphylaxis are different than for an individual who develops painful abdominal bloating some hours later. The impact of FA and FI can extend beyond the physical to the social, emotional and financial⁹. As such, Health Related Quality of Life (HRQL) has been argued to be the most meaningful outcome measure available for individuals with reactions to food¹⁰.

The challenges of eating out and avoiding allergens

Avoidance of the trigger food(s) is the cornerstone in the management of FA and FI and accurate information regarding allergen content is therefore critical¹¹. Communication regarding allergen information that is available, clear and trustworthy is imperative for those with FA and FI¹². Consumer confusion and uncertainty with regards to the presence of allergen may have a negative impact on HRQL, which may be further compounded by a lack of awareness and understand

⁸ Johansson, S., Bieber, T., Dahl, R., Friedmann, P. S., Lanier, B. Q., Lockey, R. F., . . . Ring, J. (2004). Revised nomenclature for allergy for global use: Report of the Nomenclature Review Committee of the World Allergy Organization, October 2003. *Journal of Allergy and Clinical Immunology*, *113*(5), 832-836. doi:10.1016/j.jaci.2003.12.591

⁹ de Silva, D., Geromi, M., Halken, S., Host, A., Panesar, S., Muraro, A., . . . Cardona, V. (2014). Primary prevention of food allergy in children and adults: systematic review. *Allergy*, *69*(5), 581-589. doi:10.1111/all.12334

¹⁰ Flokstra-de Blok, B., & Dubois, A. (2012). Quality of life measures for food allergy. *Clinical and Experimental Allergy*, 42(7), 1014-1020. doi:10.1111/j.1365-2222.2011.03927.x

 ¹¹ DunnGalvin, A., Chan, C. H., Crevel, R., Grimshaw, K., Poms, R., Schnadt, S., . . . Austin, M. (2015). Precautionary allergen labelling: perspectives from key stakeholder groups. *Allergy*, *70*(9), 1039-1051. doi:10.1111/all.12614
 ¹² Barnett, J., Vasileiou, K., Gowland, M. H., Raats, M. M., & Lucas, J. S. (2013). Beyond labelling: What strategies do nut allergic individuals

¹² Barnett, J., Vasileiou, K., Gowland, M. H., Raats, M. M., & Lucas, J. S. (2013). Beyond labelling: What strategies do nut allergic individuals employ to make food choices? A qualitative study. *PloSOne*, *8*(1), e55293. doi:10.1371/journal.pone.0055293

ding on the part of staff serving in shops, restaurants, coffee shops, cinemas, and the general public.

For both food allergic and, to a lesser degree, food intolerant individuals, the challenges presented when eating out or ordering takeaway foods are well-recognised. Choices in eating out environments were explored as part of a previous FSA project focusing on nut allergy¹³. One key finding was that nut allergic individuals avoided particular types of establishments, dishes or courses. Leftwich et al.¹⁴ also noted the variability in whether consumers chose to address guestions to restaurant staff: some were confident to do so whereas others preferred to either avoid food or to take a risk than to ask questions. Two later papers also addressed the challenges of eating out and recommended management techniques in order to minimise potential allergen exposure within these settings. A systematic review of 24 studies¹⁵ observed that 21-31% of accidental allergen exposure and reactions occurred in restaurants, and 13-23% occurred in school or work settings. Food allergic individuals were found to be unduly restricted in their eating out behaviours as a result of the potential for accidental allergen exposure. A paper intended to provide guidance on the management of childhood anaphylaxis, highlighted the need for clarity and consistency in allergen information provision, given that peer pressure, embarrassment, stigma, alcohol consumption, choice, and spontaneity, can all be factors which lead parents and adolescents to make risky venue or food selections¹⁶. Four separate studies illustrated the difficulties encountered, and precautionary behaviours adopted, by food allergic and intolerant individuals. One study, using food diaries, reported that 66% of the population experienced problems finding suitable foods when eating outside the home¹⁷. This led to participants having to take risks by eating food that may contain allergens (57%), or having to go hungry/not eat because no safe food was available (46%). For young people, problems eating within a school setting, and eating out/buying snacks when out with friends, presented social as well as health challenges¹⁸. For parents of food allergic children¹⁹ and adult coeliacs²⁰, planning ahead and constant vigilance were key to minimising the risk of accidental allergen exposure when eating out or travelling away from home.

Eating out venues present an increased risk of allergens being consumed; food allergic and intolerant consumers experience stress and uncertainty, and indeed, may feel unable to make safe food choices. Moreover, as there is discretion around how allergen information is made available in such situations, it is important that this is informed by the preferences of allergic and intolerant consumers. This research thus first seeks to develop an understanding of the choices and behaviours of individuals with food allergies or intolerances when purchasing and consuming non-prepacked foods. Secondly, it will identify any changes between their conduct in the first phase of the research immediately before the FIR regulations were introduced and the second phase 18 months later.

This research and the knowledge exchange processes within which the research is embedded has been designed to inform the development of clear advice, guidance and tools for both consumers and Food Business Operators (FBOs) regarding the 14 allergens covered by the FIR. In so doing, it may also

¹³ Barnett, J. et al (2011) Understanding the food choice reasoning of nut allergic consumers. Final technical report. Retrieved from <u>http://www.food.gov.uk/science/research/allergy-research/t07058</u>

 ¹⁴ Leftwich, J., Barnett, J., Muncer, K., Shepherd, R., Raats, M. M., Gowland, M. H., & Lucas, J. S. (2011). The challenges for nut-allergic consumers of eating out. *Clinical and Experimental Allergy*, *41*(2), 243-249. doi:10.1111/j.1365-2222.2010.03649.x
 ¹⁵ Versluis, A., Knulst, A. C., Kruizinga, A. G., Michelsen, A., Houben, G. F., Baumert, J. L., & Os-Medendorp, H. (2014). Frequency, severity

¹⁵ Versluis, A., Knulst, A. C., Kruizinga, A. G., Michelsen, A., Houben, G. F., Baumert, J. L., & Os-Medendorp, H. (2014). Frequency, severity and causes of unexpected allergic reactions to food: a systematic literature review. *Clinical and Experimental Allergy, 45*, 347-367. doi:10.1111/cea.12328

¹⁶ Muraro, A., Agache, I., Clark, A., Sheikh, A., Roberts, G., Akdis, C. A., . . . Wickman, M. (2014). EAACI Food Allergy and Anaphylaxis Guidelines: managing patients with food allergy in the community. *Allergy, 69*(8), 1046-1057. doi:10.1111/all.12441

¹⁷ Peniamina, R. L., Mirosa, M., Bremer, P., & Conner, T. S. (2016). The stress of food allergy issues in daily life. *Psychology & Health, 31*(6), 750-767. doi:10.1080/08870446.2016.1143945

¹⁸ Stjerna, M. L. (2015). Food, risk and place: agency and negotiations of young people with food allergy. *Sociology of Health and Illness,* 37(2), 284-297. doi:10.1111/1467-9566.12215

¹⁹ Stjerna, M. L., Vetander, M., Wickman, M., & Lauritzen, S. O. (2014). The management of situated risk: A parental perspective on child food allergy. *Health:, 18*(2), 130-145. doi:10.1177/1363459313481234

²⁰ Bacigalupe, G., & Plocha, A. (2015). Celiac is a social disease: Family challenges and strategies. *Families, Systems, & Health, 33*(1), 46-54. doi:10.1037/fsh0000099

improve the quality of allergen information provision for those avoiding these foods. Indeed, hopefully this work will facilitate the provision of a greater range of foods from which food allergic and intolerant consumers can make safe and confident choices.

Research Aims

The project had four main research aims which were addressed in both Part A (pre legislation) and Part B (post legislation):

- To conduct a rapid evidence assessment to assist with defining the structure and content of the qualitative and quantitative work in particular to inform decisions about inclusion criteria for participants for this work and how to recruit them.
- To understand the preferences for information provision that food allergic and intolerant consumers have relating to the 14 allergenic ingredients when buying and eating foods that are non-prepacked, and to examine how these preferences have changed since implementation of the FIR.
- To identify if there have been any changes in the quality of life for food allergic and intolerant consumers since the implementation of FIR and, if there are, to assess if any changes are attributable to changed information seeking practices and preferences.
- To review project findings and to derive implications for practice, communication and information provision.

Both Part A (pre legislation) and Part B (post legislation) had four corresponding phases:

- Phase 01: To characterise developments in the peer reviewed and grey literature regarding the purchase and consumption of non-prepacked food by food allergic and food intolerant individuals
- Phase 02: In depth qualitative research consisting of interviews and diaries with food allergic and intolerant individuals from across the UK to explore their information seeking practices and preferences around non-prepacked foods and how these changed, if at all, over the pre to post legislation period.
- Phase 03: A questionnaire survey to quantitatively characterise any changes over the pre and post legislation period in preferences for information provision and in quality of life. Returning participants were supplemented with new participants in the Part B survey and additional questions about the role of support groups and social media in providing support around eating out practices were addressed.
- Phase 04: Conducting workshops to understand the views of key stakeholders around the ongoing implementation of the FIR

In this report we will describe each of these phases in turn bringing together the findings from Part A (pre legislation) and Part B (post legislation). Following a discussion of the results the final section will outline the implications and recommendations of the research.

Phase 01: Rapid Evidence Assessment

In Part A the scoping phase focused on preparing a clear rationale for the approach to be taken in the quantitative and qualitative phases. Part of this related to (a) the criteria for designating participants as food allergic or intolerant, (b) identifying the best method for recruiting participants and (c) measurement of quality of life for those with food intolerance. We will report the outcomes of this

work along with the qualitative work of Phase 02 and the quantitative work of Phase 03. The main aspect of the scoping work was to conduct a rapid evidence assessment in order to ascertain what was already known about the eating out behaviours and information preferences of food allergic and intolerant consumers, and more broadly, to situate this in the context of eating out behaviours of non -intolerant/allergic consumers.

A rapid evidence assessment was conducted in order to identify literature relating to consumer preferences and practices when eating out. This relates to *where* to eat and *what* to eat. It also sought to identify evidence relating to information-seeking behaviour(s) of consumers when eating out as well as around preferences for, and use of, different types of information provided about allergens.

In the pre legislation work, a total of 315 articles were identified through structured searches of online databases²¹ and a further 100 articles retrieved from other sources, including references and citations. Abstracts of all articles were screened for inclusion and 63 selected for inclusion in the assessment²². In the post legislation work, a further 165 new articles were identified through searches or retrieved from other sources, including reference lists. Abstracts of all articles were again screened for inclusion²³ and 24 selected for assessment.

The overall conclusion of the RER was that the vast majority of studies address the choices available to, and made by, the non-allergic consumer with very limited evidence for food allergic and intolerant consumers. It is clear from the limited studies to date, that for food allergic and intolerant individuals, their condition is often the primary driving force in food and venue choice.

Issues explored in the review that are relevant to the subsequent empirical work are as follows:

Classification of venues

As part of the focus of Phases 02 and 03 is on understanding preferences for, and practices within, particular venues, it is important to understand whether there are established classification systems that could be used in order to refer to venues.

A number of the studies were conducted in a single type of food venue e.g. fast-food outlet, finedining restaurant, with others including a range of venues. The terminology used to describe the different sectors varied, particularly between the US-based studies and other countries. Classification of outlets is sometimes related to the type of service e.g. fast-food, takeaway, but in other instances may refer to a particular type of cuisine e.g. Asian. Olsen et al.²⁴ highlight the difficulties of classifying venue types based on market research which use the hybrid criteria of cuisine, function and sector. Cousins et al.²⁵ suggests classifying venues based on the nature of the customer demand being met rather than the operation.

²¹ Overarching terms, used in all searches: {Eat* out} or {Din* out} or {Restaurant} AND {food service}, {choice} or {selection} or {preference}, {attitude} or {perception}, {consumer} or {customer}, {food allerg*} or {food intoleran*} or {food sensitiv*} or {coeliac} or {celiac}, {information} or {labelling} or {intervention*}, {non-prepacked food} or {non pre-packed food} or {non prepacked food}

²² Studies were included if they met the following criteria: written in English, involved consumers paying for food at the point of purchase in a catering outlet, related to venue choice, food choice, service experience, related to the provision of or use of information in the context of eating out, related to the impact of food allergy or intolerance within the eating out context. Studies were excluded if they did not report outcomes relevant to the aim of the RER.

²³ A number of articles reported (primarily US-based) studies relating to the provision and impact of menu-based information relating to the calorific, energy, or sodium content of non-prepacked foods. Although these articles met criteria for inclusion, their relevance to the RER was limited. The majority of these articles were excluded with the exception of those pertaining to the impact of information delivery formats.

²⁴ Olsen, W. K., Warde, A., & Martens, L. (2000). Social differentiation and the market for eating out in the UK. *International Journal of Hospitality Management*, *19*(2), 173-190. doi:10.1016/S0278-4319(00)00015-3

²⁵ Cousins, J., Foskett, D., & Gillespie, C. (2002). Food and beverage management. Harlow, UK: Pearson Education.

The approach chosen in the current research was to base the classification of venues in the survey work on those most frequently visited in recent market research²⁶ which is based on all consumers – not just those with a food intolerance or allergy.

Factors affecting venue choice

Few studies were identified which specifically addressed the issue of venue choice for food allergic/intolerant consumers. In a study with nut allergic participants, Leftwich et al.²⁷ note that one strategy to manage the risk of allergic reactions when eating outside the home was avoidance of eating out. Some participants at least avoided particular types of cuisines and venues (e.g. Indian, Chinese and Thai restaurants or takeaways). Seeking familiar places to eat was a key strategy that enabled those with nut allergies to reduce uncertainty and anxiety. More generally, going to restaurants was highlighted as a major concern for young people with allergies²⁸ and spontaneity in restaurant choice was impossible according to participants in a Swedish study of patients with coeliac disease²⁹. In a study on the impact of a gluten-free diet on Canadian adults with coeliac disease, 79% of respondents reported avoiding restaurants³⁰, whilst in a Brazilian study, eating out was reported as one of the major concerns for patients with coeliac disease³¹.

Factors influencing the choice of venue for non-allergic/non-intolerant consumers included price, type of food and familiarity/trust, type of food, recommendation by family/friends and type of atmosphere. Other factors included convenience of location, price promotion, branded chain, use of ethical food, recommendation by food critics, service delivery, cleanliness and food safety.

In terms of implications for the current research it was evident that there is a paucity of evidence in this area. There was evidence of concern about eating out but this was not differentiated by venue types. Work with non-allergic/intolerant consumers suggests that it is also important to recognise the range of factors other than reactions to allergens that are likely to play a role in shaping the venue choices of those with food allergy or intolerance.

Little additional information was available about venue choice for those with a food allergy or intolerance although in wave 3 of the FSA Food & You (England) interview survey (Dec 2014)³² 10% of respondents identified availability of 'food for restricted diets' as an important factor when selecting a venue to eat out. Of course diets may be restricted for many reasons other than allergy or intolerance.

Factors affecting food choice

In 2012, Sommer et al.³³ reported the factors influencing food choices of food-allergic/intolerant consumers in the UK through focus groups with adults who were diagnosed food allergic (DFA), self-reported food allergic or intolerant (SFA) and non-food allergic (NFA). Compared to NFA participants, DFA consumers reported less satisfaction and pleasure from foods, experienced difficulties finding safe foods and felt they needed to be very organised when eating out. SFA participants faced similar

²⁶ Mintel (2013) *Eating Out Review – UK – June 2013*. London, UK: Mintel.

²⁷ Leftwich et al. (2011) *Op cit*

²⁸ Worth, A., Regent, L., Levy, M., Ledford, C., East, M., & Sheikh, A. (2013). Living with severe allergy: an Anaphylaxis Campaign national survey of young people. *Clinical and Translational Allergy*, *3*(1), 2. doi:10.1186/2045-7022-3-2

²⁹ Sverker, A., Hensing, G., & Hallert, C. (2005). 'Controlled by food'– lived experiences of coeliac disease. *Journal of Human Nutrition and Dietetics*, *18*(3), 171-180. doi:10.1111/j.1365-277X.2005.00591.x

³⁰ Zarkadas, M., Cranney, A., Case, S., Molloy, M., Switzer, C., Graham, I. D., . . . Burrows, V. (2006). The impact of a gluten-free diet on adults with coeliac disease: results of a national survey. *Journal of Human Nutrition and Dietetics, 19*(1), 41-49. doi:10.1111/j.1365-277X.2006.00659.x

³¹ Araújo, H. M., & Araújo, W. M. (2012). Coeliac disease: eating habits and quality of life. *British Food Journal, 114*(9), 1297-1309. doi:doi:10.1108/00070701211258835

³² FSA: The 2014 Food and You survey. England Bulletin 3- 'Eating outside the home' (2014). Retrieved from

http://www.food.gov.uk/sites/default/files/england-bulletin-3-food-and-you-2014_0.pdf. Accessed 22 March 2017

³³ Sommer, I., Mackenzie, H., Venter, C., & Dean, T. (2012). Factors influencing food choices of food-allergic consumers: findings from focus groups. *Allergy*, *67*(10), 1319-1322. doi:10.1111/j.1398-9995.2012.02883.x

problems but to a lesser degree and their food choices were strongly influenced by emotional factors or health awareness. DFA participants perceived their choice of foods in supermarkets to be limited and consistently expressed dissatisfaction with current food labelling practice. In a study with clinically diagnosed nut allergic individuals (most of whom had a moderate or severe allergy) food choice practices related to three themes - product qualities, past experience and sensory appreciation³⁴. In relation to eating out specifically, in results from the same project, Leftwich et al.³⁵, reported that when eating outside the home, nut allergic participants not only avoided particular venues but also meal courses (e.g. dessert) or particular foods (such as sauces and curries). Relevant to the current study, in making choices about acceptable foods, participants made a judgment as to the likelihood of the dish containing self-evident allergens or hidden allergens. Planning was a key part of eating out for many nut allergic participants and the associated lack of spontaneity was sometimes a source of regret.

In terms of implications for the current research it is clear that there is little systematic or detailed evidence about the factors that affect food choice for those with a food allergy or intolerance. It is clear that food choice for food allergic and intolerant individuals is subject to informal if not explicit risk assessments. More understanding is needed about this alongside a picture of the information that is needed in order to make food choices.

The service encounter

The service encounter is a key part of eating out for all consumers not just those with an allergy – this includes speed of service and the behaviour of employees (such as their attentiveness, promptness of service, friendliness and competence in delivering a service – including the way in which complaints are handled³⁶). Again there is limited evidence but the service encounter seems to have elements of particular significance for those with food allergy. The Leftwich et al. study noted that the need to check whether the food on offer contained the allergen sometimes necessitated extended and public conversations with restaurant staff. This was a source of social embarrassment for some and the desire to avoid this, on occasion, led to increased risk taking. On the other hand, others did not disclose their allergy to restaurant staff as they feared an unnecessarily conservative response that would further constrain food choices.

The greatest concern for coeliac disease (CD) consumers was eating out. In order to ascertain if foods contain gluten, most ask waiters how the dish is made but staff do not usually know what CD is³⁷. Eating out was classed as a dilemma by participants in Sverker's study of coeliac disease and the feelings of shame in social situations can be exacerbated by staff attitudes³⁸. Many participants asked about food content at restaurants but often found staff to be ignorant of hypersensitivity to gluten. Being excluded from social situations involving food was an additional concern associated with following a gluten free diet by respondents in a national survey of members of the Canadian Celiac Association³⁹.

Consistent with prior literature^{40 41}, three studies after 2014 reported a mismatch between staff confidence in their knowledge of food allergens and ability to cope in the event of an allergen related

³⁴ Barnett et al. (2013) *Op cit*

³⁵ Leftwich et al. (2011) *Op cit*

³⁶ Jaafar, S. N., Lumbers, M., & Eves, A. (2008). Eating out: what really matters? *Hospitality Review, 10*(3), 47-54. Retrieved from https://www.cabdirect.org/cabdirect/abstract/20083237924

³⁷ Araujo et al. (2012) *Op cit*

³⁸ Sverker et al. (2005) *Op cit*

³⁹ Zarkadas et al. (2006) *Op cit*

⁴⁰ Bailey, S., Albardiaz, R., Frew, A. J., & Smith, H. (2011). Restaurant staff's knowledge of anaphylaxis and dietary care of people with allergies. *Clinical and Experimental Allergy*, *41*(5), 713-717. doi:10.1111/j.1365-2222.2011.03748.x

⁴¹ Common , L. A., Corrigan, C. J., Smith, H., Bailey, S., Harris, S., & Holloway, J. A. (2013). How safe is your curry? Food allergy awareness of restaurant staff. *Journal of Allergy and Therapy*, 4(4). doi:10.4172/2155-6121.1000140

emergency, and their actual knowledge in practice. In a US study⁴² more rigorous training was called for on the grounds that, although willingness to help was high amongst staff, their knowledge was poor and they had an inappropriately inflated sense of their own efficacy. Another US study⁴³ observed the wide variability in knowledge exhibited by staff. For example, amongst kitchen staff accuracy of knowledge regarding the allergen content of foods, and management of allergic reactions and anaphylaxis, ranged from 55% to 93%. Similarly, in a New Zealand based study reporting restaurant and café managers' knowledge about food allergens⁴⁴, only 13% were able to provide correct answers to all the questions although 93% felt confident that they could provide safe food and 64% were confident that they could manage an allergic reaction. Those with past training were more likely to have plans in place to provide safe food (14.8%), manage an emergency (37.8%) and provide allergy-awareness training for staff (42.9%). Seventy-seven percent of managers expressed an interest in further training for themselves and their staff. In a UK based research study⁴⁵ a small-scale pilot intervention in the form of a 'food allergy training event' developed by a multidisciplinary team showed some improvement in staff knowledge that was sustained over a short period of time. Prior to the intervention, 82% staff were able to answer allergy related questions correctly, 91% were able to answer correctly post-intervention. Furthermore, improvements in practice of front of house and kitchen staff were observed one month later.

Taken together, the importance of the service encounter alongside sub optimal staff knowledge and awareness sets a challenging background for the continued implementation of the legislation and the potentially vital role that consumers might reasonably expect that staff will play in providing information about allergens in food. Certainly the legislation permits the venue to invite those that react to and/or wish to avoid the 14 allergens to speak to staff in order let them know their requirements. It is crucial to understand the perceptions of this interaction more clearly and how requirements for written information relate to this.

Information provision

The provision of information to enable consumer choice is a strong theme in the literature. Information here is defined in the broadest sense including recommendations from family and friends to nutritional and calorie information on menus. There is evidence that consumers desire information about the product (e.g. ingredients), nutrition (e.g. energy) as well as about food preparation. In one FSA report⁴⁶ simple information being provided at the point where decisions are made was valued - menus or menu boards.

Turning to information provision for use by food allergic/intolerant consumers, some of the work here focuses on the information providers.

Results from a report prepared for the FSA⁴⁷ on the provision of allergy information noted considerable variability in how this was provided in respect of different allergens. Restaurants were more likely to provide allergen information while hotels and cafés/sandwich shops were least likely.

 ⁴² Dupuis, R., Meisel, Z., Grande, D., Strupp, E., Kounaves, S., Graves, A., . . . Cannuscio, C. C. (2016). Food allergy management among restaurant workers in a large U.S. city. *Food Control, 63*, 147-157. doi:http://dx.doi.org/10.1016/j.foodcont.2015.11.026
 ⁴³ Prenner, B. M., Hollingsworth, J., Oliver, R., & Brew, L. (2014). Food Allergy Survey Among Food Service Workers. *Journal of Allergy and*

⁴³ Prenner, B. M., Hollingsworth, J., Oliver, R., & Brew, L. (2014). Food Allergy Survey Among Food Service Workers. *Journal of Allergy and Clinical Immunology*, 133(2), AB207-AB207.

⁴⁴ Wham, C. A., & Sharma, K. M. (2014). Knowledge of café and restaurant managers to provide a safe meal to food allergic consumers. *Nutrition and Dietetics*, 71(4), 265-269. doi:10.1111/1747-0080.12104

⁴⁵ Bailey, S., Kindratt, T. B., Smith, H., & Reading, D. (2014). Food allergy training event for restaurant staff; a pilot evaluation. *Clinical and Translational Allergy*, 4(1), 26. doi:10.1186/2045-7022-4-26

⁴⁶ FSA: Consumer response to nutrition information available in catering outlets. Report Food Standards Agency- Online (2009). Retrieved from <a href="http://collections.europarchive.org/tna/20100927130941/http://food.gov.uk/healthiereating/healthycatering/cateringbusiness/consumerresponse150109http://collections.europarchive.org/tna/20100927130941/http://food.gov.uk/healthiereating/healthycatering/cate

⁴⁷ FSA: Baseline study of the Provision of Allergy Information to Consumers for Foods which are not prepacked. Report Food Standards Agency- Online (2013). Retrieved from <u>https://www.food.gov.uk/sites/default/files/research-report-baseline-allergy-foods-sold-loose.pdf</u> Accessed 26 May 2015

Information was provided orally by 20%, both orally and written by 64%, written only by 6% and no information at all by 7%. The reasons given for not providing information included a lack of customer demand, focus on more common allergens and lack of knowledge about food allergens.

Voordouw and colleagues have explored the preferred information strategies for food allergic consumers and optimised delivery formats for information^{48 49} in retail outlets. Clear and unambiguous labelling on product packaging was valued highly. In a study of young people living with food allergies checking food labelling/ingredients and packaging were the main allergy management strategy for this group⁵⁰. A range of other sources of information were used including health professionals, the school nurse, Anaphylaxis Campaign, friends and family. Eating out was identified as one of the principal areas where information was needed.

A Food Standards Agency report⁵¹ on consumer understanding of labelling terms for food marketed for people with gluten intolerance indicated that a wide range of information sources were used to understand which foods are suitable for consumption, e.g. word of mouth, relevant literature and Coeliac UK, the latter being a key trusted source.

Again this work is a highly relevant backdrop to the present project although it does not illuminate information in the context of eating out. Nor more specifically, does it shed any light on one important focus of the present work – that is, around the interplay of written (in store or online) and verbal information (either face to face or over the phone).

Impact of the FIR legislation

A Royal Society for Public Health mystery dining investigation⁵² in July 2015 sought to map the availability of allergy information in 65 London-based fast food takeaway venues. Seventy percent of venues were non-compliant with requirements to provide clear indicators of how customers could obtain information about the allergen content of foods. Fifty-four percent of staff questioned did know about the allergen content of their foods, 80% of venues had no clear system in place to ensure that allergen information was accurate or verifiable and, 90% of venues were unable to produce recorded evidence of the allergen content of their foods.

Two other studies in the grey literature sought to evaluate the impact of the FIR legislation. In a snapshot survey of food allergic consumers' post legislation eating out experiences⁵³ in April 2016, results indicated that 44% of respondents had observed that allergen information provision was 'slightly improved'. These improvements included an increase in the provision of a 'special allergy menu' (51%), 'signposting' to allergen information (45%), and 'staff actively checking' the allergen content of foods (48%). Fifty-two percent of respondents also reported feeling more confident in asking staff about the allergen content of foods. However, 25% of respondents had experienced a reaction to food consumed in a restaurant setting and other issues were reported including, 'staff not understanding the severity of allergy' (69%), lack of knowledge of menu content (68%), 'over caution'

⁴⁸ Voordouw, J., Cornelisse-Vermaat, J. R., Pfaff, S., Antonides, G., Niemietz, D., Linardakis, M.,Frewer, L. J. (2011). Preferred information strategies for food allergic consumers. A study in Germany, Greece, and The Netherlands. Food Quality and Preference, 22(4), 384-390. doi:http://dx.doi.org/10.1016/j.foodqual.2011.01.009

⁴⁹ Voordouw, J., Antonides, G., Cornelisse-Vermaat, J. R., Pfaff, S., Niemietz, D., & Frewer, L. J. (2012). Optimising the delivery of food allergy information. An assessment of food allergic consumer preferences for different information delivery formats. Food Quality and Preference, 23(1), 71-78. doi:http://dx.doi.org/10.1016/j.foodqual.2011.08.001

['] Worth et al. (2013) *Op cit*

⁵¹ FSA: Consumers understanding of new labelling terms for foods marketed for people with gluten intolerance. Final Report. Food Standards Agency- Online (2009). Retrieved from

http://tna.europarchive.org/20120419000433/http://www.food.gov.uk/science/research/foodcomponentsresearch/allergyresearch/survey allergy/glutenintol Accessed 22 March 2017 ⁵² Royal Society for Public Health: Allergy Information and fast food takeaways (2015). Retrieved from

https://www.rsph.org.uk/resourceLibrary/allergy-information-and-fast-food-takeaways-.html Accessed 22 March 2017 ⁵³ FSA: Eating out with a food allergy (2016). Retrieved from http://www.food.gov.uk/news-updates/news/2016/15103/quarter-of-people- with-food-allergies-suffer-reactions-when-eating-out Accessed 22 March 2017

in the form of 'may contain' labelling (64%), and being 'made to feel like an inconvenience' about their food allergy (56%). Finally, a further pre and post legislation online omnibus survey was conducted for the FSA⁵⁴ with different respondents' pre and post legislation. Part of the survey was conducted with the general public and there was a significant increase in their awareness of the introduction of the FIR. There was also a significant increase in the proportion of people noticing signs inviting people to make staff aware that they had a food allergy or intolerance. Another part of the survey was with Allergy UK members and although there was evidence here too for improvement over time with respect to awareness of the FIR and awareness of signage, it remained the case that the majority had not seen such signage and no improvement was seen in the clarity of allergen information when in eating out.

Conclusion

In conclusion, whilst the results of the rapid evidence assessment provides an important backdrop to the current project, more information is needed in relation the practices of people with food allergy or intolerance in respect of venue choice, food choice, the service encounter and information provision. Most particularly, we know little about the detailed practices and preferences of people for seeking and receiving information about allergens when they are eating out. This is the focus of the qualitative and quantitative research to be considered now.

⁵⁴ <u>https://www.food.gov.uk/sites/default/files/food-allergy-report.pdf</u> Accessed 22 March 2017.

Phase 02: Information seeking practices and information provision preferences: a qualitative approach

This section of the report relates findings from the qualitative components of the project that were conducted before and after the legislation came into effect in December 2014. The qualitative work consisted of interviews and diaries in order to gain greater understanding of the diversity of information-seeking strategies and information provision preferences of consumers with an allergy / intolerance to one or more of the 14 main allergens. All participants in the qualitative research ate out sometimes, that is, those that did not eat out at all were not eligible to be recruited. Additionally, eligible participants reported that they were allergic to, and seeking to avoid at least one of the 14 allergens defined in the legislation. Participants seeking only to avoid allergens outside the list of 14 were not included (some were sensitive to allergens among the 14 and additionally outside the 14). A clear intended focus of the project was to recruit participants on the basis of their self-reported food allergic and food intolerant status, in order to include participants who were self-diagnosed alongside those who had received a clinical diagnosis of food allergy or intolerance. This was entirely appropriate given that anyone is entitled to ask for and to receive information about whether any of the 14 allergens covered by FIR are an ingredient in the food that has been prepared.

Diaries are an ideal complement to interviews. Within social science research, diaries have been used to build upon the insights derived from in-depth interviews by allowing participants to describe and reflect on their daily experiences in their own words, in non-prescribed formats, and in real time^{55 56}. As such, diaries are less dependent on the potential biases derived from retrospective research, and provide a longitudinal view from the participant's perspective⁵⁷. In previous research, written^{58 59}, audio^{60 61}, and photographic⁶² diaries, or a combination of these techniques, have been used to investigate a variety of contexts including aspects of children's and adults' eating and food consumption experiences.

Interviews:

Participants

At the pre legislation stage, specialist market research field agency (Acumen Fieldwork- Medical) recruited 75 food allergic and/or intolerant participants from across England, Wales, Scotland and Northern Ireland to complete in-depth interviews and optional eating-out diaries. Participants were drawn from across the four UK nations to reflect the breadth of the FSA and FSS's⁶³ remit and the implementation of the FIR allergen rules. Of the total population, 60 were adults reporting food allergy/intolerance, and 15 were parents/carers of children aged up to 16 years who reported food

⁶³ Food Standards Scotland.

⁵⁵ Alaszewski, A. (2006). Using diaries for social research. London, UK: Sage

⁵⁶ Hawkes, G., Houghton, J., & Rowe, G. (2009). Risk and worry in everyday life: Comparing diaries and interviews as tools in risk perception research. Health, Risk & Society, 11(3), 209-230. doi:10.1080/13698570902906439

⁵⁷ Day, M., & Thatcher, J. (2009). "I'm really embarrassed that you're going to read this...": Reflections on using diaries in qualitative research. Qualitative Research in Psychology, 6(4), 249-259. doi:10.1080/14780880802070583

⁸ Hawkes et al. (2009). *Op cit*

⁵⁹ Wills, W. J. (2012). Using spoken and written qualitative methods to explore children's and young people's food and eating practices. Sociological Research Online, 17(3), 16. Retrieved from http://www.socresonline.org.uk/17/3/16.html

⁶⁰ Worth, N. (2009). Making use of audio diaries in research with young people: Examining narrative, participation and audience. Sociological *Research Online, 14*(4), 9. Retrieved from <u>http://www.socresonline.org.uk/14/4/9.html</u>⁶¹ Childers, C. C., Haley, E., & Jahns, L. (2011). Insights into university freshman weight issues and how they make decisions about eating.

Journal of Consumer Affairs, 45(2), 306-328. doi:10.1111/j.1745-6606.2011.01204.x

⁶² Valentine, A. Z., & Knibb, R. C. (2011). Exploring quality of life in families of children living with and without a severe food allergy. Appetite, 57(2), 467-474. doi:10.1016/j.appet.2011.06.007

allergy/intolerance. Within the latter group, parents/carers were the primary focus of the interview although their food allergic/ intolerant children were sometimes present.

In the post legislation study, 57 of these participants returned to the study of whom 56 were interviewed and 26 completed diaries⁶⁴.

The pre legislation interviews were conducted in June – July 2014 and the post legislation interviews in June – July 2016.

In addition to diversity of demographic characteristics, the sample represented a broad spectrum of food allergy and intolerance. Participants were recruited to allergy/intolerance groups on the basis of their reported reactions to, and avoidance of, one or more of the 14 main allergens. The full protocol for recruitment and group assignment can be found in Annex 1.

Table 1 below shows the criteria for allocation of participants to allergy and intolerance groups and for allergy severity. This was based on a classification previously used for peanut allergy⁶⁵.

Table 1: Allergy or intolerance classification criteria and allergy severity classification criteria

Classification	Symptom	Severity
ALLERGY	'Stinging nettle' rash, urticaria,	MILD
(may also have	hives	
symptoms of	Itching or swelling of the lips,	
intolerance)	tongue or mouth	
	Asthma, wheezing	MODERATE
	Facial swelling	(may also have mild symptoms)
	Breathing difficulties	SEVERE
	Anaphylaxis, collapse	(may also have mild &/or moderate symptoms)
INTOLERANCE	Absence of 'allergy symptoms'	
	Vomiting	
	Diarrhoea	
	Sneezing	
	Catarrh	
	Hyperactivity	
	Tiredness	
	Stomach cramps	
	Other digestive problems (e.g.	
	bloating, constipation)	
	Eczema flare	
	Migraines/headaches	
	Aching joints/muscles	
	Behavioural/mood changes	

Building on this, participants were allocated to one of three groups in line with the criteria laid out in Table 2 below. Group 1 were classed as having an IgE mediated allergy. The specific purpose of the division between Groups 2 and 3 was to recognise whether, and by whom those reporting a food

⁶⁴ Due to illness one person completed a diary but not an interview.

⁶⁵ Hourihane, J. O. B., Kilburn, S. A., Dean, P., & Warner, J. O. (1997). Clinical characteristics of peanut allergy. *Clinical and Experimental Allergy*, 27(6), 634-639. doi:10.1111/j.1365-2222.1997.tb01190.x

intolerance had been diagnosed. Those allocated to Group 2 were classified as food intolerant according to their reported symptoms and had been diagnosed by a doctor, dietitian, health visitor or a specialist in a hospital clinic. Those in Group 3 were classified as food intolerant according to their reported symptoms and diagnosed by an alternative/complementary therapist, some other practitioner or did not know who they had been diagnosed by. Participants who reported a diagnosis of Coeliac disease were allocated to Group 2 or 3 dependent on who had made the diagnosis.

Participants were screened for their eligibility for the study using a screening questionnaire characterising their or (for parents) their child's reactions to one or more of the 14 specified allergens. Characteristics were based on nature of reaction, speed of onset, and how FA/FI was diagnosed. This information was used to classify participants as Groups 1, 2 or 3 and these designations were retained and updated for the post legislation interviews (see Table 3).

Table 2: Screening tool criteria for allocation to food allergic and intolerant groups

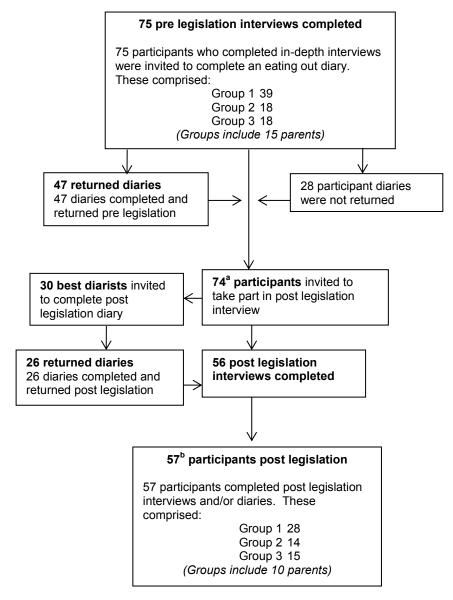
- Group 1 IgE-mediated: Participants that report (a) having a reaction to food (b) avoiding one of the 14 allergens (c) whose reaction starts immediately or within the hour and (d) who have <u>at least one</u> of the following symptoms: 'Stinging nettle' rash, urticaria, hives, itching or swelling of the lips, tongue or mouth, asthma, wheezing, facial swelling, breathing difficulties, anaphylaxis, collapse'. (Participants may <u>additionally</u> have one or more of the following: 'vomiting, diarrhoea, sneezing, catarrh, hyperactivity, tiredness, stomach cramps, other digestive problems (e.g. bloating, constipation), eczema flare, migraines/headaches, aching joints/muscles, behavioural/mood changes').
- Group 2 Non-IgE-mediated or intolerant, diagnosed : Participants that report (a) having a reaction to food (b) avoiding one of the 14 allergens (c) whose reaction starts 1-24 hours later, after 24 or hours or who cannot remember when it started (d) who do not have any of the following symptoms: 'Stinging nettle' rash, urticaria, hives, itching or swelling of the lips, tongue or mouth, asthma, wheezing, facial swelling, breathing difficulties, anaphylaxis, collapse' but who do have at least one of the following: 'vomiting, diarrhoea, sneezing, catarrh, hyperactivity, tiredness, stomach cramps, other digestive problems (e.g. bloating, constipation), eczema flare, migraines/headaches, aching joints/muscles, behavioural/mood changes', and (e) have been diagnosed by a doctor, dietitian, health visitor or a specialist in a hospital clinic.
- Group 3 Non-IgE-mediated or intolerant, not diagnosed exactly as Group 2 except diagnosed by an alternative/complementary therapist, other or do not know who they have been diagnosed by.

In the pre legislation qualitative work, of the 75 allergy/intolerance participants (60 adult and 15 parent/child participants) the population comprised 39 (52%) Group 1 participants; 18 (24%) Group 2 participants; and 18 (24%) Group 3 participants. Of the Group 1 participants 16 participants were severely allergic (41.0%), 14 were moderately allergic (35.9%) and 6 participants were mildly allergic (15.4%). 3 participants were unclassified (7.7%).

The majority of participants in Group 1 were allergic to peanuts (56.4%), tree nuts (46.2%) and/or milk (23.1%). Eight other specified allergens were also represented as minorities within Group 1. Group 2 mainly comprised cereals containing gluten (77.8%) and/or milk (50%) allergy/intolerant participants; with 6 other specified allergens being represented. Group 3 was primarily made up of participants

intolerant to milk (66.7%) and/or cereals containing gluten (33.3%); 6 other specified allergens were also represented.

Figure 1 shows the breakdown of interview and diary participants pre and post legislation.



^a One pre legislation participant deceased

^b One post legislation participant completed a diary but was unavailable for interview

Figure 1: Flow chart of pre and post legislation interview and diary participant numbers

As shown in Figure 1, 57 pre legislation participants returned to complete the post legislation interviews and/or diaries two years later. Of these, two participants were children at the time of the pre legislation interviews and qualified for individual adult interviews (alongside their parents) post legislation. Nineteen participants (25%)⁶⁶ were unable to take part post legislation due to a change in their personal circumstances, or non-response to invitations to do so. Of the total post legislation population, 47 were adults reporting food allergy (FA) or food intolerance (FI), and 10 were

⁶⁶ Percentage calculated out of 76 participants (Original 75 participants – 1 *deceased*, + 2 children *now adults*=76)

parents/carers of children aged up to 17 years with FA/FI. A breakdown of participant characteristics is shown in Table 3. See also Annex 4 and 5.

Variable	Group 1	Group 2	Group 3	Total (%)
	n=28	n=14	n=15	N=57
Gender of				
adult /parent				
Male	7 (25.0)	2 (14.3)	3 (20.0)	12 (21.1)
Female	21 (75.0)	12 (85.7)	12 (80.0)	45 (78.9)
Gender of				
child				
Male	2 (40.0)	0	2 (50.0)	4 (40.0)
Female	3 (60.0)	1 (100)	4 (50.0)	6 (60.0)
Age ^{67 68}				
<8	0	0	1 (6.7)	1(1.8)
8-12	2 (7.1)	0	0	2 (3.5)
13-17	2 (7.1)	0 ⁶⁹	3 (20.0)	5 (8.8)
18-30	8 (28.6)	5 (35.7)	1 (6.7)	14 (24.6)
31-45	9 (32.1)	1 (7.1)	3 (20.0)	13 (22.8)
46-60	3 (10.7)	6 (42.9)	2 (13.3)	11 (19.3)
60+	3 (10.7)	1 (7.1)	4 (26.7)	8 (14)
Region				
England	10 (35.7)	7 (50.0)	7 (46.7)	24 (42.1)
N Ireland	1 (3.6)	1 (7.1)	3 (20.0)	5 (8.8)
Scotland	10 (35.7)	3 (21.4)	3 (20.0)	16 (28.1)
Wales	7 (25.0)	3 (21.4)	2 (13.3)	12 (21.1)

Table 3: Characteristics of the 57 post legislation food allergic/intolerance adult participants and children of parent/carer participants

⁶⁷ One 'adult' value missing. Two children (13-17yrs) pre legislation were classified as adults (18-30yrs) post legislation. Their parents also completed post legislation survey, but 'child age' for these parents was removed from calculations. ⁶⁸ 'Child' age or 'Adults' age only (no 'Parents' age included). Child age shown for 8 participants only (Total=10-2 children aged 18yrs post

legislation ⁶⁹ Child aged 13-17 pre legislation and 18 yrs post legislation, so no 'child age' recorded

Twenty-eight participants (50%) were classified as Group 1, 14 (24%) were classified as Group 2, and 15 (26%) classified as Group 3. Of the 14 allergens covered by the legislation, avoidance of peanuts (28.1%), tree nuts (26.3%), milk (35.1%), soya (3.5%), mustard (5.3%), fish (5.3%), crustaceans (8.8%), cereals containing gluten (36.8%), sesame seeds (3.5%), celery (1.8%), and/or eggs (7.0%) were reported. No participants reported avoidance of lupin, molluscs or sulphur dioxide. Thirty-nine percent of participants reported avoiding more than 1 allergen.

Procedure

An in-depth interview was carried out with each participant in their own home. Each interview was recorded with the permission of the participant. See Annex 2 and 3 for the full interview topic guides for the pre and post legislation interviews.

For the pre legislation interviews, the initial questions were designed to engage participants with the topic of food and their experiences relating to allergy/intolerance diagnoses, adaptation, and day-to-day coping strategies. The interview then focused on participants' experiences and behaviours when eating out. Participants were encouraged to discuss the strategies and environmental / social cues which influenced their decision-making processes and to consider these preferences in relation to current and future information provision. Participants were guided through this process by a series of questions which encouraged them to focus on aspects of their eating out behaviour and information seeking preferences in-depth, and to relate these to their perceptions of the new legislation and related information provision.

For the post legislation interviews, returning participants were asked about any changes that had occurred in their lives, the impact on their life of their FA/FI and its importance in how they saw themselves. The conversation then turned to their eating out practices and experiences and any changes in this, including in their encounters with information about allergens. They were asked for their reflections on, and evaluations of, any changes (or the lack of them). As for the pre legislation interview, they were asked about their information preferences in terms of information passed on by staff and written information. Finally, they were asked about the perceived impact of the legislation and two new areas not specifically covered in the pre legislation interviews: the role of support groups and social media in managing eating out with a food allergy or intolerance.

Following the pre legislation interview, participants were invited to complete a two week 'diary' of their experiences when eating out or ordering take-away/non-prepacked foods. This component of the study included an optional written and/or audio diary, and photographic record. Consenting participants were provided with a diary notebook, dictaphone and disposable camera to be returned using a pre-paid envelope. Some of those who had completed a diary were followed up with a short phone interview. Of the 47 participants who returned a pre legislation diary, 30 fully engaged with the task by providing rich descriptions of their eating out experiences. These 30 'best' diarists were invited to complete diaries post legislation (see Figure 1). Diary participants post legislation were asked to complete the diary in the two weeks before the interview.

Analysis

In order to communicate the diversity of views and perspectives surrounding participants' eating out experiences, interview recordings were fully transcribed and considered using framework analysis⁷⁰. Framework analysis has become popular in social, policy and health research because it applies a systematic approach to qualitative analysis which prioritises the transparency of the analytical process; thereby maximising accessibility and strengthening confidence in subsequent results and

⁷⁰ Srivastava, A., & Thomson, S. B. (2009). Framework analysis: a qualitative methodology for applied policy research. *Journal of Administration and Governance*, 4(2), 72-79. Retrieved from <u>https://papers.srn.com/sol3/papers.cfm?abstract_id=2760705</u>

conclusions⁷¹⁷². Interviews were coded and analysed using the qualitative data analysis software QSR NVivo (version 10). Interviews were analysed across the population as a whole, and also based on classifications to facilitate investigation of group similarities and differences.

The potential to generalise from qualitative data has received considerable attention, with some researchers dismissing the notion as being inherently incompatible with qualitative research^{73 74}. Since qualitative research is commonly based on purposive sampling and is focused on the depth and nuances of human experience from people's own perspectives, often within their 'natural' environments^{75 76 77}, a statistical conception of generalisation is irrelevant.

The present research sought to achieve maximum variation of the cases that were of interest (e.g. allergy vs intolerance; clinically diagnosed vs self-diagnosed; various age cohorts, locations etc.) with a view to capturing a diversity of experiences - from the most common to the least common. Thus the notion of representational generalisation is applicable. This refers to the possibility of extrapolating the findings to the population from which the sample was drawn⁷⁸. A second sort of generalisation that seems relevant for the present research findings is the so-called inferential generalisation which concerns the transferability and relevance of results to similar contexts or settings⁷⁹. Thus, one might expect that people suffering from food allergies or intolerances would employ similar strategies and go through similar decision making processes in order to manage food choices under conditions of uncertainty and reduced control over the food preparation.

Identified themes are illustrated in results. In order to maintain anonymity of participants, where quotes are used, participant details are indicated in brackets as follows: PRE or POST indicates whether the quote was part of a pre or a post legislation interview or diary. 'A' or 'P' refers to Adult or Parent, 'G1', 'G2' or 'G3' refers to the allocation of group, 'E' England, 'S' Scotland, 'W' Wales and 'NI' Northern Ireland refers to the country in which the participant lived and text indicates the allergen(s) that each participant avoided. Italicised text reflects questions or prompts used by the interviewer. Quotes are derived from interviews unless otherwise stated.

Findings

The focus of the results section of the qualitative work is on representing the spectrum of participant views around each theme and to map the diversity and/or consensus evident in these. In particular however, in the light of the longitudinal nature of the data, we will reflect on evidence for stability or change between the pre and post legislation phases of the work. This may take the form of views that are more or less positive but might also be evident in the identification of new perspectives, the reconceptualization of issues, or perhaps greater complexity around previously less differentiated or perhaps less considered issues.

We have integrated the insights from the pre and post legislation stages and present these in five main sections. First, strategies for venue and food selection that are independent of information provided about food that is either written down or delivered by staff. Second, written information

⁷¹ Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Medical Research Methodology, 13(1), 117. doi:10.1186/1471-2288-13-117

⁷² Smith, J. & Firth, J. (2011). Qualitative data analysis: application of the framework approach. Nurse Researcher, 18(2). 52-62. doi: 10.7748/nr2011.01.18.2.52.c8284

⁷³Larsson, S. (2009). A pluralist view of generalization in qualitative research. International journal of research & method in education, 32(1), 25-38. doi:10.1080/17437270902759931.

⁷⁴ Lewis, J., & Ritchie, J. (2003). Generalising from qualitative research. In J., Ritchie, & J., Lewis (Eds.), Qualitative research practice: A Guide for social science students and researchers (pp. 263 – 286). London, UK: Sage Publications. ⁷⁵ Mason, J. (2002). *Qualitative researching – 2nd edition*. London, UK: Sage Publications.

⁷⁶ Willig, C. (2013). Introducing qualitative research in psychology - 3rd edition. Berkshire, UK: Open University Press.

⁷⁷ Yin, R.K. (2011). *Qualitative research from start to finish.* New York, NY: The Guildford Press.

⁷⁸ Larsson (2009) Op cit; Lewis & Ritchie (2003) Op cit

⁷⁹ Ibid

provided by eating out venues. This is mainly about menus but includes insights about written information online, the symbols used to denote allergens on menus, separate menus aimed at customers avoiding different allergens, other sources of information about the ingredients/allergens in each dish, and about the increasingly common signs and statements on menus inviting consumers to speak to staff if they have requirements relating to allergens. The third section is about information provided by staff and outlines the range of signals that consumers attend to in seeking to discern the trustworthiness of staff. The fourth section deals with views on the legislation and its impact. Finally, the fifth section considers differences between groups – with a particular focus on how the post legislation period has seen an accentuation of differences between those seeking to avoid different allergens.

Overall, many of the ways of accessing information were evident pre legislation but participants generally indicated that these options were more common post legislation, although they still reported encountering many venues where there were no indications of actions to support the food allergic or intolerant consumer.

The graphic below indicates the range of options for seeking and obtaining information about allergens on the journey from planning to eat out through to the moment of consuming the food. Of course, any or all of these options can be unavailable or if they are, consumers may not avail themselves of them for a range of reasons. Within the following sections we will refer to these points in the journey and the reasons why the associated encounters may be more or less satisfactory for food intolerant or allergic consumers.

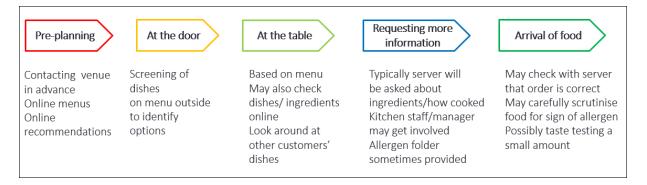


Figure 2: the possible information journey when eating out with a food allergy or intolerance.

Strategies for venue and food selection

The understanding that we developed in the pre legislation work around the drivers of venue choice was less of a focus in the post legislation interviews. However across both time periods it was evident that these heuristics for assessing risk in selecting venues and dishes within a venue were largely consensual and operated independently from factors related to information provision.

When selecting eating out venues, participants consistently emphasised their preference for familiar and regularly attended eating establishments. The preference for familiar venues was largely based on levels of trust and confidence gained over repeated visits with no associated side-effects. Cues provided by one environment were transferred to another and thus the standardisation afforded by retail chains in the context of unfamiliar places was valued. In the absence of familiarity, other cues are used to assess risk and to maximise the likelihood of a safe and enjoyable eating experience. Indicators that the food was fresh, that the place was clean and hygienic, where there was the possibility of constructing a meal from simple basic ingredients, all served to increase the possibilities for confident eating out. Conversely, complex meals, a lack of clarity about how the meal had been prepared led to the venue being less positively regarded. Indicators of institutional care and vigilance were valued though the bottom line was often that eating out was a risky affair. Ultimately, participants were accustomed to weighing the balance of risk, and the requirements of vigilance (taking care) and compromise (playing it safe) in their eating out selections.

When selecting eating out venues, participants emphasised their preference for familiar and regularly attended eating establishments. Such venues provided a sense of comfort and reassurance based on successful past experiences. The reasoning behind venue selection revolved around issues of safety and trust based on past experiences:

You know that it's safe there because they do take it seriously, because we've been there so many times and I've never had an issue with them, whereas, a few places, we've been a couple of times and reiterated things, and it will still come back with things on the plate, and you think, 'right, well, we'll give this place a miss now then'. (PRE A39 G1 W: Peanuts, Celery)

For parents of allergic/intolerant children, it was that familiarity based on past experience, and coupled with a sense that their child was relaxed in their food choice which made the experience 'easier':

For me, it's familiarity. It's the same... It's what you're used to. We've just always stuck there because you know when you get in, you know when you can just automatically look at something. He'll know what he wants as soon as he gets through the door, which is quite nice. (PRE P12 G2 W: Peanuts, Milk)

Criteria related to familiarity were used when selecting eating out venues away from home. For example, some participants looked for restaurant 'chains'. Although these venues were not necessarily rated highly in terms of food 'quality', participants had an expectation that the range of dishes and food preparation would be standardised across establishments, and this was reassuring:

If it's a chain, you know it's a chain so it should be to a certain standard. I know that they all don't claim they're all, let's say a 5-star standard, but you would hope they would be all about three ... So I think, when you go to a chain .., it's normally to a certain level, whereas, when you go to a non-chain, so maybe that's what I would consider maybe [for like] a non-chain, you're taking the risk. (PRE A23 G2 NI: Milk)

Familiarity was the most valued source of reassurance; it minimised the possibility of unwanted and unanticipated dilemmas. Other qualities of the meal or of the experience were secondary to this key rule of thumb for driving venue choice. Where venues were unfamiliar, other cues were deployed.

Participants tended to interpret freshness, quality and hygiene standards as proxies indicating an underlying level of care, knowledge of ingredients, and awareness of food safety, which led to a greater degree of trust and confidence in the venues:

Because it's all fresh and it's all...they've got the turmeric in it and all like herbs basically from scratch, and you know that there's no like artificial stuff in it. (PRE A21 G3 NI: Peanuts, Tree nuts, Gluten, Fish)

I always think hygiene is very, very important, even if it wasn't to do with allergies, but it's bound to come into it because, you know, especially (sandwich outlet), now, they'll change their gloves when they're handling the meat, and they're always changing their gloves, and I would have more confidence in that. (PRE A20 G1 NI: Peanuts, Tree nuts)

Participants also expressed a preference for venues where they could exercise an element of choice and control; either by selecting components of their meal directly or ordering an allergen-free meal in advance:

It wasn't a carvery company or anything like that. It was a pub that sort of had everything on show and you went and picked what meat, and then all the veg was there, so you could... I prefer that, because, when you buy a roast somewhere, sometimes they put cauliflower cheese on your plate, but when it's like that, you can put whatever you want on, so I haven't got to worry about saying, 'oh, I don't want cauli cheese and I don't want...' you know... (PRE A3 G3 E: Milk)

In line with participants' preference for fresh foods, venues where ingredients were complex and unclear, or in pre-prepared / processed dishes which did not allow the potential for alteration or exclusion of allergens from recipes were deemed to be a particular risk. This absence of simplicity suggested a lack of appreciation regarding the potential difficulties experienced by food allergy / intolerance sufferers which restricted participants' food selections and caused feelings of frustration:

You tend to find the sort of higher quality restaurants, more the Michelin star type, are using a lot more nuts and you know, won't declare it even on the menu, so we avoid them completely. (PRE P8 G1 S: Peanuts, Tree nuts)

I asked for an omelette on the breakfast menu and because their omelettes, little did I know, come already done, all they do is put them in a microwave. She couldn't tell me – I said 'I don't want cheese in it,' because it's a cheese omelette. I said, 'I don't want cheese in it – can I just have the plain omelette?' 'Oh no, we can't do that,' and she wasn't explaining to me, 'no, they come already'...because she didn't know herself. (PRE A44 G1 E: Milk)

Similarly, the risks of allergen cross-contamination and a lack of information relating to food preparation were of great concern to a number of participants. Again, this scenario limited participant choice and served as a cue suggesting a lack of knowledge, understanding and concern for food allergy / intolerance sufferers:

I was at someone's birthday in a (name of Asian restaurant), and most of the menu...so I have to keep asking, and I had the plainest thing on the menu, just in case. But you never know if it's cooked in oils or... So, yeah, I was really worried then. I'd never go back. (PRE A25 G1 E: Peanuts, Tree nuts, Sesame)

Despite the care taken by participants in selecting suitable venues, many reported that they would still 'play it safe' with their food selections when eating out. This was particularly the case when participants went to a new venue, and highlighted participants' experiences of compromise and the need to 'settle' for the limitations imposed by their condition when information provision was poor:

What I do is stick to what I know. For instance, again, with steak, I make sure, you know, I only have the steak, I only have the chips or jacket potato, whatever. I don't have any sauces now. (PRE A26 G2 E: Milk)

I'd probably be looking at something very simple...so I could be assured of what's inside it. So if we were going to order chicken, I'd look for the simplest chicken meal, something with little on top and less underlying stuff so there would be less to make (name of child) flare up. (PRE P2 G1 E: Peanuts, Tree nuts)

Participants noted venues where their options to 'play it safe' were further restricted both in terms of eating outlet and food selection, for example in settings such as hospital or school or during air travel. Positive experiences in these settings were again linked to the provision of simple ingredients and other indicators of institutional care:

I'm in the school every day, so I'm going to be eating school dinners, which I usually do, because trying to make yourself something in the morning or the night before, you just don't have the...and I don't eat bread, so that makes it more difficult. I don't eat sandwiches, so school meals are sort of the...the good option, because there's always vegetables and there's always healthy things on there. (PRE A8 G2 E: Milk, Soya)

That's probably it, the school meals thing, he has school meals, but the school...a lot of them now have a policy that they are nut free, if that makes sense? There was a letter a little while ago that said, 'if your child is bringing in food for birthdays', it's a tradition, 'no nut products whatsoever, and no cake'. So basically, it has to be small sweets or an apple. That's something I hadn't considered. (PRE P2 G1 E: Peanuts, Tree nuts)

However, where mistakes were made or alternative options were unavailable, participants experienced particular difficulties resulting in worry and concern, hunger or exacerbation of symptoms. Again the lack of institutional vigilance lies behind the worry:

The nursery has spare clothes.... they give him stuff that I know for a fact I can say off the top of my head, I said 'don't give him Angel Delight', there's at least four different types of lactose in that and milk powder. They said they'd make it up with his own milk but I said 'look, you're not reading the back of the packet'. (PRE P9 G1 NI: Milk)

Overall, regardless of the care taken, many participants felt that the risk – mainly through the presence of the unexpected – was ever present when eating out or ordering take-away food:

I've been to restaurants before where you tell them you have an allergy and they still serve you up, you know... And you ask for, you know, 'What's in the sauce – are there any nuts?' Is there this, that or the other.... 'Oh, no, no, no, you're absolutely fine!' and, sure enough, there are... think, with people with severe allergies, you take a bit of a punt any time you go out, for any meal really. (PRE A60 G1 E: Peanuts, Tree nuts)

When you go and eat out, you have to...it's like playing roulette. (PRE A45 G1 W: Gluten, Milk)

The menu as an information resource

Overall, both pre and post legislation participants tended to prefer to access information about allergens through written information. Within this, again both before and after the legislation, participants used the menu as their primary source of written information although other written resources were also accessed. Post legislation, participants made more extensive use of information and menus available online. Participants emphasised the merits of accessible written information often as this excludes or lessens the necessity for a conversation with a member of staff, or at least provide a reference point for it. Menus were scrutinised frequently online, in window displays, and at the table prior to food ordering. In situ, menus containing symbol/abbreviation-based warning systems were the preferred source of allergen information and participants advocated that these be delivered in a 'universal' format to simplify understanding. The need for greater detail in menus was emphasised as a means of maximising consumer choice and trust. Separate menus were appreciated by some though these were not available for the majority of allergens. Other participants reported being provided with a detailed supplementary reference source of ingredients/allergens by staff. Although these provided some reassurance, some participants were concerned that folders were being used as an alternative to the menu, and shifting the onus from the venue to the customer. The provision of separate or additional allergen details was not welcome as the initial basis for making a food selection rather they were considered useful as a check once selection had been made. They are also valuable to peruse in conjunction with a member of staff. Signs conveying allergen information were widespread and appreciated - despite their poor placement on occasion. Although some welcomed signs inviting consumers to 'ask staff about the allergen content of foods' and saw them as evidence of increased allergen awareness, others were negative and sceptical seeing them as locating responsibility with the consumer and lessening the responsibility of the venue. Scepticism about the value of, and motivation for these signs was more pronounced after the legislation.

Overview of the role of the written information in food choice

The information provided on the menu was seen by many to be the main source of information about allergens and certainly overall people wanted it to be so. Written information provided by the venue may not completely preclude needing to ask but on the whole, having access to information that was written down inspired confidence. Inadequate written information limited confident food choice and meant that there had to be greater engagement with staff which was not generally desired. There was a strong theme both pre and post legislation that menus, rather than staff, should constitute the primary and comprehensive source of information about allergens. Overwhelmingly participants wanted allergen/intolerance information to be available in written form, and preferably on the menu. Any dependence on staff for the delivery of dietary information immediately introduced the potential for embarrassment, an element of risk and a threat to trust and was seen to reduce participants' potential for freedom, independence and control when making their food choices:

I don't think that it should be left to people. It's not very secure. It's not a very... they may not say to every customer 100% of the time... so it's pointless. Unless you're going to write it down, it's pointless. (PRE A23 G2 NI: Milk)

My initial reaction there was, oh my God, oral passing over of allergy information, because who's going to remember all of those things? I would rather see it written down... absolutely, and I wouldn't like to have to go off and search for it. I'd rather have it right there and then so I could make an informed decision right there and then. (PRE A60 G1 E: Peanuts, Tree nuts)

My view is, if you're going to be providing information, provide the information – don't make the customer go and ask for it...Human beings are human and they make mistakes... In a busy restaurant where people are talking to you, you know, you could be given the wrong information actually, so I would like that information provided in written form somehow, online preferably, as well as in the restaurant, for me. I wouldn't want to have to ask for it. (PRE A52 G1 S: Tree nuts, Gluten)

Primarily, participants' first and favoured point of contact with a venue was written information usually provided by the menu. This was sometimes accessed as part of advance information gathering before eating out/ordering in, and enabled participants to exercise an early element of control over where and what they chose to eat. A closer inspection of the menu followed at a later point before ordering dishes as a take-away or in situ.

Ahead of inspecting the menu, another source of written information was signage and information outside the venue itself. Participants inspected menus displayed in the restaurant windows in order to check available food options and the potential suitability of a venue before making the commitment to dine there:

Places normally have a menu in the window, to check before you go in so that you're not looking like an eejit. (PRE A29 G3 S: Crustaceans)

We look in the windows and we try and read, they'll put a sample menu or whatever, or outside and you try and read what kind of things are in there and if you can see that there is something that you think would be okay, then it's worth a try. That is how we normally do it, just try and see as much as we can understand before we go in. (PRE P1 G1 E: Peanuts, Tree nuts, Milk)

In the post legislation interviews there was less mention of menus displayed outside the venue; participants rather drew attention to signs indicating that a venue catered for particular allergen related requirements – most commonly for those wishing to choose gluten free food.

There was also greater mention in the post legislation interviews of using venue websites in order to inspect menus, explore allergy awareness and available food options, and make decisions on potential food selections prior to eating out:

I'll look usually online – I thank God for the internet – at what their menu is. As I said, before we went to (European restaurant), I'd decided...I'd looked it up online and looked at their menu and gone, right, and I know I had a penne pasta dish, which was a spicy penne pasta, wasn't creamy, so I knew that one was going to be fine. (PRE A14 G2 S: Milk)

...certainly pizza [name of outlet] and the fish bar, yes, they are very good and the websites actually say what it does and doesn't contain, this seems to be very good for food allergies. (PRE P8 G1 S: Peanuts, Tree nuts)

Okay and how do they present that information online?

Usually there's a chart or they will label the actual food and then just you know state whether it's milk, gluten, nuts you know really it's like a chart, almost like an excel spreadsheet and do it that way. (POST P8 G1 S: Peanuts, Tree nuts)

Within the venue itself, participants used the menu as their primary information resource, and appreciated the opportunity to familiarise themselves with what was available. Overall then, written information was a key part of the information seeking journey - from looking online, noting any signs and detailed menus outside the venue, and looking at the menu at the table:

I read the menu first, I'll be honest with you, because you obviously don't want to bring attention to yourself so early, and if you could get away with something and think that's really safe, you know, if something said it's chicken and it's rice noodles and it's fresh, daily vegetables, I think you've a rough idea that's good, and as long as you ask the staff, 'there's no soy sauce being added to this – what's in the sauce?' if there is a sauce, you know what I mean. (PRE A30 G3 NI: Gluten)

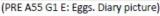
Overall, when clear allergen-related advice was provided on the menu, participants trusted this information, and experienced greater confidence and control in their food selections.

Symbol-based and abbreviated indicators of allergen content in menus

Both pre and post legislation, many participants expressed an interest in, and preference for, simple information about ingredients and/or allergens to be provided on the menu. Some suggested that this information could take the form of symbols or recognised abbreviations, whilst others recommended the use of 'contains...' or 'free-from...' notations.

It would need to be...like they've got the 'V' and the 'N' on the menu, it would need to be a symbolbased thing, I think. Because if you...had a particular allergy, you would just be scanning the menu for that particular symbol or letter or whatever it may be. I think that would be far more useful than having the huge long list of every ingredient. (PRE A7 G1 E: Peanuts, Tree nuts)





All it's got to have is a GF next to it and I'm happy. Or even if it says 'not GF'. It would be better... all I want is just for it to say... I think that would be really, really useful, and if it doesn't do that then I feel like I'm a pain. (PRE P5 G2 E: Gluten)

I went to a new place on Saturday and it was brilliant because they just had '(N)', in brackets, beside anything that had nuts, and then I could just ask what nuts were in there, so that was okay. (PRE A31 G1 S: Tree nuts)



Went for a walk at lunchtime and stumbled upon a fabulous place in the train station. It is a chain I have never heard of before. I have enclosed an example of how their menu looks. I will be coming here gain- so excited. (Pre A56 G1 E: Eggs. Diary entry)

Post legislation, symbols used to denote the presence of allergens were more widely reported and there was

more obvious appreciation of 'symbol-based' and abbreviated indicators of allergen content of dishes.

In part this increased provision was seem to be an extension of using symbols indicating the suitability of the meal for other non-allergen based dietary preferences (e.g. V = vegetarian). It seemed that the provision of this symbol based information was primarily related to gluten free food, to some allergens in particular and certainly was not used in relation to all 14 allergens.

But I'd rather you know, yeah have kind of symbols next to... because the place that does the pizzas, they have things on the menu, it says GF gluten free, V vegetarian and VN vegan, DF dairy free. (POST P2 G1 E: Peanuts, Tree nuts)

It took me, when I was, two years ago, it took me longer to order food, because I didn't know what to have, but now because it's got the symbols and everything, it's like I know what I'm having. (POST P11 G1 W: Milk- child response)

There's little symbols. The 'V''s for vegetarian I know that. What's the milk one? A lot of places put things in bold now, 'contains milk', 'contains nuts'. So I've noticed that's a definite change so that's fantastic. (POST A26 G2 E: Milk)

I think seeing the symbols is what's clearest. You've got it on the menu that everyone's got and you can choose from there. (POST A32 G2 S: Gluten)

Some participants recommended that such provision should be more widespread and based on a 'universal' format – symbols varied in their form and were sometimes difficult to read. A key was considered essential:

It would be icons on the menu next to each dish, it's as simple as that, and it would just be menus laid out, a key along the bottom with the things we mentioned, gluten free and all the rest with a symbol and one of the symbols is going to have a hazelnut on it or something like that and it's just a circle with a basic hazelnut shape, if that icon's next to that dish, that's it. (POST A15 G1 E: Peanuts, Tree nuts)

But it can be as simple as just, like you say, a key at the bottom with the traditional N for Nuts, V for Vegetarian, L for Lupin, whatever they want to develop. But it would be nicer if it was a universal format. (POST A7 G1 E: Peanuts, Tree nuts)

However, for one participant, the prospect of having to understand symbols on menus was a source of potential confusion:

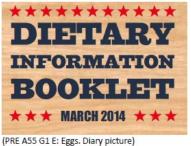
They don't work for me because I've got to learn what the symbols are and then I've got to go down and then I've got to look back again because I can't remember because I'm useless. (POST A34 G2 W: Sesame, Gluten, Milk)

Supplementary allergen reference source

Where allergen advice was limited, the presence of written resources about ingredients *additional* to the menu was deemed to be a source of reassurance. This additional resource sometimes took the form of a comprehensive list of ingredients and/or allergens in each dish. Various formats were reported for this including a pamphlet, spread sheet, book, folder, bi-fold menu and a poster on the wall. Many participants were either unaware of such information because they had not been offered it or it was not available in the venues that they frequented.

This reference source was used by both serving staff and the customer. Participants were often positive, suggesting that it simplified their food selections and raised their confidence in being able to order a meal avoiding particular allergens:

Like I say, (pub restaurant chain), brilliant, because they have the list on every single item in there – you know, dressings, even, stupid things, sauces... It's listed, all the allergy ingredients, information, is listed on there. So, any time you go there, you know what you're getting and you know exactly what's in everything..... and they update it as well, so it's always up to date, so that's brilliant. (PRE A39 G1 W: Peanuts, Celery)

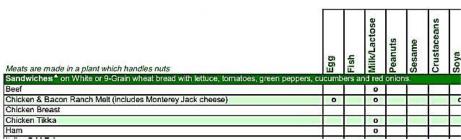


Interestingly although simply making a decision about what to eat based on the menu before and after the legislation was the most desirable option, it seemed that interacting with staff around an allergen reference source seemed to be less problematic than asking staff about particular items on the general menu.

So I asked them if they did anything and they actually came out, the waiters and waitresses have got a book a bit like what you're holding there, everything listed and what's in it. And they can actually say 'yes that hasn't got that in'. (PRE P5 G2 E: Gluten)

I would think that would be a very good idea, if they have a...a bible, if you like, of all the dishes in their restaurant, yeah. I'd probably be more likely to ask for that than ask a member of staff. (PRE A7 G1 E: Peanuts, Tree nuts)

One participant (A33 G1 S) drew on their experience as someone with an allergy and also a member of restaurant staff to illustrate the level at which he believed the customer would like to be involved in the inspection of a separate reference source listing ingredients:



But I know that (pizza restaurant chain) have a big massive folder of the menu items, so you can look through for peanuts or gluten or dairy, egg, milk, cheese, to make sure – like, if you've got an allergy, you just look

(PRE A25 G1 E: Peanuts, Tree nuts, Sesame. Diary picture)

for the starter you're looking for....Usually, the server goes to the book and tells...like, if they wanted to find out if they've got peanuts in the pasta, the server could tell you straightaway from looking at it. But, for a practice, I like to show the customer as well, so you're not just telling them. (PRE A33 G1 S: Peanuts, Crustaceans)

Access to an allergen reference source seemed to be more commonly encountered post legislation. Participants suggested that this can be a useful adjunct to a menu but not something that can easily assist with the initial choice of a dish and that being given this as a first response when asking about allergens is not helpful.

I think if you knew there was something specific you wanted to look at that you wanted to find. But apart from that, it's not something you'd use to decide what you wanted to have.

It's not an alternative to a menu? No, definitely not.

It's once you've narrowed down...Then you can look. (POST A32 G2 S: Gluten)

Yeah it kind of feels a bit sort of unwieldy you know. Something feels, it's sort of old fashioned, even though they only started...thumbing through a folder sort of feels a distinctly 20th Century thing to do, you know.... it's reassuring, it's just you know, you said how does that feel, and it feels unwieldy and slightly time consuming and you want them to kind of find out instantly, you know. (POST P13 G3 E: Milk)

Post legislation, the participant cited above (A33 G1 S) who worked in a restaurant explained that, allowing the customer to inspect the allergen folder for themselves was now standard practice:

...we don't tell the customers ourselves that there's not whatever in it, they read for themselves so they can make the decision themselves rather than us just saying 'there's definitely not peanuts in it' or 'there's definitely not wheat in it.' They can read for themselves. (POST A33 G1 S: Peanuts, Crustaceans)

Consumers themselves sometimes perceived that provision of the supplementary allergen reference source meant that responsibility for making safe choices was being placed on them and required them to make the effort to find something they could eat. This was not always appreciated, being interpreted by some as shifting responsibility away from the venue and back to the customer:

...you sort of get 'yes here's our file' and you can go through because you have to find your food, 'is it on the list? gluten yes'. And I found that a pain, I mean it's useful to have the information but ...it feels like I'm having to do all the hard work and you know it would just be very useful to have it on a menu, just simplified like, well like [name of another restaurant] do... I have to go back to square one and reconsider everything. So I find that probably the most annoying really, frustrating. (POST A50 G2 E: Gluten)

Okay so even if that was in a folder that would be acceptable?

Yes so yes, I mean it's, that's normally because (name of daughter) has said, 'has this got dairy in?' and they've been helpful and gone and got you that list. And that I think, that's the way they're getting out of knowing or whatever because I guess they then put it back on you, that it's your responsibility isn't it, that you've looked through and if you've misread it, then it's your problem. (POST P13 G3 E: Milk)

No obvious info on menu but when I ask for info they provided a book with all dishes on the menu with the ingredients so customer has full info. They did not want me to take a photo of it. Onus to work out for yourself. (POST A17 G3 E: Gluten. Diary entry)

Separate allergen free menu

Two years after the implementation of the legislation, participants reported an increase in the provision of *separate* menus. This was particularly true for participants requiring gluten free foods:

....they came out with a menu for gluten free and I looked at the original menu and they just about had everything that was on that menu on a gluten free menu and they'd never ever said anything about it before and it wasn't till then she says oh I'll get you the gluten free and I just ...I looked, I thought the meal that I was going to order is actually gluten free! (POST A53 G2 E: Gluten) Some considered that the provision of separate menus was an ambitious requirement, and others reported that this facility was not available for their specific dietary requirements:

At the minute my preference is a gluten free menu, a separate gluten free menu but I realise it's probably unrealistic to expect everywhere to do that so I guess, if I'm going into a place I know doesn't have a gluten free menu, it just makes things 10 times easier if they've got a little symbol. (POST A13 G2 W: Gluten)

I prefer, like I said, I do feel like the awkward person at meals so I do prefer if I can go in a place and not ask questions too much other than 'can I have a gluten free menu?' boom, you're done. (POST A13 G2 W: Gluten)

We were in Edinburgh in a restaurant there, and they produced a gluten-free menu, which I thought, wow, yeah! ...There, they actually had their own personal gluten-free menu, which was wow! (PRE A57 G2 E: Gluten)

Some participants recognised that the inclusion of too much information on the main menu might pose practical problems for food businesses and indeed that a detailed menu including unfamiliar ingredients may cause confusion for some:

I think, as long as it's not too prescriptive.... like small restaurants wouldn't be able to... sometimes they have a particular... atmosphere they want to create or evoke with their menu, and it's all like themed or something, and they were having to like, after every single thing, have like little symbols and stuff, it may not be fitting. Or sometimes, you know, if there's too much of a prescriptive thing anyway, I think that's like...it can kill the spirit of a place if they have to be very conforming to 'These are the rules'. (PRE A49 G1 E: Crustaceans)

Well, I would prefer a simple description, but I have been in restaurants where they maybe list about six different ingredients and such and such, and I maybe, I can recognise so many of them, and some of them, I'm not too sure about. So I really don't like that. (PRE A20 G1 NI: Peanuts, Tree nuts)

One particular variant of a separate gluten free menu was noted as being really useful

This was another (international restaurant) and their menu was a separate gluten free menu and it broke it down into 'if you have an intolerance' and 'if you don't' and the 'intolerance section' was definitely 'gluten free' and the 'not' was things that were subject to cross contamination...I thought it was really good that they made the distinction between 'you definitely cannot have any gluten, these are for you' and 'if you're not really affected by it, these meals'. That's helpful, it goes a step further if they bother to identify cross contamination issues. (POST A13 G2 W: Gluten)

Accessing and providing allergen related information online

There was certainly pre legislation evidence that alongside access to online menus, the internet was a valuable resource for participants seeking information about venues or dishes prior to eating out or ordering in. Participants used search engines to look up the standard ingredients and recipes of dishes. They also used review sites to assess the suitability of potential eating out venues when trying somewhere new. By acquiring this knowledge in advance, participants were attempting to pre-empt

potential problems, and this increased their control and confidence in subsequent venue and food choices:

I'd do a little bit of planning in advance. I'd have a look on the internet to see what food places are around, and if there were one or two that caught my eye, I'd have one or two places I know that were safe to eat. (PRE P2 G1 E: Peanuts, Tree nuts)

Just if I think, you know, we're going to go somewhere else, and I think, 'oh, I wonder if they've got a website', and I'll maybe have a wee look. A couple of times, you know, if we're going up to Glasgow things like Italian restaurants, I'll maybe say to my partner, 'Oh, they do have gluten-free – we'll just go up there.' (PRE A32 G2 S: Gluten)

...if I was out on my own, I would probably look at Trip Advisor, if I was going for a dinner, if I was somewhere on my own, or like Google restaurants in whatever area. (PRE A23 G2 NI: Milk)

Post legislation, participants reported much greater prominence for the role of information online this included information provided by the venue about their general approach to catering for customers with allergies/intolerances as well as allergen information on the menu or as a separate reference source. Such information increased confidence that the venue was fully aware of, and



cared about, allergy issues as well as allowing the customer to check that they would be able to find something that they could eat.

I looked online and I put in 'Gluten free Chinese - Edinburgh' and there were two choices, both of which I tried. I'm sure there's other places that maybe do small modifications or maybe I could choose very carefully but actually there's a security in knowing, first of all, that they're making special efforts and second of all, that I can have things that I wouldn't be able to have from a normal Chinese restaurant, things like battered chicken. They use a rice flour batter, that kind of thing. (POST A52 G1 S: Tree nuts, Gluten)

And then (Italian chain restaurant)...one that I've only been to recently because a friend suggested it and I checked out the website and they have a separate gluten free menu and that instilled a bit of confidence in me that there was a separate menu

and that I could choose anything I wanted off it. (POST A19 G2 NI: Gluten)

If my friends suggest going somewhere I always check the website or call up and check that they do it and not just arrive and hope for the best. (POST A19 G2 NI: Gluten)

We went somewhere a couple of weeks ago and there wasn't really much on the actual menu itself in terms of symbols, but the website was really, really good and it had a whole section just on allergies. (POST P4 G3 E: Milk)

Researched local restaurants for a meal out with a friend... A did not have a menu ... B was very clear but everything had dairy in it, C had no mention of allergens, D said to ask about food with allergens, E lists the foods with gluten and dairy, F had an excellent menu saying which foods have dairy and gluten and which they could accommodate for you... G has a separate gluten free menu which gave me reassurance they may know what they are doing. (POST A51 G3 E: Milk. Diary entry)

Food allergy? Intolerance? Coeliac? Find a restaurant that caters for you

We have food allergies. We love eating out. But until now, it hasn't always been easy to find restaurants with allergy menus or allergy policies. So we're making it easier for people like us to find restaurants where we can eat. On our website, you can search for a restaurant by location, cuisine or allergy. View menus from over 13,000 restaurants (with more being listed daily) and filter menus by allergy to see the dishes you can eat before you book. And you can read and leave reviews to help other people with food allergies decide "Can I Eat There?"

Have you discovered an allergy-friendly restaurant that's not in our directory?

(POST A25 G1 E: Peanuts, Tree nuts, Sesame) Diary picture) Venue and delivery websites sometimes gave the opportunity to make allergen related requests when booking online. Information was also obtained from sources other than venues such as social media and other web sources. These were more common for those wishing to avoid gluten e.g. the <u>Glutenfreecuppatea</u> and <u>Glutenfreeroads</u> sites, but were also appreciated by participants seeking to avoid other allergens:

A friend recommended a website to me today called 'canieatthere.co.uk' when I researched this site it seemed extremely helpful as you can input your allergies/intolerances/dietary requirements, postcode and it will tell you what restaurants are suitable. (POST A25 G1 E: Peanuts, Tree nuts, Sesame. Diary entry)

Participants also noted that sometimes there were signs in the venue pointing people in the direction of allergen information online. WiFi availability permitting, participants reported accessing online resources whilst in the venue to supplement information available on the menu.

Well pizza [name of chain].... We also have the thing on the menu that says if you want to make sure of anything else in the ingredients, take a picture of this QR code, and if you take a picture of the QR code, it takes you to (name of chain) website and you can check yourself. (PRE A33 G1 S: Peanuts, Crustaceans)

On that ('full allergen information on website' sign) I looked up and thought, 'well I'll sit in there', thinking I'll have a look on the website. I couldn't get any WiFi so it wasn't working so I couldn't look anything up anyway. (POST A44 G1 E: Milk)

Signs and notices

Prior to the legislation, the use of signs and notices was noted as one way in which venues communicated the allergies that they catered for. Participants had observed these signs - most often about catering for those seeking to avoid gluten - in restaurant windows, on billboards outside the venues, or on chalk-boards and notices within the venue itself and welcomed them. The availability



(PRE A57 G2 E: Gluten. Diary picture)

of foods that omitted the allergen they were sensitive to meant that more food choices were open to them and it made them feel more like everyone else:

There was somewhere that said 'gluten-free', on a board, and I thought, 'God, that's a first!' I have seen it, but it's very, very rare. (PRE A53 G2 E: Gluten)

If I was sitting there and saw signs saying 'gluten-free', I would just think, great, and order it. And I know you could say, well, they've maybe just stuck that bit of paper up, but I would believe... There's another bakery (see photo)... They've now got

signage up, gluten-free bread, scones... So I went in and I tried the bread – it was like a stottie, and a scone, and I got something else as well. (PRE A57 G2 E: Gluten)

Following the implementation of the legislation, participants identified the widespread use of signs and notices. For many, these were a welcome addition which suggested greater understanding of, and interest in, the dietary requirements of FA and FI customers, and a willingness to cater for their needs:

The chippy down the road from me has a big massive banner across the front of the shop, 'gluten free fish suppers'. He's smart because he's becoming known for that. (POST A29 G3 S: Crustaceans)

They've got a sandwich board outside which said, the main thing on it, it doesn't say what they serve, it just says gluten free, allergy something, something, nut, wheat, we cater for all here. (POST A34 G2 W: Sesame, Gluten, Milk)

Not unreasonably, signs are taken to indicate current availability of the products in question - though this was not always the case.

Me and my sister went out when we were in Nottingham to a cake shop where they advertised 'we can do gluten free and dairy free cakes' so my sister and I were hungry and were like 'great, let's go get a cake'. It was very much false advertising because they said that they did but you had to special order them a week before in advance. So, obviously we were like, 'should you really be advertising these?' It was really gutting (POST A51 G3 E: Milk)



Sometimes signage depicted the detail of which allergens were in particular products:

Photo #4: Allergen chart at (where I got the burrito). Very allergen friendly! (POST A11 G1 S: Crustaceans. Diary entry)

Whilst participants appreciated the effort made to communicate the presence of allergens through this detailed signage, they also observed that such signs were often not helpful in practice as they were placed in ill-considered or unsuitable locations:

(POST A11 G1 S: Crustaceans. Diary picture)

It's difficult with signage because I think about signage a lot with hospitals, airports, shopping centres and other places like that... because people don't always notice, people don't always put signs in the place where a person approaches (POST A15 G1 E: Peanuts, Tree nuts)

Was the notice in the right place so that you saw it before you ordered?

No. The notice should have either been in the menu or in the door as you came in. (POST A12 G3 S: Mustard)

You know, the placement isn't great, the placement design in that whole restaurant is pretty terrible. They haven't done it to be unfriendly or anything it's just poorly thought...You go in and then there's the counter, there's the till..... And then there's a sort of wall there sort of being the till area and there's a gap where the staff can come and go and the allergen chart is on the wall. So it can feel like you sometimes can't quite stand there, they really should've put the chart where people queue up next to the counter. But by the same measure, I've never seen the place like heaving and...the chart is there. (POST A9 G1 E: Peanuts, Tree nuts, Gluten, Milk, Fish, Soya)

Interpretation of signs/statements on the menu: Please engage with staff

Signs in the venue and statements on menus inviting food allergic and intolerant customers to engage with staff were a key development that participants particularly discussed post legislation. Pre legislation, this was rarely mentioned. Where it was participants reported that stating that '...please ask our staff...' on the menu was a welcome starting-point from which to make further enquiries in the knowledge that their questions would be taken seriously:

I mean, if they just had a nice wee clear 'We supply gluten-free' or 'Ask our staff', you know, to provide a list of, you know, if you do have any form of intolerances, and we can leave any ingredients out or something, yeah. (PRE A30 G3 NI: Gluten)

Post legislation, the use of signs and messages inviting customers to 'ask staff' was seen as the most common response to the legislation conveying the message that venues accommodated customers with special dietary requirements. For some participants, such messages were seen as a positive step forward in information provision, serving as a signal of allergen awareness and care on the part of venue, and providing 'permission' for customers to ask questions with an expectation of a constructive response:

I see a lot of signs at a local café, a local breakfast bar, or a burger van, which says 'any queries, just ask.' That will be for cakes and things for cafés or breakfast places. I mean they're aware and they're trying to help. (POST A58 G1 E: Peanuts, Tree nuts)



There are cafés I've been into that will have it now on like a little blackboard thing on the side of their till or

just before you go up to say, 'if you have any allergies or intolerances then please ask'. At least that's one step further forward than others... It's quite welcoming. It's like 'don't be scared. If you've got a question just ask and we'll answer'. (POST A44 G1 E: Milk)

I've definitely seen cafés, little greasy spoons that have a crappy laminated sign up saying 'oh if you want to ask about allergens, please do', which is nice... And I think 95% of the time people will know now, which is really good. (POST A11 G1 S: Crustaceans)

I'm definitely noticing a lot more, like a board outside saying to 'ask' or it's written somewhere, there always seems to be something on the menu that says, if they don't have an option or they don't have the symbols, then it will say to ask someone that works there which you wouldn't really see before. And that stops me from thinking, 'I'll not ask'. (POST A32 G2 S: Gluten)

The response of some participants was less enthusiastic; this individual (A29 G3 S) recognised that the message conveyed may not be borne out in reality:

If somebody puts up a sign and says 'Ask about allergens, our staff would be happy to help' then it doesn't feel like you're breaking the news to them that people could be allergic to shellfish or other things. So it makes you feel as if they're a bit better informed though it's probably perception rather than reality... (POST A29 G3 S: Crustaceans)

For another participant, the wording of such a sign intimidated, rather than reassured them:

I went to this really nice tea-rooms that served cakes and stuff and it didn't really say much about allergies at all. It was a really angry menu, but at the bottom it said in bold red that 'we are not a gluten free or nuts free institution so do inform us before you order' and it was more of a warning than a suggestion. (POST A9 G1 E: Peanuts, Tree nuts, Gluten, Milk, Fish, Soya)

Other participants took a sceptical approach and questioned the motives of venues that seemed to do the minimum in response to the legislation.

I'd say it's pretty much the same as it was in terms of 'in your face' allergen advice. I guess more of the places I've been going to have taken more of that kind of, the sort of basic approach to it. 'We'll put a sign up saying we give allergen advice' rather than making it front and centre. But at least now, you know... (POST A11 G1 S: Crustaceans)

Why do you think they've put that notice up then?

Because they have to. Because they legally have to say that, I suppose equal opportunities or fair trading or whatever you want to call it but I think because they have to. I've notice them come up more but it doesn't mean that anything has changed behind the counter, it just means they've advertised the fact that 'if you have an intolerance, let us know', but they still can't help you. (POST A44 G1 E: Milk)

Yeah, I would say maybe about 80% of the time when you're going out, especially in more restaurants that have like a chain or other restaurants with the same proprietor, they would have a 'oh if you do have an intolerance or an allergy, please let your server know



(POST A52 G1 S: Tree nuts, Gluten. Diary picture)

and we will act accordingly.' But it always says after that, 'although every care will be taken, we cannot guarantee that the dishes will be completely allergen free.' Every time.... Just covering themselves, aren't they? (POST A59 G1 S: Peanuts, Tree nuts, Milk, Eggs)

I think there is a line about whether it's in there, it's very much throwing the ownership back to me the parent, they've kind of got round it, but not really got round it, because they are telling you that yes, they are aware that there's allergies, but you need to let us know. Whereas would a lot of people always ask? I don't think they always would. (POST P6 G1 E: Peanuts, Tree nuts)

Others noted that participants may not know what to ask or expect from the venue, and a number had not tested the invitation as they did not wish to ask or thought there was little point in doing so because they did not expect a constructive response. Participants speculated that by rephrasing 'please ask our staff' messages, venues could convey a more positive and proactive approach whilst maintaining their fundamental message:

Put it in on a plaque somewhere, or on the menus. 'We cater for allergens' and name them. That's how it should be done. (POST A28 G1 W: Peanuts)

...'we cater for different dietary requirements'...wording like that as opposed to, 'ask us if you've got an intolerance'. Because saying to 'ask', the general feel is that when you ask they say 'no' anyway, whereas if it was to say on the front on a board or whatever to say, 'we do cater for different dietary

requirements' will make me think, 'oh well, maybe they've now changed, they do, do a dairy free option. (POST A44 G1 E: Milk)

The responses of participants indicate that this very general 'please ask our staff' message may potentially be seen as another variant of 'may contain' - that is that it is a box ticking exercise that is fulfilling the letter of the law but not its spirit.

Staff as information resources

In familiar venues, participants valued the reliability of established relationships with staff and the levels of knowledge and care associated with 'safe' eating out environments. Where these relationships were not yet established, there were a range of signals from staff that were used to infer trustworthiness. Evidence of being known and of their allergy being known, of staff knowledge and awareness even when contacted ahead of time, of proactive staff with a willingness to adjust the dishes, with a positive and engaged, who dealt with difficulties in a positive manner and communicated well were all interpreted as being likely to mean that the venue would provide a safe and enjoyable eating out experience.

Fundamentally, although participants appreciated the need to ask questions of staff, and valued these social interactions when helpful, for many the mere act of asking carried with it an inherent risk of being seen as 'making a fuss', and the additional potential for misinformation and mistakes. Where information was judged to be satisfactory, participants' feelings of 'drawing attention' and being seen as 'different' were reduced; and their levels of control and freedom in their food choices were enhanced.

Post legislation, participants felt that there was greater awareness in relation to the needs of FA/Fi customers. This normalised the eating out experience of participants to some degree, and made them feel more included; particularly where staff were seen to be proactive in volunteering information or accommodating customer's needs. Overall, although post legislation participants continued to express a preference for written information as the base line expectation, for many, greater staff awareness coupled with the 'permission' to ask questions afforded by the legislation, made participants more willing to engage with, and trust staff as an information resource

Reticence about relying on staff

Overall, the attitudes and actions of staff had the ability to make or break the eating out experience. Staff served as a supplementary resource in the context of insufficiently detailed menus, and as a guarantor of the menu's accuracy. As such, participants reported that they used staff as an information resource to a greater or lesser degree. However, pre legislation many participants reported that the mere act of asking staff for further information caused them difficulties as it singled them out as different.

...the waiter goes away and brings the chef to the table, and everybody in the restaurant's looking at you. That gets embarrassing because you feel like you've insulted his meal or something like this, or you've said something and he's come to sort it out, you know. People don't know what the conversation is and you're trying to lighten it, in that you're feeling embarrassed because the chef has come to talk to you, do you know? (PRE A53 G2 E: Gluten) Yeah. And it's a social situation. You don't really want to make a big bloody fuss, do you?! (PRE A54 G3 E: Gluten)

Although they appreciated that such enquiries of staff were necessary to ensure the safety of dishes, participants stated that they did not wish to draw attention to themselves, be seen as bothersome or make life difficult for others in their party. These were fundamental causes for concern which resulted in discomfort for food allergic/intolerant customers:

You don't...it is the kind of...you don't want to make a fuss, rather than it worries me what people think. You just kind of don't want to be a big fat attention-seeker over something stupid. (PRE A29 G3 S: Crustaceans)

Well, yeah, making a fuss, yeah, yeah, exactly so... You don't want people thinking, 'oh, look at him, what's he doing [laughing]?!' We're all trying to order and... (PRE A42 G3 W: Milk)

For some participants, the perceived embarrassment of asking staff for further information led to the potential for self-imposed limitations in their food selections:

...if I don't ask, my wife will say, 'but that could contain nuts,' and she will ask for me, which is a source of embarrassment for me because they're probably thinking 'Why doesn't he ask?' but it's just who I am – I don't want to...any bother. I'd just rather choose a safer option. (PRE A7 G1 E: Peanuts, Tree nuts)

For others, the need to make enquiries of staff was, in itself, an undesirable scenario because it implied a lack of care on the part of the venue in not providing adequate written information:

I've never complained about it, I think because I'm kind of in the way of asking, but it is irritating when you feel that...that not everything is mentioned [on the menu]. That would be my pet hate. (PRE A29 G3 S: Crustaceans)

Yeah, you'd have to totally scrutinise the menu to try and... And again, yeah, you end up asking as well, you do end up asking them, because sometimes they don't...you know, I can imagine they don't put all the ingredients, so you do have to end up checking, which isn't ideal. (PRE A42 G3 W: Milk)

Other participants were less reticent about making enquiries of staff. For these participants, there was a sense that they had a legitimate entitlement to ensure their own safety when eating out. The idea that they might be seen as fussy was only a secondary consideration resulting from a lack of staff understanding of the seriousness of their condition:

Like you ask the...like the waiter or waitress, 'Can you just check for me if the chips are gluten-free?' and they'll just be like ...'Yeah...' or they'll be like 'Yeah, I think so...' I'm like, 'No, that's not good enough – I need to speak to the chef or someone in the kitchen who can give me a definite answer.' Or if they kind of disappear and come back with an answer, I'm like I didn't hear that conversation that went on... but I feel like I have to be that picky because it's such a serious problem. (PRE A13 G2 W: Gluten)

On occasions where participants were more willing to interact with staff, it was often the perceived response of others within their eating out party which made participants feel less comfortable or limited their routine behaviours when making enquiries or complaining to staff:

... sometimes I'm more worried about the people with me, you know, when I say, you know, 'Can I have this, but I don't want that and...' and, you know, you can sort of see them going 'Sorry!' you know, kind of thing, to the waitress [laughing]. It's more that, because they don't necessarily always get why I'm doing what I'm doing, you know, you can...sometimes I feel a little bit self-conscious for them. (PRE A52 G1 S: Tree nuts, Gluten)

Post legislation increased confidence to ask

For some participants, implementation of the legislation had resulted in greater confidence in asking staff for information about allergens. Participants described their rationale for this behaviour change in terms of greater awareness of food allergies/intolerances, venues' invitation to 'ask our staff', and the backing of legislation that gave them permission to ask staff about allergens as a 'legal right':

I don't know if it's because now it's a legal thing, I feel I've got the confidence to... it's an expectation now, I don't know... I think it's a progression probably because people are more aware of intolerances now and they know that they can ask now. I think it's sort of been a progression and I think it's progressed more since... Oh, it gave me more confidence to ask. Yes, definitely. Because now I know it's legislation and they have to do it now. (POST A18 G3 E: Milk)

But it wouldn't frighten me to, well it would frighten, it scares us, but it wouldn't really faze us if I wanted something to go in and ask, because I've got the right to ask. (POST A55 G1 E: Eggs)

Okay and why have you asked more?

Because I guess because people are kind of generally more aware, so I don't feel so much of a fusspot. (POST A46 G2 E: Gluten, Milk)

There is certainly a lot more information available now and it's more to the fore and it's easier to ask and you hope that people are better trained now. (POST P8 G1 S: Peanuts, Tree nuts)

...obviously since participating in the survey last time, I know that it's an option and I know I can get arsey if they don't give it to me. (POST A9 G1 E: Peanuts, Tree nuts, Gluten, Milk, Fish, Soya)

Whilst asking staff was seen as a more viable option post legislation than previously, there were occasions when making enquiries of staff was simply not practical. As one participant noted:

Are you quite happy to ask?

Yes, I'm kind of used to it now but it would be easier yes, if the menu told you exactly because if the place is busy it's not always so easy to ask as well. (POST A25 G1 E: Peanuts, Tree nuts, Sesame)

For other individuals, asking staff still proved to be a challenging prospect and the fear of being seen as fussy still limited the enquiries that they were prepared to make:

Eventually there will be more questions I should be asking, you know, whether they're cooked in the same fryer, something that's got a coating on it, things like that which I'm not always thorough with these things. I can see that I'm getting better and better all the time but I'm not there yet. (POST A32 G2 S: Gluten)

It's not an embarrassment thing for me because as I said, I'm happy enough to, well actually no, I don't know if it is an embarrassment thing, because when I'm doing it for my daughter, in my mind I'm doing it for her and I don't mind making a fuss for her, whereas I think for me, it's more, 'oh I don't want to make a fuss', I think that does impact on me but I don't even notice....If I were really interested, no I probably wouldn't ask, I'd probably try and then find out the hard way. (POST A14 G2 S: Milk)

...it should be on the menu. I don't think you should have to (ask) - sometimes people will act like you're making an unnecessary fuss so I tend not to because of that, I tend not to make a fuss. (POST A45 G1 W: Gluten, Milk)

Staff signals that warrant confidence

Participants used a range of more or less objective and subtle cues relating to staff as a means of estimating broad levels of trust and confidence in venues, and subsequent food selections. These were used to assess the extent to which staff could be relied upon as information sources when making enquiries before, and when ordering food.

It's the uncertainty of not knowing that people know what they're doing. I know it sounds stupid... (PRE A39 G1 W: Peanuts, Celery)

Being known

As noted above, participants tended to frequent eating establishments that were familiar and where they felt safe. This was in no small part due to their prior experience of interactions with responsive and accommodating staff. Participants prized such relationships:

...the (Asian restaurant). We always ask the man, he's very nice and just ask him to check there isn't any flour. And he always says it's fine. (PRE P5 G2 E: Gluten)

...like (British restaurant), the waiters know us, and they're like, right – I still say I've got the allergies, you know, and they're like, 'yeah, okay', you know, 'no problem'. So, you know, we're quite regulars. (PRE A39 G1 W: Peanuts, Celery)

I tend to go to places that I've been before and I've spoken to the chef and really explained the situation and feel that they fully understand it. (PRE A60 G1 E: Peanuts, Tree nuts)

Evidence of knowledge and awareness

When seeking information from staff, many participants equated knowledge about ingredients and food preparation with a better understanding and appreciation of food allergies and intolerances as a whole. Participant trust was increased when staff exhibited good knowledge, and this knowledge was particularly valued when it was also shown on a practical level. Conversely, trust was undermined and breached when staff displayed a lack of knowledge either about the content of the food or the implications of consuming allergens:

(Sandwich chain) are usually quite good because I've been...went to one years, a couple of years ago now, and I said, 'Oh can I have that, but I'm allergic to cucumbers so you're going to have to completely...' you know, and she said, 'Well, that's cut in the same machine, so you can't have that.' So, they kind of know what's...what's cut what and what's doing what. So, (sandwich chain) are quite good for knowing what's in the products and stuff. (PRE A39 G1 W: Peanuts, Celery)

...the number of times you ask for soya [milk] and people, they just do not listen at all, and you'll say to them 'Is that soya?' 'Yeah, yeah,' take a sip, no, it's not! And then you go to them, 'Excuse me, I asked for soya milk and you acknowledged I asked for soya milk, and you've given me cow's milk.' 'Oh, really sorry about that.' 'I have an allergy to it, you know, could be quite serious for me...' 'Well, would you like a glass of water – I'm sure that will make you feel better!' No understanding, no concept of... (PRE A60 G1 E: Peanuts, Tree nuts)

Staff that were assumed to have poor or incorrect knowledge were not asked as they were not considered to be a reliable source of information:

So, deli counter, they don't have a lot of... you don't know what's in it, and even the person behind the counter, they don't really care what's in it, so there's no point in asking them the question. (PRE A44 G1 E: Milk)

Being proactive

A proactive approach on the part of staff was often considered to be indicative of being a reliable source of information. By proactive we mean where staff were giving information or acting to indicate care or concern ahead of time rather than simply responding to the questions of FA/FI consumers. People valued this and it was a signal that they were to be trusted:

When we had the children, they brought out these pizzas, and everything was in bowls and he said, 'oh, this is this, this is that...' He asked if any of the children had any allergies. They were just much more...aware. (POST A45 G1 W: Gluten, Milk)

If the restaurant was of a reasonable quality and you were paying a reasonable amount for the food, why couldn't the waiter come along and say 'Before I take your order I would like to discuss, do you have any allergies? If the food we prepare here gives you any sort of reaction?' (POST A22 G1 NI: Fish)

Has never a waiting staff member come up to you and one of the first things they say is, has anyone got any allergies or intolerances? No never. Would that be good? Yeah it would be good. Also it wouldn't make you feel so different. (POST A44 G1 E: Milk)

But if someone was proactive in sort of saying, you know, 'here's the menu today, we've got this, we've got that, and it's got a gluten-free section', it may make those people with gluten-free...'oh, fair enough, that's quite good, I'll look at that'... So I suppose the confidence of knowing what's in the food and how it's prepared and all that sort of stuff, I suppose... (PRE A4 G2 E: Gluten)

A willingness to adapt dishes

A willingness to adjust dishes to accommodate dietary needs was particularly valued by participants. Such actions were seen as practical demonstrations of being able and willing to meet the needs of people eating out with an FA/FI.

The (Asian restaurant), as I said, they done gluten-free. They were able to offer an alternative to soy sauce and everything. So, she was able to say, 'Well, you can't have noodles but you can have rice noodles.' So, she was actually more knowledgeable than me on coeliac [laughing], so that was good. (PRE A48 G2 S: Gluten)

You can see the chefs and they're totally accessible to just nip up and say, 'Excuse me, do you bind the burgers with egg or not?' you know, and they'd say 'No, we don't, but the breadcrumbs on the chicken are, but we can do them without if you want.' And it's just like that quick – you don't have to ask a waitress... so that makes a difference. (PRE A56 G1 E: Eggs)

Yeah, I think because I tend to sort of stick to the places that I go to, so that sort of...it's been like a gradual thing of, you know, of building up a relationship with them, if you like, that sort of...that I know that I wouldn't feel uncomfortable with asking them to alter something for me. (PRE A38 G3 W: Gluten, Mustard)

I was going out with friends, so I researched the places that someone suggested...One of them did mention that they could be gluten free, dairy free and then listed which ones they could adapt. (POST P13 G3 E: Milk)

Reception when contacting the venue ahead of time

The reception that participants were met with when getting in touch with potential eating out venues ahead of time was also used as an assessment of the reliability of information provided by staff.

Well, nine times out of 10 now, if we book to go for a meal, we will say 'Somebody has coeliac disease, can you cater for it?' and that's usually what we always say now, and the answer is nearly always yes, but it's always, 'Can you remind us nearer to the date?' (PRE A57 G2 E: Gluten)

And to be honest, if we're not sure, we'll ask and then we just go out. If they can't reassure us, if we don't have a choice then obviously we have to ask. And if they can't reassure us then we don't take the chance. (PRE P8 G1 S: Peanuts, Tree nuts)

Demeanour of staff

Within the venue or when ordering take-out food, participants picked up cues based on their perceptions of the general demeanour and attitude of staff. Levels of trust and confidence were particularly enhanced where participants perceived a good level of engagement on the part of staff characterised by a cheerful, attentive, and proactive attitude. When these impressions were positive, participants experienced raised levels of trust and confidence:

They can fob you off. But sometimes waitresses will go in and come back out and say 'yep, the chef says this and this' and it sounds quite positive. You sort of get more confident from other people's confidence. (PRE P5 G2 E: Gluten)

If they looked like they were enjoying their jobs and they looked like... If someone was just like saying to you like, 'Oh yeah, what do you want to order?' or do they look like they actually wanted to serve you and wanted you to ask questions really... (PRE A41 G1 W: Gluten, Celery)

Yeah. Also, if a waiter is really keen on like listening and just writing all the ingredients, just to make sure she speaks or he speaks to the chef. So, yeah, just basically communication and the way they treat those things. (PRE A9 G1 E: Peanuts, Tree nuts, Gluten, Milk, Fish, Soya)

Equally, when demeanour and attitude were judged to be more negative, participant trust and confidence were eroded, and this reduced their enjoyment of the eating out experience:

There's been times in the past when I know...I can read people, and I know that they're thinking 'Oh, for God's sake, this is a fad!' sort of thing, you know, and it's not good enough. (PRE A18 G3 E: Milk)

I've had somebody tutting and going 'Oh!' and walking back to the kitchen like, oh, making you feel a nuisance, yeah. (PRE A36 G2 W: Gluten, Milk, Eggs, Mustard)

I've had them just shrug their shoulders and say 'I don't know.' 'Well, does the chef know?' 'I don't think he will,' you know, sort of thing... and you're thinking, 'you're joking!' (PRE A53 G2 E: Gluten)

...if you get brushed off really: 'Oh yeah, yeah, we can deal with that, that's absolutely fine – oh yes, of course it's nut-free,' or 'of course it's wheat-free.' There's no substance to that whatsoever. (PRE A60 G1 E: Peanuts, Tree nuts)

If they're umming and aahing and saying maybe it has, maybe it hasn't, you think avoid it, but if they're pretty certain or they go and check then I'm always fairly happy. Nobody turns their nose up and says why are you asking that. It's not disrespectful. (POST A58 G1 E Peanuts: Tree nuts)

...it's good more than mixed. But every now and then if we do go to an odd place you think oh god, you can see their faces drop when you say dairy free menu or dessert, they're going 'oh God here we go again'. (POST P11 G1 W: Milk)

Dealing with difficulties

Even in the face of staff mistakes, participant confidence could be restored where staff follow-up was positive, attentive, and informed:

Because I think I... I just returned my meal because I ordered pork and it had nuts, and I just asked her to exclude nuts, but she forgot I think, and when pork arrived, I clearly saw nuts, so I just said, 'Can I just kind of replace my meal?' So, I was quite confident because I know that I said to her so it was not really my fault, so they replaced the meal so it was fine... they were really... especially the manager, so really good and nice and friendly. (PRE A9 G1 E: Peanuts, Tree nuts, Gluten, Milk, Fish, Soya)

There was a bit of... she had a reaction because they'd given her something wrong. So, that was bad, but then she emailed and told the manager about it and they said, right, they apologised profusely, and were like, 'when you come back, tell us you're coming back and we'll make sure your experience is much better'. We actually went back about two weeks ago, and she explained, 'this is me from before, bad experience, and you told me to let you know if I was coming back – I'm back'. And it was like, right, and there was a huge wait for tables, but they gave us a table straightaway. We got to speak to one of the higher staff, like with the manager, who knew more about it. She took our order and she was like, 'right, we'll make sure there is no cross-contamination'. (PRE A13 G2 W: Gluten)

For many participants, it was not lack of knowledge per se that reduced their confidence in the information provided, but rather the perception that staff were not prepared to admit their ignorance and to use their initiative in seeking out the information required. Where staff showed a willingness to facilitate access to more informed personnel, participants were reassured:

Quite often, they don't know the answer, so they will say, 'oh, I'll go and speak to the chef.' Quite often, the chef actually comes out. I tend to use all the sources of information that are available to me to make a decision. (PRE A60 G1 E: Peanuts, Tree nuts)

I'll say to him, 'this is what he wants but he's allergic to nuts. He cannot eat anything. If it's touched with nuts, get it away.' And they go back and ask the chef, and they come back and say, 'it's fine', and then we go from there. (PRE P12 G2 W: Peanuts, Milk)

Communication problems caused by language difficulties

Communication processes were further disrupted where understanding was perceived to be compromised by accent, dialect, and/or language issues:

Problem is, half the time, understanding the answers, and getting yourself understood.... Whereas I can't understand certain accents in Scotland, and it's only very few, there are other nationalities that can't understand me as clearly because I don't speak in a Scottish accent, obviously. (PRE A14 G2 S: Milk)

I know that sometimes, if maybe it's like a small (European restaurant) or whatever, and the people are from those countries, they might not necessarily – like sometimes, you know, I'm not saying in general, not stereotypical, but like, you know, sometimes they may not really fully understand what you're asking about, and so that's the only time when it can be a bit confusing. (PRE A49 G1 E: Crustaceans)

And I don't know if it's a language thing... but the (Asian restaurant) they don't know what you're talking about. They're very friendly and will cook you something but they don't really know what you're talking about. I guess the (other Asian restaurant) would be like that as well. (PRE P5 G2 E: Gluten)

A number of the waiters were from Europe and they weren't particularly articulate, the foreign language aspect of the European Union in restaurants has I think had a not particularly good effect on whether the waiter is going to be able to discuss in detail or much detail with you because they lack a good command of English (POST A22 G1 NI: Fish)

Staff perceived as less experienced

More broadly, participants identified other factors which inspired confidence or served as barriers to their perceptions of staff members as reliable information resources. Younger staff members were sometimes viewed as inherently less reliable as information resources. This was largely put down to an absence of life experience, and the perception that there was likely to have been minimal investment in their training:

... maybe if there's more young staff, they're probably new and they don't know much about the kitchens, yeah, that would put me off a little bit. (PRE A25 G1 E: Peanuts, Tree nuts, Sesame)

It depends. If it's an older person serving you, then yes, but if it's a younger person, they go, 'oh, what's coeliac?!' (PRE A48 G2 S: Gluten)

But, you know, you get young girls, young lads, you know, who are just working there randomly, who look at you as if, 'oh, just a minute, I'll have to check in the kitchen,' and that's where you're a bit wary. So, then, if I was already in there, I would pick something totally plain. (PRE A57 G2 E: Gluten)

Sometimes you get a lot of young counter staff, no disrespect to them, but they are just sales staff. Then you get older staff who know a little bit more, or who've been there longer, who know a bit more about the ingredients within the products. It seems to be an age thing, the older the member of staff, the more kind of proactive... (PRE P2 G1 E: Peanuts, Tree nuts)

...these young waitresses when you ... you know and they're 16 - 17 year old and they haven't got a clue and they disappear to see the chef to see if they even do a thing like gluten free. You'll think you'd mentioned a space ship or something you get you'll get that blank look and away they'll go and they'll come back and say yes we do and you know (POST A53 G1 E: Gluten)

Better training was thought to hold the key to greater levels of trust and confidence in the information provided by staff. Participants reported their first-hand experience of inadequate staff, and also appreciated where sufficient training was evidently in place:

I think that the people that employ them should train them on, you know, people...that there are people that are food intolerant and have allergies and are not being difficult. (PRE A18 G3 E: Milk)

And again, training probably for staff is another thing because sometimes, some places, no matter how many times you say I'm allergic to something, it comes out with it on and you think... (PRE A39 G1 W: Peanuts, Celery)

No. See, that's the biggest problem – train them properly on the contamination part. That's the problem. (PRE A48 G2 S: Gluten)

And even in the run up to legislation coming in you could see that there were places where the training for staff had been taken more seriously and was a lot more professional in the approach to allergies. (POST P8 G1 S: Peanuts, Tree nuts)

I suppose you could only expect clarity on every product couldn't you. That's what you'd expect but whether that's possible, um for the reasons we've just discussed because the staff aren't as knowledgeable and if staff are changing you know there's got to be a proper training programme hasn't there. (POST A17 G3 E: Gluten)

Post legislation improvement

Post legislation, participants used similar cues to assess whether staff were a trustworthy information resource about allergens in food; could confidence be placed in their words and actions? When commenting on how this had changed over time, this was often along the lines of there having been an improvement. Participants reported observing an increased awareness of food allergy and intolerance and a greater likelihood of finding staff with a positive and helpful manner.

I definitely think so (that staff members are better informed). Because before, you would often find that they would say 'I don't know' or 'I need to check' but now I think they are more on board and it seems they got a proper brief on that... Yeah, I think the staff have been way more informed than they were before, menus I think have been updated really well. (POST A9 G1 E: Peanuts, Tree nuts, Gluten, Milk, Fish, Soya)

... they'll come over and speak to you about what's in the food as well and how they're cooking it which they didn't used to do... I do feel that they're more able to answer the questions straight away without having to run off to the kitchen and come back. (POST P10 G1 S: Crustaceans)

The only reason they would be different would be if they were new. But no, on the whole, the places I go to, if I've been there a long time or they're knowledgeable or if they don't know, they'll ask. But I haven't had a problem yet with any of the staff or with any of the questions that I've asked. (POST A26 G2 E: Milk)

Everyone is usually helpful, no one is ever like 'um I don't know', everyone is like 'oh I'll definitely go and check for you'. But I don't know whether that is because... well of course they care, but it's sort of their job to be friendly isn't it and they are doing it out of their best interest as well. I've never had a negative experience of someone shooting me down when I ask. (POST A59 G1 S: Peanuts, Tree nuts, Milk, Eggs)

... she'd obviously had a conversation with the kitchen so she knew what to offer. I had a lovely cooked breakfast plus she bought me out a carton of soya milk for tea. This place made me feel nothing was too much trouble and that the waitress/kitchen were confident with the information they'd told me. Definitely going to take the family back here one day. (POST A44 G1 E: Milk. Diary entry)

Over and above improved interactions with staff, post legislation, some participants were keen to relate improvements in the range of food that was now available suggesting that such experiences were still a relative novelty within the eating out context:

(Burger chain), so it was 'create your own'. So they did a bun free skinny, so the lady said 'You go on the menu and go bun free skinny'. So instead of your bun, they serve it with salad and then you could have whatever topping you wanted on it. So that was a dream, oh I haven't had a burger like that in, I don't know how long. You can get gluten free burgers but this wasn't like a gluten free burger. (POST A57 G2 E: Gluten)

... there's a café called (name of café) and (name of daughter) and I popped in for a tea and I said 'do you want anything to eat?' and she said 'I'll have a look about, I think I'll have a muffin'. And the girl was straight in and said 'can I just check, does she have an allergy, because I've got a really bad nut allergy and I need to just let you know...' and I'm thinking 'that's amazing, you never get that'! It was really, I was quite taken aback and the girl said '... I've got to advise you that we do prepare with nuts in the kitchen'... it's a blueberry muffin, I wouldn't have anticipated that there should be nuts in that, but I was very impressed that that was somebody who actually had, I suppose, taken the initiative to actually be as forward as that. (POST P6 G1 E: Peanuts, Tree nuts)

(Artisan burger chain). I'd gone out with a friend about 12 months ago and we were in Solihull shopping and she said, 'oh can we eat here, oh I bet you can't eat here'. And the girl at the front said 'why don't you think you can eat here?' and I said, 'I need gluten free and it's obviously burgers' and she said 'yeah, but we've got a gluten free menu'. And I had a gluten free burger, they bring the bun in a separate, they're sealed still in the packet, so that they know they're not going to cross contaminate the bread. I was quite shocked and very excited and quite emotional because I had a burger. I hadn't had a burger in a bun for a long time! (Parent & adult child) (POST P5 G2 E: Gluten)

The legislation and its impact on food allergic / intolerant consumers

Pre legislation, participants were generally positive about any legislation which would be likely to enhance information provision and reduce risk when eating out. In principle, participants believed that the legislation would 'normalise' their food allergy / intolerance conditions. This in turn would result in greater freedom to try new venues and foods. Participants also believed that the legislation would empower them to seek information, and to expect constructive and knowledgeable responses from staff in return. However, the fact that issues of allergen cross-contamination, food preparation, and ingredient substitution were not covered in the legislation was a cause for concern which had the potential to restrict some participants' new-found freedoms. Overwhelmingly, participants believed that delivery of the legislation should be conveyed in written form, and preferably on the menu, in order to maximise levels of consumer control and independence in selecting their food choices.

The greater allergen awareness exhibited by food providers and staff post legislation, had improved many FA/FI customers eating out experiences. For many, this was also translated into greater freedom and choice when eating out; though this depended on the allergen which participants avoided. In the absence of adaptation of meals or provision of alternative ingredients, greater information did not necessarily equate to greater choice for participants. The risk of allergen cross-contamination limited choices and was still a cause for concerns for many. In line with pre legislation findings, participants preferred allergen information to be delivered in written form or using recognised signs/symbols; though greater awareness on the part of staff made participants more amenable to the potential for their input in order to ensure a safe eating out experience.

When informed about the introduction of the FIR legislation, participants initially responded positively and surmised its likely impact on their eating out experiences. They felt that it would increase their trust, and the variety of options available to them:

Oh, I think it would be fabulous, especially, you know, going out, I think you would have a lot more confidence and you would try different things. Even the menu, to have the menu and, you know, to know exactly... So, I think if I could see exactly what was on that menu and what didn't have nuts, I would try... It would be fantastic actually, and I would try so many different things. (PRE A20 G1 NI: Peanuts, Tree nuts)

Well, I think it's great, honest to goodness. Well, I mean obviously, it's just down to providing as much information as possible, you know, being a wee bit more sympathetic, you know, just giving a few more wee alternatives. (PRE A30 G3 NI: Gluten)

Interestingly however, although largely positive in their assessment, a number of participants added caveats, noting that the legislation could have gone further or did not entirely apply to their personal circumstances. It was evident that participants retained a level of apprehension and wanted to see the legislation in place before making a final assessment:

Some of it will, absolutely. The nuts, certainly, that would be my concern, if Brazil nuts are in there. Pistachios, again, you know, if I can see them, there might be a problem, and if I can't see them, I don't think there will be. But yeah, Brazil nuts, certainly. Gluten would make a big difference, you know, not having to sort of constantly ask, you know, 'Is there, is there...?' (PRE A52 G1 S: Tree nuts, Gluten) I think it will just make it quicker to order, maybe, or just a bit easier to see what's in things, which is – it's a step in the right direction anyway. That's the main thing, isn't it? You know, from having nothing years ago, and don't even know what's in it, to, you know, listing things that's in it... It's a step in the right direction and it's going to make it easier for a lot of people, I can see, but there's always going to be questions so... (PRE A39 G1 W: Peanuts, Celery)

So it's that typical kind of... the first step is not quite going far enough. But it is a step, hopefully, it's a step towards it, and having... making all the places aware that you can't just ignore, and that people are not coming in with intolerances to spite you. (A29 G3 S: Crustaceans)

Despite this initial reticence, participants identified a number of ways in which the legislation had the potential to increase their trust and confidence, and improve their eating out experiences.

Two years on from the implementation of the legislation, participants gave mixed reviews about the impact that it had on those experiences. The majority had observed some improvements in allergen information provision when eating out, although the pre legislation reservations expressed by participants were borne out for many in their day to day experiences.

A28 G1 W Pre & Post quotes

Yes, that should be...that would be very helpful if you knew, because...I have to ask, but if it was there, you wouldn't have to ask, would you?...I guess it might change things because I'd know what choices – I might have more choices of what I could eat. So, it would be a good thing, yes. (PRE A28 G1 W: Peanuts)

Most of them are knowledgeable now. But before, they weren't, they did have to go ask because not a lot of people were aware of it but now they are knowledgeable. (POST A28 G1 W: Peanuts)

A47 G1 S Pre & Post quotes

Yeah, I mean, for me, that's lovely, but it doesn't have carrots on there, or apples or all the other fruits that I'm allergic to [laughing]. But it's good - I'm not knocking it! It's better than what we've got now... For me, it's not going to help very much, but there we go, it will definitely help other people. (PRE A47 G1 S: Tree nuts)

About the same... I do feel like I have more information and I think people are more aware. I think that's probably the most useful thing... It's definitely better but it's not perfect though, because you've still got people who aren't doing it. (POST A47 G1 S: Tree nuts)

P6 G1 S Pre & Post quotes

Fantastic, brilliant... Yes I think it will help, yes definitely. I think if it's actually highlighted, then I can say 'oh look, that dessert (name of daughter)... you can have this', or 'can't have that.' It's there for you to see. It will be great if staff can answer the questions as well, it's better for them. (PRE P6 G1 S: Peanuts, Tree nuts)

I think you were so hopeful with what the legislation was going to do. Yeah that it's going to change the world, but it hasn't. I know. It is interesting that in 18 months... 18 months on and we've probably moved a little bit but you really would have hoped that it would have moved a lot more than this and it's a bit of a shame it hasn't, isn't it? (POST P6 G1 S: Peanuts, Tree nuts)

Raising awareness

Participants believed that the implementation of the legislation would raise awareness amongst staff in eating out venues, and in turn this would lead to greater knowledge, understanding, and information provision. Underlying these sentiments were the notions that the legislation would serve to legitimise, validate, and in a sense, 'normalise' allergies and food intolerances so that these consumers would not feel 'different' when eating out:

And the other thing is that hopefully it will make people more aware of providing food that doesn't contain these allergens and therefore providing a better service for everybody and making places more accessible. (PRE A29 G3 S: Crustaceans)

As soon as you ask if it's got gluten or wheat in it and they say 'yes, and so does this range'...'But you can have', perhaps they'll be able to start saying, 'you can't have that but you can have this'. Not just telling you what you can't have, but offering you what you can. (PRE P5 G2 E: Gluten)

I would expect to be able to ask and get some decent answers yeah, because if that's what they have to do then they need to make sure that whoever is on the phone or whatever, there is someone there who can give me that information because that would then be my right. (PRE P1 G1 E: Peanuts, Tree nuts, Milk)

Increased awareness on the part of food providers was a consistent theme which underpinned many of the other changes and recommendations that participants made following introduction of the legislation. Although some participants were not yet satisfied with the provision of allergen information as it currently stood, raised awareness was deemed to be a first step from which other improvements could follow:

I think it's a progression probably because people are more aware of intolerances now and they know that they can ask now. I think it's sort of been a progression and I think it's progressed more since (the legislation)... (POST A18 G3 E: Milk)

... partially because of the legislation, partially culture change because, as I said, I don't know anyone who isn't fussy in some way or intolerant rather than allergic. So yeah, everyone's just a little bit more aware of that, you know. And it's good. And it's really good because no longer do you have to pretend... it just expands your options I think. If I'd been like this 20, 30 years ago, I'd still be mocked for having these kinds of preferences. (POST A11 G1 S: Crustaceans)

Yes, I think a lot of people are aware of it aren't they and how dangerous it can be and they don't want to see somebody flat out on the floor... if you go to a café just for a cup of coffee and you fancy a piece of cake and they look at you and you tell them that you've got an allergy and it will kill you and then they will make the effort to find out if they've got it in or not. (POST A27 G1 W: Peanuts)

I think slowly but surely it's getting a bit more normal. There is still the issue, I hate causing a fuss and sometimes when you go out you do feel awkward. But then I think restaurants and supermarkets have really caught on and it does feel a bit more normal. (POST A13 G2 W: Gluten)

Permission to ask

Crucially, given the discomfort that many participants reported when making enquiries of staff, it was felt that the new legislation would give consumers 'permission' to ask for further information, with the expectation of a constructive and sympathetic response. It should thereby reduce their discomfort in asking:

Well, I will be more confident choosing not only restaurants but even like different places, just to make sure that it's... I get this service. I think I will be more confident to speak to staff members, will not be wasting their time, because sometimes that's what I feel, and also, will be more confident in large parties, as we spoke, because it will not cause that much trouble. (PRE A9 G1 E: Peanuts, Tree nuts, Gluten, Milk, Fish, Soya)

So, you know, I think that just puts the information out there for everyone, that I would feel...I would probably feel comfortable asking about it if I'd already seen it on the menu, because it would make me think, well, they're already aware of it, rather than asking and then having to explain and, you know, describe what's going on and why I'm asking. (PRE A32 G2 S: Gluten)

Okay, so you've said at the moment, if you needed to, you'd have a quiet word but this legislation then, would make you feel more confident, more able just to ask any...

Yeah, definitely...he would probably be more confident with it as well if it was the norm. Then that makes it easier for a teenager, that you're not standing out or being different. (PRE P7 G3 NI: Milk, Soya)

Furthermore, participants reported that this 'permission' to ask with the expectation of a knowledgeable response, would shift the responsibility away from the customer and onto eating out establishments and their staff:

Yes, I think that would be very helpful, you're starting off almost like you're on level pegging; you don't feel like you might be being fobbed off. You feel like they have a little of your interest at heart. Because one, they want you to come back; secondly, if the staff are much more aware, it just lessens the issue of 'do I want to go in here?' (PRE P2 G1 E: Peanuts, Tree nuts)

So it's very unsympathetic and so we were always a bit uncomfortable and he would've been a bit embarrassed about it and things so I think if it is a legal rule that they have to do that, then it takes away from the emphasis being on us and the emphasis then becomes on them. (PRE P7 G3 NI: Milk, Soya)

Freedom to be more adventurous

Participants felt that the legislation would increase their confidence in food safety when eating out, and would open up new opportunities for variety and autonomy in relation to the venues and dishes that they might try:

I'd definitely be more adventurous. If I was sure there was no nuts in it, and somebody could say to me, yes, or even if it's on the menu. Oh no, I would definitely love to try different things and, you know, I would do that, mm. I think it's fantastic, you know, if it all works out and... (PRE A53 G2 E: Gluten)

I would slowly build up a repertoire of restaurants and things, foods, that I can have, and if we go there, I can have A, B and C, and if we go there, maybe I can have that, you know, and you start to build up a bit of a thing again, and suddenly your social life opens up a little bit when you want to go for a meal. (PRE A53 G2 E: Gluten)

I wouldn't have to try the same sort of pizza – I could try different ones... Definitely change things which I would eat, and definitely try other meals and see what they are because I like to experiment, try different other meals because the ordinary isn't always so good. It's good to get different nutrients and vitamins in your diet as well, try other foods and try them out. (PRE P7 G3 NI: Milk, Soya- child response)

Again, I'm the kind of sort of person that would likely look at the thing and think, 'oh, I know that's alright', and take the chance maybe. But if I had somebody to discuss it with, and it was something that I really liked the sound of, and I could say to them, 'there's definitely not nuts in that?' and they say, 'no, definitely not,' I would feel really good about that. I would try different things. It would be very, very good, and I definitely would use that, I would speak to somebody, yeah. (PRE A20 G1 NI: Peanuts, Tree nuts)

One parent also observed that it would give them the opportunity to encourage their child to be more adventurous:

I think I'd push him to try other foods because at the moment I don't tend to push him because he knows what he likes, and if he's out on his own what he's eating is safe for him to eat because there's no nuts or anything in it that can make him ill. So I'd rather him stick. But then if they got these things in place I'd more than likely encourage him to start eating something different. (PRE P12 G2 W: Peanuts, Milk)

Post legislation, some participants observed that the new legislation had afforded them more choice when eating out, and that this had improved their eating out experience by giving them more freedom:

So I'm more likely, you know, it's a high profile and I respond to that because otherwise you know it's just interesting, it broadens my horizons and they tend to be the more independent and sort of quirky places that I would prefer to eat in anyway. (POST A50 G2 E: Gluten)

Because I might go to a cafeteria which is, you know there's a high chance that something's tinned or it just says like 'lentil soup', well, does it have cream in it? And I think 95% of the time people will know now which is really good. Whereas before it was...yeah, I'd be like 'oh okay, can I just have a plain roll then please', you know. (POST A11 G1 S: Crustaceans)

I think there's more choice out there now, more awareness. So I think it has got easier in terms of eating out, going to supermarkets etc... When it comes to my friends saying '(name), you choose where we eat' I can turn round and say 'anywhere' these days, more or less. Rather than having to struggle to find one or only going to one I know has a separate gluten free menu, now I can 'oh, you choose somewhere'. Chances are, they'll have the symbols and yeah, more choice. (POST A13 G2 W: Gluten)

So I do think it is a bit more managed. I think before I felt as if I couldn't go out anywhere or I would be restricted to what I could choose but even since last time I've noticed there's so much more about, a lot more things. A bit more clear cut about what they have on their menus with the allergen symbols and I just feel as if there is a lot more choice. Whereas before, it was a bit of a, you were put out by asking 'what's this option?', now I feel as if there's so much more about it that it's easier. (POST A32 G2 S: Gluten)

Others noted however, that some eating out providers appeared to adhere to the letter, but not the spirit of the legislation. These providers did not offer alternatives, and simply declared what FA/FI customers 'could not' eat:

I know there's no point in me asking questions in certain areas, there's no point in me saying, 'do you have this?', 'can you do that?' because they don't, and even though they have the little small print on all these menus saying, 'if there's an allergy, then let us know', their answer is, 'ok then, that means you can't eat this', not, 'we'll provide you that instead'... At no point do they (supermarket café) ever come back with a carton of soya milk, when, to be fair, it's in their own shop! You'd think they'd just be able to go and get one but they don't look at it as though they need to have it... their easier answer is just to say, 'no we don't provide soya, or dairy free spreads'. (POST A44 G1 E: Milk)

They might be a bit more aware but they're not widening their search, they're not widening things to accommodate. They're just simply saying, 'right, we've got to tick this box by law, so let's tick it'. That's not necessarily accommodating for people and saying 'right, let's look at what we can do'. 'Can we do a couple of gluten free meals, mainstream gluten free meals?' (POST A53 G1 E: Gluten)

...when I said about the burger, I said 'what's dairy free?' and they said 'well you can eat it if you don't have the salad dressing, the coleslaw' and something else. But they didn't offer an alternative. So just to say 'we can give you a balsamic dressing', nothing came as an alternative and I think that's the thing is there's still very few places think outside the box and go, 'I could give you an alternative'. (POST P13 G3 E: Milk)

Allergen cross-contamination, food preparation and ingredient substitution

Participants expressed concern pre legislation, that the issues of allergen cross-contamination, food preparation, and ingredient substitution were not addressed in the legislation. Although they appreciated that the legislation may be of benefit to some, from their perspective, these concerns reduced their levels of trust considerably. The need for stricter legislation relating to staff training and food preparation practices in the kitchen was recommended:



(POST A25 G1 E: Peanuts, Tree nuts, Sesame. Diary picture)

It's whether they're going to wash the pans out properly and, you know, after cooking a nut dish, and then cooking yours specifically. A lot of times, they'll just re-oil it and...or just wipe it out with a cloth and redo it, but it needs to be washed off obviously in hot, soapy water... It's all about trust, isn't it? It will make it easier for a lot of people, you know, with the crustaceans and even the eggs and milk, but again, it will still be for them the cross-contamination, education in the kitchen and for plating up, I suppose, is the big thing that needs to be... (PRE A39 G1 W: Peanuts, Celery)

I think there's a larger concern when you can't see what they are doing to the food, and what they are using as a substitute for something else. (PRE P2 G1 E: Peanuts, Tree nuts)

It would be even better if they could say what animal it's from. Because if it said it was cow's milk free then he couldn't have it, creamy things, and milky things. Of course if it says milk free he can have it but because it's not making the distinction, then if it doesn't say milk free then you think you can't have it

but maybe they used goats or sheeps milk or cheese. (PRE P13 G3 E: Milk)

Sorry, genius people, your thoughts are great but it's not going to work! Yeah. Because it just won't stop the cross-contamination?

I don't know what chefs have to do to be qualified nowadays, but you can work in a kitchen without being qualified as a chef, so there has to be some kind of food hygiene or something that you have to pass, an allergens course, that would be great... (PRE A48 G2 S: Gluten)

Concerns over cross-contamination and ingredient substitution were still present post legislation, and participants gave examples of their first-hand experiences of the potential for allergen cross contamination and broader perceptions of food providers' rationale for failing to consider these issues:

You can go and choose your own doughnuts and they've actually added a Nutella one in the middle and the servers can all get mixed up... Well it's just all-normal doughnuts and then they put the new Nutella one in the middle. Yes and obviously someone could just pick it up and then touch another one. (POST A25 G1 E: Peanuts, Tree nuts, Sesame)

Say it's got pasta and sweetcorn but it's got a sauce, I would definitely ask what's in it. The problem is, when they're together they're quite near each other and you don't know if anything is contaminated or whether somebody's used a spoon that's in another dish, so I ask for another spoon as well. (POST A26 G2 E: Milk)

I've noticed some places, I think the staff have probably been told to say it, 'yes, we can do you something gluten free but we can't guarantee cross contamination. We'll make it in the same kitchen, we've only got one preparation area'. (POST P5 G2 E: Gluten)

Participants also took the opportunity to highlight helpful experiences of good practice on the part of venues in relation to allergen cross contamination:

I got recommended by a friend through work that said they had eaten at this restaurant and they were fine with letting people in with nuts because everything is cooked in separate pots in that restaurant. So they are really good with cross contamination. And then another friend has an allergy, I think gluten or something, and she was eating and she was like 'oh is there anything in this?' and then they showed her the cross checking list... (POST A59 G1 S: Peanuts, Tree nuts, Milk, Eggs)

Yeah, without asking I've been told - 'oh by the way, you've ordered toast and just want to let you know we use a separate toaster'. I think if it's an independent business that maybe focuses on gluten free as a USP maybe then I trust them, they're making an effort and doing it properly. (POST A13 G2 W: Gluten)

Similarities and differences between groups

Analysis of the pre legislation interviews revealed few differences between participant groups in relation to their information seeking and preferences; use of information resources; and views regarding the new legislation. In addition to the core themes reported above, parents emphasised the need to spare their child disappointment; allergic participants identified some reliance on an early warning reaction which alerted them to unsafe foods. Sometimes there was a perceived under-representation of information resources relating to particular allergies and this created distance between the experience of one's own allergy or intolerance and that of others.

Developments post legislation, led to greater concerns about the misrepresentation of certain groups and the under-representation of information resources for particular allergies/intolerances. Coeliac and gluten intolerant participants observed that although a fashion for 'gluten free' diets had provided them with greater choice, there was also a risk that their gluten avoidance was seen as a 'fad' and not taken as seriously as it merited. Participants noted a disparity in information provision meant such that those avoiding particular allergens (gluten, nuts) were relatively well catered for, and in contrast and in particular, milk allergic/intolerant participants were less likely to have seen an improvement in awareness, choice, or improvement in their eating out experiences.

It was clear pre legislation that there were few differences between adults in the three allergy and intolerance groups, and between adults and the parents in terms of their information seeking and preferences when eating out. They shared preferences regarding availability and effectiveness of information resources, their perspectives and preferences when interacting with restaurant staff, and their views on the impact of the new legislation. Over and above these common core perceptions and behaviours, it was noteworthy that certain characteristics were represented more strongly for some groups than for others.

The role of parents

For parents, alongside the processes of venue and meal selection characterised by all groups, there was an emphasis on their child's gradual adjustment to their food allergy/intolerance, and the need to avoid disappointment and minimise their child's frustration. These priorities were largely dependent on the age of the child and their capacity to understand and accommodate the nature and implications of their food allergy or intolerance.

For younger children, parents focused on limiting their child's distress and helping them adjust to their condition:

So if some of the other kids were having like milkshakes and your daughter sees that they are and is keen to have one as well, what would you do in that situation? Um... that's quite hard actually. She's always been brought up on water and juice. So quite often she doesn't realise she's missing out on anything else. (PRE P4 G3 E: Milk)

He will eat the crusts off the pizza, he won't get his hands near a piece of garlic bread and he will cry his eyes out. If he wants a piece of the pizza you have to take the cheese off it, and there's still maybe milk... It's unfair, there's something of some description, everyone else has it and he can't and he can't understand because he's so young... You get milkshakes in these places, ice cream. Kids are finishing their food and then going straight up for their (chain milkshake drink). I tend to do drive through for that particular reason. (PRE P9 G1 NI: Milk)

For older children and teenagers, parents still focused on limiting distress whilst trusting in their child's adjustment to manage their own condition:

Yeah it impacts a lot because most desserts, unless he just gets fruit, he can't have them. So what I do then is if he's made something or I'll try and get something he can have when we go back home. But it means that he can't be, he can't enjoy it the way he used to and the way the rest of the family does because he can't and he looks on the menu, even for the main meal, any part of the meal, we just don't know. (PRE P1 G1 E: Peanuts, Tree nuts, Milk)

I mean he is sensible. He knows what he can and can't have, and his friends know. They'll go to (Burger chain) and he'll have chips and an ice cream because he knows he's fine with that. If they're going into Edinburgh he'll go into (store chain) for a sandwich, I mean he's not stupid. His friends accept it. They've known him since primary school. It's not a new concept with them so he's fine with that. (PRE P8 G1 S: Peanuts, Tree nuts)

Early signs of allergic response as an early warning system

Following the processes of venue and meal selections characterised by all groups, some food allergic participants [predominantly those allergic to nuts] described an additional strategy which they used for checking the safety of their food. They reported early warning reactions which allowed them to stop eating or remove themselves from the environment before their reaction became too severe or distressing:

I feel like I can taste it because my tongue swells, my lips swell, and then I just think, 'yeah, it's nuts', and then I go to the toilet, and I make myself sick on that occasion. (PRE A58 G1 E: Peanuts, Tree nuts)

Yeah, taking a bite and then just waiting like a few minutes to see, because you would know sort of within a few minutes if anything was going to happen. (PRE A31 G1 S: Tree nuts)

Because I have like an early warning system, where my body, my throat reacts to it, I just stop at that point. With peanuts especially, and most particularly peanut butter, I can't even be in the same room as someone opening a jar of it and I have to leave. (PRE A7 G1 E: Peanuts, Tree nuts)

Food intolerant participants had no such early warning response and they were less able to predict and pre-empt any potentially delayed and unexpected symptoms. The absence of obvious symptoms within the eating out setting, made these participants feel that their condition was not appreciated or treated with the seriousness that it deserved.

It becomes stuffy. I don't have any swellings or any hives or anything like that. And then I have to go to the toilet. I have to go...quite urgently really, and it's, you know, it is embarrassing. You know, it's embarrassing for my family that I've got to sort of rush off, but you know, also for me, you know, it's embarrassing. (PRE A38 G3 W: Gluten, Mustard)

It can affect my everyday life by...if I'm going out for something to eat with a friend, then I really have to be careful of what I'm eating because I know that, if we want to go shopping afterwards, I'm going to have to really look at what I'm eating because, otherwise, I'm going to be running to the toilet, and it is embarrassing, having to say 'I'm going to the toilet', and then being in there for 10, 15 minutes or whatever while you're really ill. (PRE A8 G2 E: Milk, Soya)

If people eat nuts, they will drop at your feet and they're calling 999. But if people eat gluten, it's a slow process. And because you're not collapsing in the canteen it's like they don't really care, because you don't do anything there. (PRE P5 G2 E: Gluten)

Restricted diets and identification with wider groups

Although no definitive group differences were identified in the study, it would be dangerous to assume that food allergy or intolerance sufferers see themselves as a united group, or that a 'one size fits all' communication is necessarily helpful. Some participants did identify with other populations with restricted diets. This conveyed a sense that they were not in the minority but part of a wider group:

...if you're eating out, you've got vegetarians, you've got vegans, you've got people with allergies, you've got Muslims and you've got Jews so... I'm trying to think if they're the people who have restricted, you know...

Restricted diets, yeah.

So, that's us, we're that group, we're all, you know, bonded together [laughing]. So, a sign or something up to say, you know, 'there's going to be vegetarian options', there's going to be, you know, things like gluten free, and there's, you know, there's kosher and there's halal, you know, and then there's allergy. There's gluten free, isn't there, people have that issue. So, normally, you know, people are conscious of... so, it's... it's not just me. (PRE A15 G1 E: Peanuts, Tree nuts)

However, for others, this sense of inclusion within a wider group had a detrimental effect. These participants wished to highlight the fact that their food allergy/intolerance was not a lifestyle choice, and that the focus and priorities of many information resources were not meeting their needs:

... a lot of it on there is more vegetarians or halal, but there's nothing that says 'may contain nuts'. It's very rare you get them. It's not the best. I think they ought to provide more information. It's like they brought out that thing with calories now. They put the calories next to the menu, the meal. It's a good idea but they should do that for allergies as well. A lot of places don't do that. (PRE P12 G1 W: Peanuts, Milk)

I got in an argument recently when (sandwich outlet) was in the news about doing halal food, and (child's) argument was they'd state if there was something vegetarian. If they're willing to state that something's halal, why won't they state if something's gluten free?... Because it's not a living choice, it's an allergy. Because they'll put on things, if something's got nuts in, at restaurants and stuff. If they put on 'it's got nuts', why won't they put on, 'it's got flour'? (PRE P5 G2 E: Gluten)

Furthermore, some allergic participants were themselves sceptical of food intolerances and wished to distinguish their food allergic status from what they perceived to be the more ambiguous 'intolerance' groups. Allergic participants felt that the seriousness of their condition could potentially be undermined when they were included within a wider grouping:

I think nut allergy tends to get bunched together with intolerances and like, preferences. Like a vegetarian can't eat something that's touched meat, and you think, 'oh, that's a bit funny', and it tends to... I think maybe some people have that reaction to nut allergy as well... if I get that reaction, sometimes I do like slip out the Epipen and put it on the table and just reflect because, you know, it is that serious so... But I think people's perception is that it's just a bit of a fad, even with nut allergy, so... Yeah, I can understand why people are like that because everybody's intolerant now, aren't they, to something? (PRE A31 G1 S: Tree nuts)

Oh yeah, intolerances. Well... you might realise from my tone that I've got a bit of an opinion about this. I mean how many people have gone to a medical professional and had a food intolerance diagnosed? You get so many people these days that have self-diagnosed food intolerance... that's not good enough... I think a lot of people with intolerances are actually just fussy eaters. (PRE P10 G1 S: Crustaceans- child response)

Equally, some food intolerant participants appreciated the distinction between their intolerance and what they deemed to be more severe, and potentially life-threatening forms of food allergy:

I think they're aware that obviously certain allergies that I guess are the most severe, nut allergies, people can die... (PRE A42 G3 W: Milk)

Like nut allergies maybe, because they can be fatal, can't they, if people have those, if they have a peanut, you know, oesophagus swells up and they can die, can't they, so they have to be more wary than me. (PRE A5 G2 E: Gluten)

Post legislation, making the distinction between being food allergy/intolerance and the avoidance of foods as a lifestyle choice was particularly important for participants who were coeliac or gluten intolerant. In a similar way to allergic participants who sought to distinguish themselves from intolerant customers pre legislation, coeliac and gluten intolerant participants expressed concern that their condition might be viewed less seriously due to a fashion for 'gluten free' diets unrelated to food allergy/intolerance. As one participant put it:

...things have changed and got better, yet I've still had reactions and of course, with the growing increase of fad diets, there is always the risk that you're not taken seriously. And you know, yeah great, gluten free is getting awareness these days but it's about whether it's the right type, or whether people just think it's... you have to be taken quite seriously as a coeliac sufferer and I don't think we are anymore. So it's kind of swings and roundabouts. (POST A13 G2 W: Gluten)

The observation that a rise in the provision of 'gluten free' foods might be more to do with appealing to a wider market rather than serving the needs of coeliac and gluten intolerant customers, was also observed by participants who were not gluten intolerant themselves:

Yes. As I said before, the only thing I've clearly noticed is the increase in the allergy advice for gluten free, gluten allergies. It does seem to be linked to the diets that people are embarking on, people who are not gluten intolerant. (POST A1 G3 E: Milk)

In light of these circumstances, one coeliac participant was pleased to have their particular condition identified in print at a venue and took this recognition as a signal that the seriousness of their dietary requirements were understood:

I was surprised when ordering by a little note that said, 'are you coeliac?' and then like information which was refreshing. I don't often see that. A lot of them will say gluten free but never specifically coeliac, I don't really see that word anywhere. (POST A13 G2 W: Gluten)

Importantly, there was also a perception of inequality in information provision for people that reacted to different allergens.

The only thing I see is 'it contains nuts', that's all I ever see. I never see anything much about dairy... I know it would be a pain for them, for the restaurants, it would be a pain. It takes up more of the

menu. But if they can... they nearly always put 'contains nuts' or 'has been near nuts'. Why can't they put 'contains dairy' or 'contains gluten'? It doesn't take much! (POST A26 G2 E: Milk)

They don't really have that for nuts in a lot of places, but I guess it's just... they don't feel they need to. I don't know why, but I think they take gluten a bit more seriously, for some reason. A lot more people seem to be allergic to it now than they were. (POST A59 G1 S: Peanuts, Tree nuts, Milk, Eggs)

Differences between those avoiding different allergens

Concerns about a disparity in the provision of specific allergen information between food allergy/intolerance groups were accentuated following implementation of the legislation. Milk intolerant participants in particular reported feeling that their dietary needs were less likely to be catered for equitably when compared to gluten intolerant customers. Whilst they appreciated the importance of gluten free provision, they believed that their milk intolerance was poorly understood, and that they had to make undue compromises as a result:

No it (information provision) hasn't jumped. Certainly not with lactose and dairy products....I would say that I think I've noticed a slight improvement in nut allergy information. I think that is standing out more than it has before and for, is it coeliacs? My friend is gluten intolerant and certainly for coeliacs it's far better and she's noticed it as well... that is the main one that... I see all the time. But from my point of view, I haven't seen much on dairy. (POST A1 G3 E: Milk)

It was mainly vegetarian and vegan, yep, and gluten free and they were the main ones... not dairy, nothing. I haven't come across a single place that talks about dairy free. But I think it's because it's not very well understood. (POST A51 G3 E: Milk)

I'm much more aware that they highlight food that is vegetarian or for coeliacs but certainly not for (son's) issues... In my experience, it's been ineffective for (son's) condition and I have actually been in a restaurant with a friend that was presented with a gluten free menu for breakfast and I was so impressed that they could do that with the gluten free but wasn't available for dairy. (POST P7 G3 NI: Milk, Soya)

I find that quite often that they'll put the two together because obviously gluten free is more dangerous which is good because I can get the lactose free stuff, but also not good because the gluten free stuff tastes horrible often...They had quite a lot of things that were gluten free and quite a lot of things that were gluten and lactose free, and not many that were lactose but not gluten free. The whole thing was mainly aimed at coeliac people because they have far greater restrictions. (POST A10 G3 S: Milk)

One participant (A46 G2 E) was keen to highlight their experience of eating out in a venue that accommodated their milk intolerance:

10th June 2016, visited a local independent café... You can also get ice cream in a little tub or something similar. They have dairy free mint chocolate chip ice cream available if you ask. I've taken a photo of the little sign of that and it's all made on the premises, the ice cream and the sorbets. The sorbets are all dairy free as well, and there's always at least one available. I've actually taken a photo of the sign outside the café. (POST A46 G2 E: Gluten, Milk. Diary entry)



(POST, A46 G2 E: Gluten, Milk. Diary picture)

More commonly, in the absence of widespread provision of information for milk intolerant customers, some participants relied on vegan dishes to ensure that they avoided milk when eating out:

I think there's more awareness of sort of intolerances and allergies, but also I think there's a lot more people who are vegan, so the dairy thing, I think it's a kind of, that seems to be, a thing that people are doing. (POST A46 G2 E: Gluten, Milk)

And (daughter) went up to London in the summer and they found, she said they found a café that did vegan stuff and she said, 'I've never had so much choice'. There was something going on in Cardiff that was a vegan day, so she went and got vegan chocolate and lots of and yes, not all of it was very nice, but just to actually have somewhere where she could go and see all these vegan things. (POST P13 G3 E: Milk)

Some considered the reasons behind the absence of provision for customers avoiding milk products, or speculated about the potential marketability of such provision:

Wouldn't you then zero in on the dairy free options? Wouldn't it make life easier? Oh, I would, it would be fantastic. In a world where they would tell you it was dairy free! Or there was a supplementary menu that tells you about the dairy free options in one place? That would be incredible. That would be really nice to see but then I think there aren't enough people who are lactose intolerant for companies to see it as viable or enough people to make a fuss. So I'm part of the problem I think. There aren't enough people making a fuss about it because of people not wanting to make it a big thing so companies don't have to make a big deal about it. (POST A51 G3 E: Milk)

I've had a lot of people ask me about nuts. Gluten free pizzas, we've certainly started a gluten free pizza. I didn't realise how big a market that was. I think that's about it. Nuts and gluten... *Not dairy?*

Not as much because people know that if they're getting a pizza, there's usually cheese on the pizza. But we have had a couple of customers who asked for no cheese or bring in their own cheese and we're always happy to deliver.

Okay, but there's no move to introduce vegan cheese, sort of dairy free cheese? Not that I know of. But it would be a good market, I'm sure, like gluten free. But not at the moment, no. (POST A33 G1 S: Peanuts, Crustaceans)

Phase 03: Information seeking practices and information provision preferences: a quantitative approach

This third section of the report relates to the quantitative component of the research. This consisted of a survey conducted pre legislation in 2014, the primary aim of which was to characterise the views of a national sample of food allergic and intolerant consumers relating to their preferences for information about non-prepacked foods for purchase and consumption when eating out and, to their quality of life. The post legislation survey conducted in 2016 repeated many of the questions in order that any changes in eating out practices and preferences, and in quality of life, could be assessed.

Research objectives

The main aim of the quantitative research was to survey, both parents of children with food allergy/intolerance and adults with food allergy/intolerance and to characterise any change between pre and post legislation in relation to:

- > Eating out behaviours
- Positivity and preferences in eating out practices
- > Satisfaction with, and confidence in, information provision about allergens
- Preferences for information provision
- Quality of life

Specifically, in the light of previous work reporting cross sectional comparisons pre and post legislation in the grey literature, we hypothesised that there would be an improvement post legislation in satisfaction with, and confidence in, information provision practices and in quality of life.

Building on the findings of the qualitative work where we observed that post legislation there seemed to be differences in the satisfaction with information provision between people avoiding different allergens, we hypothesised that in the post legislation survey those avoiding milk would be less satisfied than those avoiding other key allergens.

Methods

Design:

Data for the pre legislation questionnaire survey was collected between 30th October and 21st November 2014 before implementation of the EU Food Information Regulation guidelines. The post legislation survey data were collected between 8th November and 19th December 2016.

Participants:

For the pre legislation survey a total of 879 individuals were recruited of whom five were excluded due to missing data greater than 20%. The remaining 874 individuals were aged 18-65 years with food allergy (FA) or food intolerance (FI) or with a child with FA or FI to one of the 14 allergens and sought to avoid those allergens when eating outside the home.

Five hundred and ninety-seven (68.3%) were recruited through the websites and social media activity of one of three online food allergy/ food intolerance support organisations: Anaphylaxis Campaign (114; 13.0%), Allergy UK (466; 53.3%) and Coeliac UK. Coeliac UK also distributed the survey to a random selection of members on their database (total 85; 9.7%). One hundred and ninety-four (22.2%) were recruited via the recruitment company (Acumen Fieldwork). Fifteen individuals were not allocated a recruitment source code (1.7%).

Of the 874 participants who completed questionnaires pre legislation, 632 agreed to be contacted again two years later to take part in the post legislation follow-up survey. Of this consenting population, 58 participants did not provide viable re-contact details (an email address or telephone number) and could not therefore be recruited. The remaining 574 participants were invited to take part and of these, 188 (33%) returned to complete the post legislation survey and their responses were subject to analyses. An additional 24 participants who completed both surveys were excluded from analyses due to a change in reported symptoms post legislation as this resulted in completion of different HRQL measures pre and post legislation thus preventing comparison of HRQL between the two time points. Figure 3 shows the breakdown of pre and post legislation survey participants.

In addition to the 188 participants who returned to complete the post legislation survey in 2016, 204 additional participants were recruited to take part in the post legislation survey. This allowed us to check the possibility that the views of returning participants had been significantly shaped by their participation in the pre legislation research.

Ethical Considerations:

The ethics guidelines of the Psychological Society of Ireland (PSI) (2011) and of the School of Applied Psychology, University College Cork (UCC) (2014) were adhered to during the course of the study. Approval was obtained from the Research Ethics Committee of the School of Applied Psychology, UCC.

Participants were given an information sheet and a consent form prior to the study and were made fully aware of what the study entails. Participation in the study was voluntary and participants were free to withdraw from it at any stage, without giving a reason. Participants were provided with contact details of the researcher for any issues or questions they had. Data was stored in compliance with data protection laws. Copies of the consent documents that participants were required to complete before taking part in the study can be found in Annex 6 and 7.

Materials:

Screening: All new participants in either the pre or post legislation surveys were required to complete a screening questionnaire to establish (a) that the individual experienced an adverse reaction to at least one of the 14 allergens covered by the legislation or had a child who did; (b) that they avoided foods containing the allergen; and (c) that they ate out at least on some occasions. Based on the nature of their reported symptoms, all participants were then routed to an appropriate version of the questionnaire relevant to allergy or intolerance, adults or parents. The criteria for classifying participants' allergy or intolerance are shown in Table 1 above (p. 28). Allergic participants were also classified based on the severity of their allergic reaction (mild, moderate, severe) for later analysis. These criteria are also shown in Table 1.

A range of questions were asked about the nature of participants' allergy or intolerance including timing of last/most severe reaction, age of starting to avoid allergen(s), source of diagnosis and any tests used; advice or treatment recommended; strictness of adherence; timing of prescription of injectable adrenaline, and reassurance or concern this prescription causes.

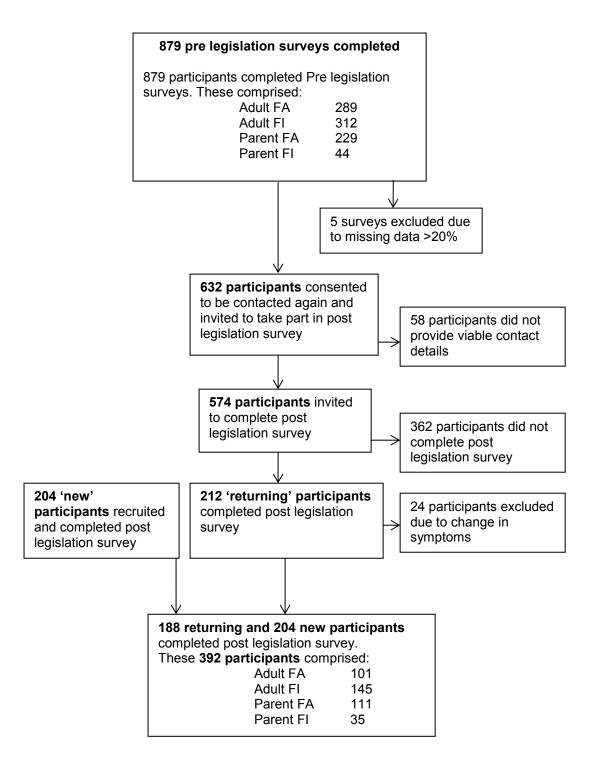


Figure 3: Flow chart of pre and post legislation survey participant numbers

Key variables that were explored both pre and post legislation included:

- Venues for eating out
- Positivity about eating out
- Adventurousness in eating out
- Preparation for eating out
- Reliance on speaking to staff when eating out

- Satisfaction with written information
- Satisfaction with verbal information
- Confidence in communication
- Preference for ingredients information
- Preference for staff as a source of information
- Preference for allergen menu
- Preference for signs and symbols
- Quality of life

In order to ensure that pre and post legislation responses were directly comparable for these key variables, the wording, structure and order of questions presented in the pre legislation questionnaire was maintained in the post legislation questionnaire.

Quality Of Life: The Food Allergy Quality of Life Questionnaire (FAQLQ - Parent Form (PF), Child Form, Teen Form and Adult Form (AF)) was developed and validated to evaluate the impact of food allergy on quality of life⁸⁰. Items scored on a 7-point scale ranging from 0 (no impact) to 6 (high impact on health related quality of life - HRQL). An overall HRQL score comprised factors including emotional impact, food avoidance, and social and dietary limitations. The FAQLQ-PF and AF have demonstrated high levels of cross sectional, longitudinal and cross-cultural validity (content, criterion, discriminant and construct validity) and reliability (internal consistency and test-retest)⁸¹. High total scores on the FAQLQ indicate higher negative impact of FA on an individual's quality of life.

In order to create a sensitive, multi-dimensional measure to assess HRQL in children and adults with food intolerance, the FAQLQ questionnaires were modified following interviews with 22 FI participants. In line with the FAQLQ, high total scores on the FIQLQ indicate high negative impact of FI on the individual's quality of life⁸².

Various measures of the role of support group membership and social media use in supporting allergy management and eating out practices were included in the post legislation survey along with measures of social support, coping⁸³ and need to belong.⁸⁴

Full copies of the parent and adult questionnaires for both pre and post legislation surveys can be found in Annex 8, 9, 10 and 11 respectively.

Data Analysis

Data was analysed using SPSS version 22. The following approach was used in relation to both the pre and post legislation surveys.

Firstly, data verification and cleaning took place. Each individual item from the questionnaire was coded; which included defining variable names, formats and labels. Items were reverse coded where appropriate (see Annex 12 and 13). Data screening was conducted to assess the suitability of the data for analyses⁸⁵. The extent of missing data (less than 2%) and non-response patterns were assessed to see if missing items would impact on analyses⁸⁶. Missing values for items within all composite variables were imputed^{87 88 89}. Composite scores were calculated based on the mean (M) scores of

⁸⁰ DunnGalvin et al. (2008) *Op cit*

⁸¹ Ibid

⁸² DunnGalvin, A., Barnett, J., Begen, F.M., Ryan, K., & Lucas, J.S. (under review) Development and Preliminary Validation of the Food Intolerance Quality of Life Questionnaire (FIQLQ): Adult Form, Food and Nutrition Research.

⁸³ Carver, C. S. (1997). You want to measure coping but your protocol'too long: Consider the brief cope. International Journal of Behavioral *Medicine*, 4(1), 92-100. doi:10.1207/s15327558ijbm0401_6 ⁸⁴ Nichols, A. L., & Webster, G. D. (2013). The single-item need to belong scale. *Personality and Individual Differences*, 55(2), 189-192.

doi:http://dx.doi.org/10.1016/j.paid.2013.02.018

⁸⁵ To ensure no violation of the assumptions of normality, linearity, and homoscedasticity

⁸⁶ Homogeneity of groups

⁸⁷ Little's MCAR test (p>.05)

the relevant items (see Annex 12 and 13). Each composite was calculated twice: i) for 'pre' imputation scores, ii) for 'post' imputation scores. Subsequent analyses were carried out separately on pre and post composites, in order to check for consistency of results. Pre and post legislation datasets were merged into one combined dataset using participants' 'unique identification' number. These numbers were common to both datasets, thereby allowing accurate matching of participants' pre and post legislation responses.

Secondly, we performed an in-depth examination of all variables in the data set. Baseline characteristics of the participants, with regards to age, gender, and socio demographic factors including education, employment and ethnicity were profiled (see Annex 16: Tables 2 to 6). Characteristics of participants' food allergen avoidance, their reactions to food allergens, and diagnosis/management of their food allergy/intolerance were also considered. In addition to existing participant variables of adult/parent and allergy/intolerance, participants were categorised based on number of allergens reported (2 or fewer/more than 2), immediacy of reaction (immediately, within 1 hour, between 1 and 24 hours, and after 24 hours), and severity of allergic response in FA participants (see Table 4 below, and Annex 16: Tables 7 to 10).

Longitudinal analyses with participants who completed pre and post legislation questionnaires

In order to compare the responses of the participants who took part in both the pre and post legislation surveys, a factor analysis of responses to 'eating out preferences and behaviours' survey items was conducted in order to determine the constructs on which we would compare pre and post legislation responses (see Annex 16: Table 1). Analysis was carried out based on the pre legislation survey responses of the original 874 participants who completed the surveys in 2014⁹⁰.

Six factors were identified: *The menu as a resource for confident food choices; Confidence in asking staff; Prioritising planning; Adequacy of menu information; Staff as a resource for confident food choices; Adventurousness* and *HQRL*. The composition of these factors, the response options, the reliability of the factors, and a summary of the means for allergic and intolerant populations for the pre and post legislation surveys can be found in Annex 12 and 13.

Mixed analyses of variance were conducted in order to explore whether there had been any changes in each of these eating out factors and in HRQL over time. Change over time was assessed by comparing differences in pre versus post legislation responses, and the impact of other key variables (for example: adult/child age, time since diagnosis) were considered between groups.

Cross sectional comparisons of pre and post legislation responses

In order to explore whether there were differences between participants who avoided particular allergens, univariate analyses of variance were used to compare the responses of key allergen groups within the pre legislation and post legislation questionnaires. The impact of other variables (for example: FA/FI, Adult/Parent) were also considered.

Comparisons were made in relation to four key constructs focused on particular dimensions of information provision when eating out: Reliance on speaking to staff; Satisfaction with written information; Preference for staff as a source of information and Potential for allergen menu use. We also compared views in relation to two single items, 'I like it when it says in the menu that they welcome customers with allergies and intolerances asking about dishes' and 'I like it when there is a sign up that says that they welcome customers with allergies and intolerances asking about dishes'. The composition of each of the constructs, the response options, and reliability and mean scores for pre and post legislation can be seen in Annex 14 and 15.

⁸⁸ Data imputation using expectation-maximization (EM).

⁸⁹ Tabachnik, B. G., & Fidell, L. S. (2013). *Using Multivariate Statistics* (6th ed.). New Jersey: Pearson Publication.

⁹⁰ Using direct oblimin rotation

Results^{91 92}

Profile of participants

All pre legislation participants

Of the 874 pre legislation participants, 751 (86%) were female. Six hundred and one (69%) reported experiencing a food allergy. Of these, 289 (48%) were 'adults' who experienced FA symptoms, and 312 (52%) were 'parents' of children who experienced FA symptoms. Two hundred and seventy-three (31%) of pre legislation participants reported experiencing symptoms of food intolerance. This FI group was made up of 229 (84%) 'adults' and 44 (16%) 'parents' of children who experienced symptoms of FI. The majority of participants reported having received a formal diagnosis of FA /FI from an NHS or private medical practitioner (725, 83%). FAs were most commonly diagnosed using a 'skin prick' (416, 50%) and/or 'blood test' (387, 64%) and were treated using 'antihistamines' (466, 71%) and/or 'injectable adrenaline' (422, 74%). FIs were largely diagnosed via 'blood test' (148 (54%) or 'elimination diet' (107, 39%), and were treated using 'food/product avoidance' (192, 70%) and/or a 'special diet' (131, 48%).

In relation to the 14 allergens covered by the legislation, pre legislation participants most commonly avoided: Peanuts (394; 45%); tree nuts (372; 43%); milk (324; 37%); cereals containing gluten (308; 35%) and eggs (218; 25%). Participants experiencing FA were most likely to avoid peanuts (378; 63%); tree nuts (353; 59%) and/or eggs (214; 36%). FA participants also reported avoiding milk, sesame, cereals containing gluten, soya, crustaceans, fish, molluscs, mustard, lupin, celery and sulphur dioxide, to a lesser degree. With the exception of lupin, FI participants reported reacting to the range of 14 allergens with cereals containing gluten (192; 70%) and milk (110; 40%) being the most commonly avoided. Participants also reported adverse reactions to foods which were not included amongst the 14 allergens covered by the legislation including fruits, poultry, pulses, legumes, onions, garlic, oils, and food additives. For full details, see Annex 16: Tables 7-10.

All post legislation participants

Of the 392 post legislation participants, 337 (86%) were female). Two hundred and forty-six (63%) reported experiencing a food allergy. Of these, 101 (41%) were 'adults' who experienced FA symptoms, and 145 (59%) were 'parents' of children who experienced FA symptoms. One hundred and forty-six (37%) of post legislation participants reported experiencing symptoms of food intolerance. This FI group was made up of 111 (76%) 'adults' and 35 (24%) 'parents' of children who experienced symptoms of FI. The majority of participants reported having received a formal diagnosis of FA /FI from an NHS or private medical practitioner (298, 76%). FAs were most commonly diagnosed using a 'skin prick' (148, 60%) and/or 'blood test' (136, 55%) and were treated using 'antihistamines' (171, 70%) and/or 'injectable adrenaline' (136, 55%). FIs were largely diagnosed via 'blood test' (56: 38%) or 'elimination diet' (85; 58%), and were treated using 'food/product avoidance' (106, 73%) and/or a 'special diet' (51, 35%).

In relation to the 14 allergens covered by the legislation, participants most commonly avoided: Peanuts (152; 39%); tree nuts (131; 33%); milk (159; 41%); cereals containing gluten (121; 31%) and eggs (86; 22%). Participants experiencing FA were most likely to avoid peanuts (141; 57%); tree nuts (124; 50%), milk (92; 37%) and/or eggs (75; 31%). FA participants also reported avoiding milk, sesame, cereals containing gluten, soya, crustaceans, fish, molluscs, mustard, lupin, celery and

⁹¹ p= significance level (ps<.05 indicate significant differences between groups)

 $^{^{92}}$ Effect sizes $(\eta_p{}^2)$ are reported. Effect sizes of .2 are small, .5 are moderate and .8 are large.

sulphur dioxide, to a lesser degree. With the exception of lupin, FI participants reported reacting to the range of 14 allergens; with cereals containing gluten (74; 51%) and milk (67; 46%) being the most commonly avoided. Participants also reported adverse reactions to foods which were not included amongst the 14 allergens covered by the legislation including fruits, poultry, pulses, legumes, onions, garlic, oils, and food additives. For full details, see Annex 16: Tables 7-10.

Returning participants – who completed the survey pre and post legislation

Of the 188 returning participants, 161 (86%) were female. One hundred and twenty-nine (69%) reported experiencing food allergy. Of these, 57 (44%) were 'adults' who experienced FA symptoms, and 72 (56%) were 'parents' of children who experienced FA symptoms. Fifty-nine (31%) of returning participants reported experiencing symptoms of food intolerance. This returning FI group was made up of 51 (86%) 'adults' and 8 (14%) 'parents' of children who experienced symptoms of FI. The majority of returning participants reported having received a formal diagnosis of FA /FI from an NHS or private medical practitioner (159, 85%). FAs were most commonly diagnosed using a 'skin prick' (90, 70%) and/or 'blood test' (81, 63%) and were treated using 'antihistamines' (103, 80%) and/or 'injectable adrenaline' (96, 74%). FIs were largely diagnosed via 'blood test' or 'elimination diet' (28, 48% respectively), and were treated using 'food/product avoidance' (36, 64%) and/or a 'special diet' (22, 37%).

In relation to the 14 allergens covered by the legislation, returning participants most commonly avoided: Peanuts (88; 47%); tree nuts (85; 45%); milk (71; 38%); cereals containing gluten (55; 29%) and eggs (51; 27%). Participants experiencing FA were most likely to avoid peanuts (86; 67%); tree nuts (82; 64%) and/or eggs (47; 36%). FA participants also reported avoiding milk, sesame, cereals containing gluten, soya, crustaceans, fish, molluscs, mustard, lupin, celery and sulphur dioxide, to a lesser degree. With the exception of lupin, FI participants reported reacting to the range of 14 allergens with cereals containing gluten (33; 56%) and milk (25; 42%) being the most likely avoided. Participants also reported adverse reactions to foods which were not included amongst the 14 allergens covered by the legislation including fruits, poultry, pulses, legumes, onions, garlic, oils, and food additives.

Each of the following sections are focused on the 188 participants who took part in the pre and post legislation surveys: these are the 'returners'. However, we firstly consider whether returners are different from those pre legislation participants who did not take part post legislation and different from the new participants who only completed the questionnaire post legislation. For full details, see Annex 16: Tables 7-10.

Were returning participants different from non-returning participants?

In order to assess whether there were any underlying differences in the characteristics of participants who returned to complete the post legislation survey and those who did not return, 'returning' and 'non-returning' participants were compared based on their pre legislation survey responses.

There were no differences in the proportion of populations in 'returning' versus 'non-returning' groups based on 'Adult/Parent', 'FA/FI', 'gender' (adult & parent; child), 'age group' (adult & parent; child), 'number of allergens' (1-2 vs >2), or 'regularity of reaction' (all ps>.05). This indicated that the groups represented similar populations in terms of basic demographic and FA/FI related characteristics, and were therefore comparable in relation to analysis of change in returners' HRQL and eating out behaviours between pre and post legislation.

Were returning participants different from new participants?

In order to assess whether returning participants were different from 'new' participants who only completed the post legislation survey, we compared the characteristics of the two groups. If there were differences we would need to control for these in subsequent analyses and we would also have to address the possibility that the post legislation views of returning participants were in part a function of having taken part in the pre legislation survey.

Shown in Table 4, there were no differences in the proportion of populations in the 'returning' versus 'new' groups based on the variables 'Adult/Parent', 'FA/FI', 'gender' (adult & parent; child), or 'regularity of reaction'.

- 'Returning' participants were older than 'new' participants; though ages ranged from 18-65+ yrs in both populations.
- ➢ For Parents, children of 'returners' were older than children of the 'new' populations; though again, ages ranged from <1-17⁹³ yrs in both populations.
- Fewer 'returning' participants and more 'new' participants reported avoidance of >2 allergens. It is possible that this reflects an overall trend in increasing numbers of people reporting and being diagnosed with reactions to allergens.
- > 'New' participants had been diagnosed with FA/FI more recently than returning participants.

Although there are logical reasons for some of the differences between returners and the new participants, these (and other) factors were considered in subsequent analyses of 'returning' participants to check if they explain any differences found.

⁹³ Children of 'returning' parents comprised n=4 18 yr olds post legislation. These participants were included to ensure that parents of children aged 15/16 yrs pre legislation were represented post legislation. There were no parents of children aged >18 yrs included post legislation.

Table 4: Differences between 'Returning' and 'New' participants for the Post legislation Survey based on descriptive and FA/FI characteristics

	Post legislation:	Post legislation:	Difference between		
	Returners (N=188)	New (N=204)	'Returning' and		
	N (%) or Mean (SD)	N (%) or Mean (SD)	'New' participants		
Adult	108 (57.4)	104 (51.0)	No ¹		
Parent	80 (42.6)	100 (49.0)			
FA	129 (68.6)	117 (57.4)	No ²		
FI	59 (31.4)	87 (42.6)			
Gender*					
Adult/Parent					
Male	27 (14.4)	24 (11.8)	No ¹		
Female	161 (85.6)	176 (86.3)			
Child					
Male	45 (28.3)	60 (29.4)	No ¹		
Female	35 (18.5)	39 (19.1)			
Mean Age (yrs)*					
Adult/Parent	43 (12.0)	37.8 (8.8)	Yes		
Child	9.8 (4.5)	7.2 (4.6)	Yes		
No of allergens*					
1-2	113 (60.1)	158 (77.5)	Yes		
>2	74 (39.4)	45 (22.1)			
Regularity of					
reaction					
Always	143 (76.1)	146 (71.6)	No ²		
Mostly	30 (16.0)	53 (25.9)			
Sometimes	11 (5.9)	3 (1.5)			
Rarely	3 (1.6)	2 (1.0)			
Time since diagnosis					
(yrs)					
Adult	14.2 (12.4)	10.4 (9.3)	Yes		
Child	7.5 (4.3)	3.8 (4.4)			

*Some values missing from dataset; ¹Based on NS Chi squared; ²Based on significant Chi squared but NS standardised residuals using +/-1.96 as minimum criteria

Eating out frequency and venue preferences: Comparing pre and post legislation

It was a pre-requisite of inclusion in the survey that participants eat out and/or order takeaway food; therefore no information regarding individuals who never eat out was considered. Participants were asked how often they had consumed food at/from each of several venue types (described in Annex 16: Table 11).

Both in pre and post legislation surveys, participants were asked to report how often they had consumed or bought food from a range of eating out and takeaway venues over the previous year. This is of interest as it might suggest that the legislation, through facilitating greater ease in accessing relevant information, would enable people to feel more confident that they can make safe food choices, and thus that they may eat out more frequently and in a wider range of venue types. For each venue, participants could indicate that they never ate there due to their allergy or intolerance or that they ate there rarely (1-2 times per year), occasionally (once every 2 to 3 months) or regularly (several times each month) – coded as 0 to 3.

Overall, mean values depicted in Figure 4 below (see too Annex 16: Table 11) indicated that the 'national' category 'pubs and bars / fish and chips / chicken or burger / British foods (non-pubs)' were the most popular types of food outlet both pre and post legislation whilst 'street food stalls' were the least popular. Looking across all of the venues, there was no change in the mean frequency of participants' eating out behaviours between pre and post legislation (Pre M= 1.10, SD= .60; Post M= 1.14, SD= .62 p> .05).

More specifically, there was no such change for adults/parents, for different age groups, between those reporting FA and FI, time since diagnosis, and number of allergens (1-2/>2) (all ps> .05). There were no changes in preferences for eating out / takeaway providers between pre and post legislation measures.

Whilst no change over time was evident, frequency of eating out differed both pre and post legislation depending on whether participants were 'adults' or 'parents of children' experiencing FA/FI symptoms (p= .049, η_p^2 = .032). At both points, 'adults' reported eating out more frequently (Pre/Post M= 1.26) than 'parents' (Pre/Post M= 0.92).

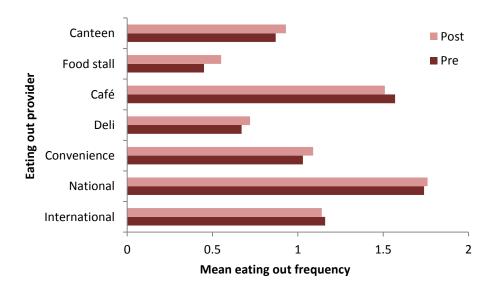


Figure 4 Participants' pre and post legislation frequency of eating out or buying takeaway from a range of food providers⁹⁴

⁹⁴ Returning participants only

Figure 5 shows the distribution of participants' pre and post legislation responses in relation to purchasing food from particular providers. Although of course people without a FA or FI vary in which food outlets they visit too, many people with a FA or FI indicated that they would 'never' purchase food from a street 'food stall' (Pre= 59%, Post= 57%) or from a delicatessen (Pre= 54%, Post= 52%) due to their FA/FI in particular. This suggests that their venue choices were being informed by a risk assessment of the greater likelihood of encountering allergens, and perhaps by a lower perceived likelihood of receiving reliable information about the presence of allergens. There were no changes in the proportion of participants who selected 'Never' in relation to each type of food provider over time.

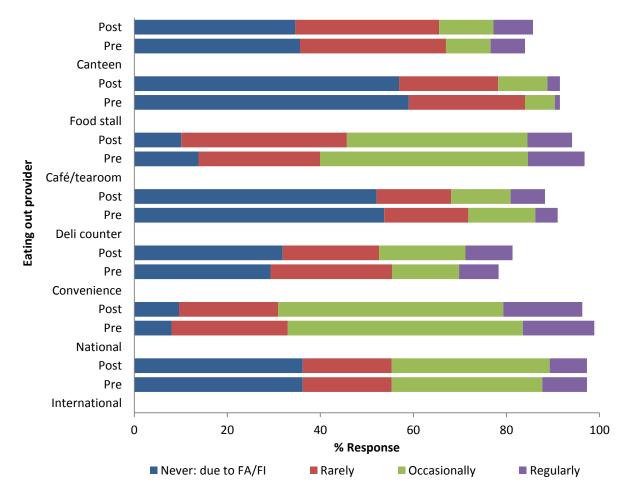


Figure 5 Pre and post legislation eating out frequency from a range of venues

Although there were no changes in preferences for types of eating out venue over time, both pre and post legislation, participants differed in their preference for particular venues depending on whether they were 'adults' or 'parents', or whether they avoided '1-2 allergens' or '>2 allergens'. 'Adults' reported purchasing foods from 'International' venues (Pre M= 1.50, Post M=1.49) and street 'food stalls' (Pre M= 0.61, Post M= 0.80) more frequently than 'Parents' (International Pre M=0.69, Post M=0.68⁹⁵; Food stalls Pre M=0.23, Post M=0.26⁹⁶). Participants who avoided 1-2 allergens reported purchasing food at 'convenience' outlets (Pre M=1.18, Post M=1.19) more frequently that participants

 $^{^{95}}$ p<.001, η_{p}^{2} =.13

 $^{^{96}}$ p<.003, η_p^2 =.09

who avoided >2 allergens (Pre M=0.78, Post M=0.91)⁹⁷. There were no differences in the population based on age group, FA/FI status, or time since diagnosis.

Participants were also asked to indicate how important eating out or getting a takeaway is, how enjoyable it is and how safe it is. Pre and post legislation scores for these questions indicated that there was a post legislation improvement in scores for how enjoyable eating out was (pre M= 3.10, post M= 3.23) and how safe eating out was (pre M= 2.73, post M= 2.89; although these changes did not constitute a significant difference. There was no pre/post change in importance of eating out (pre M= 3.54, post M= 3.60).

Changes in information seeking behaviours and preferences over time

There was evidence of changes over time indicating greater positivity in information seeking behaviours and preferences, as summarised in Table 5. There were significant increases in 'Confidence in asking staff', 'Adequacy of menu information', 'Staff as a resource for confident food choices', and 'Adventurousness' between the pre and post surveys. For parents there was evidence of improvement in ratings of the 'Menu as a resource for confident food choices'. The effect sizes are small but the significant results are consistent across most of the factors and in the same direction. Notably this was the case independently of FA/FI status, time since diagnosis, and severity of allergy (for FA only).

CONSTRUCT	Pre legislation	Post legislation	Pre/Post	р	η_p^2
	Mean (SD)	Mean (SD)	Change?		
Confidence in asking staff	3.32 (1.32)	4.00 (1.33)	Yes	=.006	=.06
Adequacy of menu	1.51 (0.72)	1.74 (0.91)	Yes	=.013	=.05
information					
Staff as a resource for	3.31 (0.92)	3.51 (0.91)	Yes	=.014	=.05
confident food choices					
Adventurousness	1.35 (0.92)	1.53 (0.98)	Yes	=.004	=.07
Menu as a resource for	2.94 (1.18)	3.08 (1.11)	No	=.81	<.01
confident food choices					
Prioritising planning	3.21 (1.47)	3.34 (1.37)	No*	=.01*	=.04

Table 5: Overview of change over time for participants who took part in pre and post legislation surveys	
(n = 188)	

*Overall difference was significant but post hoc test was not

Confidence in asking staff

There was a significant increase in 'confidence in asking staff' between the pre and post legislation surveys (Pre M= 3.32, Post M= 4.00, p= .006, η_p^2 = .06). Greater confidence in asking staff refers to being happier to ask more questions, feeling less embarrassed to ask questions and feeling more confident to ask questions about the allergen content of foods being served. Participants were generally quite confident in asking staff and this was reflected in mean scores ranging from 2.58 to 3.25 based on 1 to 5/0 to 6 scales with a mid-point of 3. There was a main effect of 'time' – the effect

⁹⁷ p<.025, η_p²=.07

was the same for FI and FA and for adults and parents and there was no difference between participants of different ages so it was not the case that this difference was simply because participants were getting older and more confident by virtue of this. The main effect of time was not affected by time since diagnosis, number of allergens being avoided or, for those with allergy or the severity of the allergy.

There were also significant differences between adults and parents in their confidence in asking staff. Both pre and post legislation, parents (Pre/Post M= 3.91) were significantly more confident than adults (Pre/Post M= 3.47, p= .045, η_p^2 = .033. This was the case no matter whether their children were FA or FI.

Staff as a resource for confident food choices

This factor included items that related to 'satisfaction with serving staff', 'counter staff', 'staff you speak to on the phone', 'staff who prepare food' and 'confidence that the information staff provide is reliable'. Participants were generally satisfied with staff and the reliability of the information that they might provide. This was reflected in mean scores ranging from 3.01 to 4.37 based on a 0 to 6 scale with a mid-point of 3. In line with the improved confidence in asking staff above, here too there was a small but significant difference, with more positive views about staff as a resource for confident food choices (Pre M= 3.31, Post M= 3.51, p= .014, η_p^2 = .05) post legislation. As above, this effect did not change for different groups based on FA/FI, adults/parents, age group, time since diagnosis, number of allergens avoided or for severity of allergy in FA participants.

Adequacy of menu information

Adequacy of information included items relating to the desire for more menu information about the ingredients contained in each dish, for the exact ingredients to be provided on menus, and for more information on menus to bring clarity rather than confusion. Participants indicated their agreement on a scale ranging from 1- Strongly agree to 5- Strongly disagree so that a lower score indicated greater levels of agreement with a need for improvement. Although the range of participant scores (mean range 1.42 to 1.88) were low, indicating that they agreed that improvements were needed, participants post legislation had slightly softened their views about the adequacy of menu information – they felt it was more adequate than they did pre legislation (Pre M= 1.51, Post M= 1.74, p= .013, η_p^2 = .05). Again, there were no differences between FA and FI, between adults and parents nor between participants of different ages. As above, this difference did not change in relation to time since diagnosis, number of allergens being avoided, or severity of allergy in FA participants.

Menus as a resource for confident food choices

Participants were asked whether the menus displayed at the counter, outside the venue, online and at the table enabled confident food choices. The mean range of scores (2.58 to 3.25 on a 1 to 5 scale) indicated that participants found menus to be quite an adequate resource. Overall, there was no difference between participant responses pre and post legislation. However, there was a small difference for parents over this time period such that they were more satisfied post legislation that menus enabled confident food choices (Pre M= 2.68, Post M= 2.99) (p= .023; η_p^2 = .043). Although it was quite plausible that this could be linked to the age of the child – that is, that parents become more confident as their children get older, in fact this was not the case - the increase in parental confidence was independent of the age of the allergic or intolerant child. There was no change in the extent to which adults saw the menu as a resource for confident choices.

Adventurousness

The measure of adventurousness concerned whether participants were inclined to pick the same sorts of things to eat and to eat in the same or different places. There was a small but significant increase in adventurousness of participant eating out practices between pre and post legislation (Pre M= 1.35, Post M= 1.53, p= .004, η_p^2 = .07) although it is important to note that the overall level remains very low – between 1 and 2 on a 7 point scale from 0 to 6. The increase in adventurousness

was the same for FI and FA and for adults and parents and there was no difference between participants of different ages so it was not the case that participants were becoming more adventurous as they got older. There were no differences depending on time since diagnosis, number of allergens being avoided, or severity of allergy in FA participants.

Planning

Participants were asked about their planning for eating out: how often they ring ahead to eating out venues, do research online, use information from support groups to inform their decisions, ask to speak to the manager or the chef, and check a particular menu selection ahead of going to the venue. The range of mean scores (2.62 to 3.73 on a 0 to 6 scale) indicated that participants would plan ahead fairly often. There was no overall significant difference between participant ratings pre and post legislation. For participants reporting avoidance of more than two allergens, there was a significant increase in 'Planning' between Pre (M= 3.37) and Post (M= 3.55) (p=. 013, η_p^2 = .051). This change over time was not evident for participants who reported avoiding two or fewer allergens (Pre M= 3.09, Post M= 3.18).

Again, there was a main effect of adults/parents: parents had higher scores for planning both pre and post than adults (Adults Pre/Post M= 3.00, Parents Pre/Post M= 3.64 (p= .03, η_p^2 = .038).

Reliability of information sources

Both pre and post legislation, participants were asked to indicate which information sources they thought were the three most reliable sources to help make decisions about allergies and intolerances. In addition, they were asked to rate the top 3 from 1 to 3. Conversely, they were also asked to select the one source they considered least reliable. Figures 6 and 7 summarise the percentages of participants selecting each option for sources judged to be most and least reliable. Broadly, there is a good deal of similarity between pre and post legislation ratings.

- A conversation with the chef remained the source selected in the top 3 most reliable sources both pre (71%) and post (63%) legislation though there was a drop of 10% in participants awarding this reliability rating post legislation
- The reverse picture was shown in selections of the website with all ingredients this too was rated a highly reliable source by over half of the participants both before (58%) and after (67%) the legislation. However, there was an increase of almost 9% post legislation.
- In line with this, there was also a rise in participants' reliability ratings for the printed menu post legislation around 12% more rated it as a top source of reliable information.
- Conversations with the manager were no longer a top 3 reliable source post legislation though this decrease is small. However, in line with the general picture that written information was considered more reliable than personal communication with staff, conversations with serving staff were considered to be in the top 2 most unreliable sources both pre (15%) and post (21%) legislation, with an increase in people taking this view post legislation.
- It is notable that the least reliable source continued to be the blackboard menu. Whether the temporary nature of 'blackboard' information or the potential for limitations in the detail provided, might have motivated participants to judge this resource as particularly unreliable is unclear.

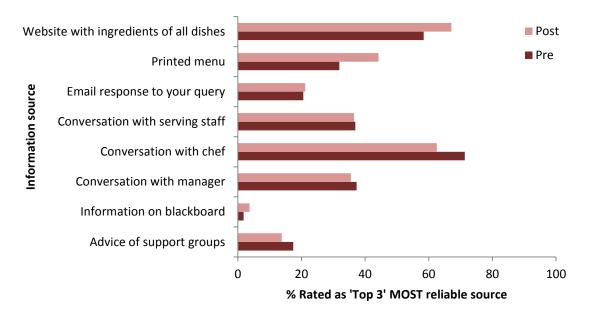


Figure 6: Top 3 most reliable information sources pre and post legislation⁹⁸

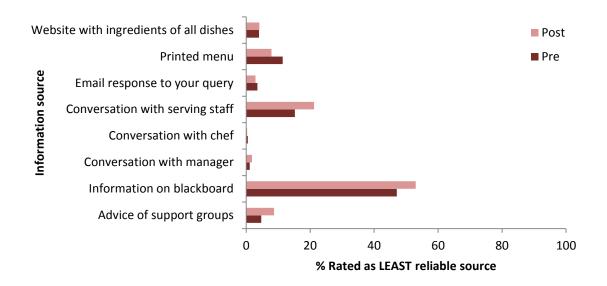


Figure 7: Least reliable information sources pre and post legislation⁹⁹

The impact of food allergy/intolerance factors and eating out preferences on HRQL

Measures of HRQL indicated the extent to which food allergy/intolerance impacted on participants' daily lives, with higher scores equating to poorer HRQL. Based on a 7 point scale ranging from 1 (not at all) to 7 (extremely) FA/FI adult and parent participants all had relatively poor levels of HRQL. As evident in Table 6 below, adult FA and FI participants all had scores higher than 5, both before and after the introduction of the legislation, indicating that their food allergy impacted on their daily life 'very much-extremely'. Mean HRQL scores for parents of children with food allergy and intolerance,

⁹⁸ Pre population= 874 original participants; Post population= 392 post participants (188 'returners', 204 'new')
⁹⁹ Ibid

both pre and post, were all between 4 and 5 indicating that having a child with a food allergy impacted on parents' daily lives 'quite a bit-very much'.

Overall, Table 6 indicates that there were no significant improvements in HRQL between the pre and post legislation measures. Changes in FI parent HRQL were not analysed due to small sample size. It is worth noting however that all four groups – adults with FA (n=57) and FI (n=51) and parents of children with FA (n=72) and FI (n=8) showed a decrease in scores, indicating an improvement in quality of life post legislation; although the changes are not statistically significant.

	Pre	Post	Pre/Post change	р	η_p^2
FAQLQ-AF	5.22 (1.12)	5.02 (1.14)	No	=.21	=.05
FIQLQ-AF	5.50 (0.97)	5.31 (1.25)	No	=.68	<.01
FAQLQ-PF	4.78 (1.22)	4.71 (1.12)	No	=.64	<.01
FIQLQ-PF ¹	4.97 (1.51)	4.26 (1.51)			

Table 6: Pre to post legislation changes in HRQL for returning participants

Repeated measures ANOVAs (Within= Pre/Post HRQL measure; Between= Age group; no of allergens: 1-2 />2; time since diagnosis, severity [FA only])

Adults' HRQL over time

In addition to there being no overall change in HRQL, there were no main effects of 'time' on HRQL subscales (AADR, RAE, FAH and El^{100} ; all ps> .05) for both adults with FA and FI. The number of allergens avoided (1-2, >2), time since diagnosis, and severity (FA only) did not impact on overall HRQL or subscale scores in adults (FA/FI), either over time, or pre and post legislation.

Parents' HRQL over time

Although there was no main effect of 'time' (Pre/Post, p>.05) on overall HRQL (or FAQLQ-PF subscales), there was an interaction between 'time' and 'FA severity' (p= .002, η_p^2 = .25) indicating that there was a significant fall in overall HRQL scores (i.e. improvement in HRQL) between pre and post legislation (Pre M= 4.27, SD= 1.11 and Post M= 3.84, SD= 1.00) for parents of children experiencing 'moderate' FA (p= .001)¹⁰¹. These changes in overall HRQL were not seen for parents of children experiencing either 'mild' FA or 'severe' FA (ps> .05). It is difficult to interpret this inconsistency and undue significance should not be placed on this finding. Indeed, there were several significant changes between pre and post quality of life scores on the HRQL subscales relating to parents of children with food allergy – generally, but not always, in the direction of improvement.

- A fall in scores between pre and post was similarly shown for parents of children experiencing 'moderate' FA in the subscales: EI (emotional impact; p= .008) and SDL (social & dietary limitations; p= .01).
- A rise in EI between pre and post (Pre M= 5.32, Post M= 5.44) was shown for parents of children experiencing 'severe' FA (p= .013).
- For the 'F-A' (food anxiety) subscale, there was a rise in scores for parents of 4-6 year olds between pre and post. This indicated an increase (Pre M= 2.42 to Post M= 3.48 p= .001, η_p^2 = .24) in food anxiety over time for this age group, that was not evident in parents of children aged 0-3, 7-12 or >12 years. This increased anxiety may be due to children starting school.

¹⁰⁰ AADR= Allergy avoidance & dietary restrictions; RAE= Risk of accidental exposure; FAH= Food allergy related health; EI= Emotional impact.

 $^{^{\}rm 101}$ Results should be treated with caution due to small sample size of some FA severity categories

The number of allergens avoided (1-2, >2) and time since diagnosis did not impact on overall HRQL or subscale scores of parents (FA) between pre and post legislation (all ps>.05).

Comparisons of key allergen groups' perceptions of pre and post legislation information provision

We explored whether there were any differences in perceptions of information provision between those seeking to avoid different key allergen groups ('Cereals containing gluten^{102'}, 'Nuts' [peanuts and tree nuts]¹⁰³, and 'Milk'¹⁰⁴) pre and post legislation. Other allergens were not included in the comparison because sample sizes were too small in these groups. There were no differences between allergen groups pre legislation, however, as shown in Table 7 (see also Annex 16: Table 12), there was evidence that allergen groups differed in their perceptions of information provision post legislation. See Annex 14 and 15 for full detail of the items included in each of the composite variables, their reliability and the mean scores for FA/FI and adults/parents.

Table 7: Post legislation perceptions of information provision for those avoiding gluten, nuts & milk (all post legislation participants)

	Gluten	Nuts ¹⁰⁵	Milk	Difference	р	η_p^2
	(n=66)	(n=94)	(n=72)	between groups?		
Reliance on speaking to staff	3.26 (1.25)	3.79 (1.27)	3.15 (1.22)	Yes	.016	.037
Satisfaction with written information	3.30 (0.91)	3.59 (0.73)	3.41 (0.73)	Yes*	.046	.028
Preference for staff as source of information	3.48 (1.29)	4.00 (1.02)	3.10 (1.23)	Yes	.017	.026
Potential for use of separate allergen menu	4.11 (0.87)	3.93 (0.97)	3.49 (0.99)	Yes	.007	.045
Menu invites you to ask staff about allergens	4.55 (0.79)	4.67 (0.67)	4.33 (0.87)	Yes	.031	.031
Sign invites you to ask staff about allergens	4.59 (0.78)	4.60 (0.81)	4.29 (0.94)	Yes*	.023	.034

*Overall difference was significant (p<.05) and post hoc bordered on significant (p<.06)

Reliance on speaking to staff

'Reliance on speaking to staff' related to five items enquiring about participants' reliance on or reluctance to make enquiries to members of staff in order to ensure a safe, allergen-free eating out experience. Based on a 0 to 6 point scale, participants reported that they relied on speaking to staff in order to gain information 'fairly often – often'. Participants avoiding nuts (M= 3.79) had a greater

¹⁰² 'Cereals containing gluten' group made up of n= 8 FAs and n= 58 FIs

¹⁰³ 'Nuts' group made up of n= 86 FAs and n= 8 FIs

¹⁰⁴ 'Milk' group made up of n= 27 FAs and n= 45 FIs

¹⁰⁵ 'Peanuts' and 'Tree nuts' were combined in a single 'Nuts' category for the purposes of 'key allergen groups' comparisons only

reliance on speaking to staff than those avoiding gluten (M= 3.26, p= .019 post hoc), and those avoiding milk (M= 3.15, p= .003 post hoc).

Satisfaction with written information

Based on a scale of 1 to 5, 'current satisfaction with written information' was made up of six items to assess satisfaction with menu information relating to potential allergens (online, on display, and at table), and via 'phone apps' and ingredients folders (the supplementary allergen menu). Participants were 'neutral' - 'slightly satisfied' with the available written information which might help them to confidently choose the food that they could eat. Post hoc analysis bordered on significant (p= .053) suggesting that those who avoided 'nuts' (M= 3.59) were more satisfied that written information could aid confident food choices than those avoiding 'gluten' (M= 3.30).

Preference for staff as a source of information

Preference for staff as an information resource differed amongst populations, based on two items which related to participant preferences for clarification of allergen details to supplement written ingredients information. Participants' mean scores (3.10 to 4.00) on a 1 to 5 scale indicated that they favoured staff as an additional information resource independent of the quality of menu/written information provision. Participants avoiding nuts (M= 4.00, p= .009 post hoc) and those avoiding gluten (M= 3.48, p= .001 post hoc) both preferred staff as a source of information in comparison to those avoiding milk (M= 3.10).

Potential for allergen menu use

Participants responded to 'potential for allergen menu use' via three items relating to preferences/expectations of separate food allergen information provision, and additional information relating to food preparation details. Relatively high mean scores suggested that participants had a preference for allergens to be listed on the menu, or a separate menu to be provided showing the dishes available to customers wishing to avoid specific allergens. On a 1 to 5 point scale, mean scores ranging from 3.49 to 4.11 indicated that participants 'slightly agreed' with the need for this resource in terms of information provision. Participants avoiding nuts (M=3.93, p=.007 post hoc) and those avoiding gluten (M=4.11, p=.001 post hoc) both considered the separate menu to have greater potential as a source of information than those avoiding milk (M=3.49).

Menu invites you to ask staff

Participants favoured a declaration on menus that customers' questions in relation to food allergies and intolerances were welcomed. Mean scores ranged from 4.33 to 4.67 in the context of a 1 to 5 scale, indicating that participants 'strongly agreed' with this single-item measure as a means of enabling safe food choices when eating out. Those avoiding nuts (M= 4.67) were more positive about the menu inviting customers with allergies and intolerances asking about dishes than are those who avoid milk (M= 4.33, p= .016 post hoc).

Sign invites you to ask staff

Participants also favoured a sign declaring that customer questions in relation to food allergies and intolerances were welcome. On a 1 to 5 scale, mean scores ranged from 4.29 to 4.60 indicating that participants 'strongly agreed' with this means of enabling safe food choices when eating out. Post hoc analysis bordered on significant (p= .056) suggesting that those avoiding nuts (M= 4.60) were more positive about the sign inviting customers with allergies and intolerances to ask about dishes than are those who avoid milk (M= 4.29).

Overall, it seems to be the case across all of the information seeking preferences that those that were avoiding milk were less positive about the role of staff and of menus than those avoiding nuts and sometimes, those avoiding gluten. This was a clear trend in relation to each of the significant results. The effect sizes are not large but findings suggest that post legislation there is a clear pattern of differentiation in perceived information provision between those avoiding different allergens, and in particular, that those avoiding milk are less positive about this compared to those avoiding nuts and gluten.

Phase 04: Dissemination and knowledge exchange

In addition to the production of this report and peer reviewed journal publications¹⁰⁶ and in order to consolidate a robust set of recommendations after both the pre and the post legislation research, one day workshops were convened for food businesses, food industry representatives, local authorities and support groups in order to present and discuss findings from the research. Both events sought to disseminate the findings of the project and provided an opportunity to refine the recommendations of the project, in particular exploring whether they are considered practicable and how their feasibility might be increased.

After the pre legislation work a workshop was held at the University of Surrey on February 19th 2015. After the post legislation work a workshop was held at the University of Bath on March 20th 2017.

Across both workshops, in addition to the project team and representatives from the Food Standards Agency, delegates included representatives from Coeliac UK, Anaphylaxis Campaign, Allergy UK, Pizza Hut, Tesco, Waitrose, Marks and Spencer, the Restaurant Group, Chartered Institute of Food Safety Integrity and Protection, Bucks Trading Standards, Bidvest, Food Solutions, the University Caterers Association, British Retail Consortium and Foods Matter, Bath and North East Somerset Local Authority Trading Standards and Environmental Health. Many of those who were unable to attend, as well as those who were there, asked to be kept up to date with subsequent reporting of the project.

There were useful and interesting discussions after each presentation. Points raised at the first workshop reporting results from the pre legislation work included:

- The value of considering how there could be legal provisions for precautionary allergen labelling (e.g may contain statements) regarding allergen cross contamination.
- Could incorporating allergy/intolerance information provision into the food hygiene ratings be considered? This might provide a possible route to greater confidence and care around issues of allergen cross-contamination.
- The challenges of training staff about allergens to the required level especially in businesses with high staff turnover.
- Other aspects to focus on in the analysis of the research findings were noted such as the impact of the age of the allergic/intolerant person, how long since they had been diagnosed and, for parents, the age of the child. The likely differences in eating out strategies in relation to these parameters were noted.
- Further information was requested from the research findings, for example, it was queried (a) whether difficulties with getting allergen information from venues in advance was an issue,
 (b) what was known about people's confidence in chefs as an information source, (c) whether there was evidence the confidence or information preferences varied by allergy/intolerance to different foods.
- Important to remember that 'free from' allergen statements should not be treated the same as 'does not contain'. For instance, businesses should only say 'free from egg' if they can demonstrate appropriate controls and processes are in place which can guarantee the food

¹⁰⁶ Begen, F. M., Barnett, J., Payne, R., Roy, D., Gowland, M. H., & Lucas, J. S. (2016). Consumer Preferences for Written and Oral Information about Allergens When Eating Out. *PloSOne*, *11*(5), e0156073. doi:10.1371/journal.pone.0156073; Begen, F. M., Barnett, J., Payne, R., Gowland, M. H., & Lucas, J. S. (*revisions invited and submitted*). Parents' and caregivers' experiences and behaviours when eating out with their food allergic or food intolerant children, BMC Public Health.

does not have egg in it at all. (Gluten-free is governed by other standards whereby the level of gluten in the food must be below 20 parts per million)

- It is a challenge to make symbols applicable and clear not just in the UK but across Europe. It is also unclear if the symbol should indicate the presence or the absence of the allergen. How are symbols currently used in eating out venues?
- Ways to legitimate asking about allergens were discussed including the possibility of the staff, as part of welcoming a party, asking if anyone has particular dietary requirements or food allergies or intolerances. Ways in which it might be appropriate to ask about allergies could be built into staff training.
- What is the relationship between consumer satisfaction with labelling of prepacked products and information provided in eating out environments? Does one increase confidence in the other?
- The need to develop models of best practice (this links in with the idea of broadcasting positive examples of legislation implementation). Case studies would be valuable.

Points raised at the second workshop reporting results from the post legislation work included discussion around the following:

- Speculation as to the possible impact of the high profile prosecution and imprisonment of food outlet proprietors responsible for serving unsafe food when allergen requirements had been specified by the customer who sadly then died. Might it be that this has prompted other outlets to improve the provision of their allergen information and or their allergy related practices?
- Consideration of the notion that the customer may often want information about what is not included in the food rather than what is.
- It was noted that the 14 allergens subject to the legislation are not necessarily the most common in the UK.
- A preference was noted for retail outlets to provide written information as the route to compliance with FIR. Standardisation of written information was particularly desired by large chains. However, it was also noted that small businesses face more practical challenges in keeping written allergen information up to date.
- The human element in eating out involves significant possibilities for error compared to pre packed foods hence the preference for focusing on written information.
- Might it be possible that allergy labelling will become well known, accepted and standardised in the same way as nutrition labelling has?
- Retailers mainly associated with prepacked foods wondered about the relative preferences for prepacked food in their café which are subject to extensive checking and testing vs nonprepacked food that is more associated with eating out but less able to be checked and where the human elements of introducing risk are unavoidably more prominent.

Discussion

The longitudinal research spanning consumer preferences and practices, both pre and post legislation, have provided a wealth of information about the way in which the FIR have been received and their early impact on food allergic and intolerant consumers and the parents of children managing a food allergy or intolerance.

Most particularly, this research has highlighted a number of issues that are pertinent to the practices and preferences of both food allergic and food intolerant consumers and to the allergen information practices of food businesses.

The first section of this final discussion will highlight some of the implications of the current work to inform the development of good practice in providing information about the 14 allergens relevant to eating out.

Implications for information provision

There is no cure for allergy or intolerance. The only way to prevent an adverse reaction is through avoidance of the allergen that causes it. It is thus not surprising that eating out is often a source of concern and anxiety for people who are food allergic or food intolerant. Eating out is seen to increase exposure to risk and may undermine a sense of being in control of what is being consumed - either for oneself or for those for whom one is responsible. It is therefore vital to understand the characteristics and configurations of information provision that are most likely to reduce concern, increase a sense of control and enable food choices that avoid consumption of allergens linked with adverse reactions – whilst also ensuring a positive and enjoyable eating out experience.

A key finding from this research programme is that the service encounter – that is the encounter between the consumer and the assets of the venue - is vital in achieving this. The venue has a range of potential assets to bring to bear on this encounter. These assets importantly include their staff as well as the ways in which allergen information is formally codified in a range of artefacts - most notably the menu and its variants but also including signs, notices and increasingly, online information. Some of the information about the venue and the provision that it makes for those seeking to avoid allergens are provided independently - for example, by other consumers (through blogs, social media or online commenting systems). More broadly, support groups as well as government bodies provide advice about allergy management when eating out.

The service encounter constitutes the immediate context in which written and/or verbal information about the presence of allergens is provided. Importantly however, a range of indirect cues are provided which can form the basis of inferences about the reliability of this information or the trustworthiness of those providing it. Inferences are drawn from experiences that are ostensibly unrelated to information provision about allergy or intolerance – for example, cleanliness of the venue or hesitant or disinterested staff – yet those seeking to make decisions about a choice of venue or a dish may use this information as part of their decision making process.

These experiences of the service encounter are linked with subsequent behavior: venues are visited, revisited or shunned; dishes are ordered, consumed or avoided.

This programme of research has revealed a complex set of interactions and contingencies between written and verbal information and the broader set of cues and signals within which they are embedded. In order to understand the best way of providing information that is required within the FIR, food businesses would benefit from systematically considering the practices and preferences of food allergic and food intolerant consumers.

The role of written information

Written information plays a key role in eating out with a food allergy or intolerance. Right from deciding where to eat out, through looking for information about a venue and its menu online, to evaluating the written signs in the venue and scrutinising the menu at the table, written information is of premium importance in deciding where to eat and what to eat.

Although there was evidence that information provided verbally by staff was considered more positively post legislation rather than pre, written information was almost always the most favoured source of information about the potential presence of allergens. Information provided orally by staff might supplement it.

Written information was used to inform venue and food choice ahead of eating out. Key questions for which people are looking for answers at this stage are (a) can I find something to eat (b) is there any/enough choice and (c) does this venue look as if it is allergen aware?

The menu within the venue is important but the post legislation research indicated that there was greater use of online information prior to, and even within the venue itself, as well as offline information in the form of appraising signs both inside and outside the venue.

The menu is generally a definitive source of information about allergens although supplementary allergen reference resources were sometimes available in larger chains, and valued as a second 'checking ingredients' stage once a dish had been selected. Separate allergen menus were also valued by some.

Rather than simply handing over the supplementary allergen reference source (folder, book etc.), consumers may value their help in navigating it so that they can check the dishes they have selected for allergens and if necessary, identify what would be safe choices.

Although the menu was often the main and preferred source of allergen information, this was often considered as providing insufficient information - it was considered as irrelevant to discerning the presence of some allergens and with too often too little detail to those that it did cover.

Participants felt information about allergens provided on menus was greater in 2016 post legislation than they did when asked in 2014 before its introduction.

Although full information about ingredients was considered by some as the gold standard of information provision (perhaps in the form of a supplementary allergy relevant menu) others attached most value to clear simple signs and symbols being used on the menu.

Those that valued the inclusion of signs and symbols on the menu advocated the value of a standard scheme for depicting allergens

On the basis of the early pre legislation research we concluded that allergic and intolerant consumers greatly valued being informed that verbal enquiries about allergens were welcome and that it was important to signal the venue was receptive to such enquiries. Although the quantitative work suggested that signs conveying this were considered as a positive, the qualitative work suggested this was more commonly seen as venues simply fulfilling minimum requirements and not an indication of genuine interest and knowledge – the new 'may contain' – i.e. that is that it is a box ticking exercise that is fulfilling the letter of the law but not its spirit.

The role of verbal information

The often desired reliance on menus and for a comprehensive system of symbols was sometimes part of avoiding conversations with staff about allergen requirements; consulting written information minimised the necessity to speak to staff about the food. Staff that are knowledgeable and confident around allergens and how particular ingredients might be excluded from particular dishes are key to increasing the confidence of the allergic or intolerant consumer.

Staff that seemed unsure, disinterested or unaware undermine confidence in the ability of the venue to manage allergens.

Evidence of staff being proactive, for example by asking early on in the service encounter if anyone had any food allergies or intolerances, gave confidence in the venue's ability to manage allergens.

Overall there was some encouragement that consumers were more confident about asking staff for information in 2016 than they were in 2014 before the FIR were implemented.

Similarly, consumers were more satisfied with staff as a resource for confident food choices in 2016 than they were in 2014.

Although there was a clear preference for written information about allergens the best experiences of eating out with an allergy were those where there were staff that were knowledgeable and attentive around allergens and the allergic/intolerant customer's need to avoid them.

Familiarity

Both pre and post legislation, familiarity was a key source of reassurance that the risk from allergens could be managed. This was so in relation to both venues and dishes. Familiarity was primarily derived from previous experience – that there had been successful visits to the venue in the past or that within a venue that a particular dish had proved a good choice.

There was considerable evidence that food allergic and intolerant customers were keen to return to venues that had served them well in the past.

Long standing and trusted relationships were an important part of the reassurance provided by familiarity.

The legislation

Prior to the legislation the overall reaction to the impending legislation was positive and it was seen to have a potential role in increasing confident choices of venues or dishes, to facilitate a wider range of eating out experiences and in reducing risk. After the legislation there was split between those that felt there was positive change and others that had not seen a difference

The presence of allergens through cross contamination rather than in the ingredients remains a significant concern that is not addressed by the legislation. It is noteworthy that reassurance in this area is often provided from what customers can see as much from any verbal reassurances (for example, a kitchen in view that has separate preparation areas or different toasters for different breads.

Participants expected the legislation to effect a shift in the onus of responsibility from the customer to the venue. Some information sharing practices did not do that - for example, the general information to ask staff if you wanted any information.

There were clear perceptions of disparity in provision for different allergens. Gluten free provision was seen as being widespread. Milk free options were less available and post legislation those that were seeking to avoid milk felt more disaffected than those seeking nuts or cereals containing gluten.

Implications and recommendations

- 1) Written information provided by the venue and increasingly available in multiple locations is generally likely to be trusted it is therefore vital that it is trustworthy.
- 2) A lack of questions and queries about allergens should not be read as a lack of demand for, or interest in, information about allergens. It might also indicate a lack of trust and confidence in the venue or uncertainty about what is best to ask and to whom.
- 3) When customers ask staff questions about allergens, they will take notice of more than the words that are given in reply. Signals about the competence of the venue to cater for their allergy or intolerance will be read from the care, interest and expertise that staff demonstrate. Staff training should take this into account.
- 4) The venue website is a key early source of information about the venue and provides an early opportunity for the venue to demonstrate care, interest and expertise in catering for customers with a food allergy or intolerance.
- 5) Venues should recognise the increasing reliance of many on digital sources of information and ensure that where possible Wi-Fi is available, that details of allergens in particular dishes are on line, and that the website is optimized for mobile devices.
- 6) When eating out, the information seeking journey of customers seeking to avoid allergens ranges from the early online search or phone call through to the scrutiny of ingredients at the table. Strategies for providing both written and verbal information should be designed accordingly.
- 7) Consider how allergen information in the main menu can be comprehensive yet simple and clear. Separate menus relating to different allergens are valued and welcome. Allergen reference sources that provide supplementary information about all the ingredients in a dish are also valued. The availability of these other options should be signaled in the basic menu and staff should be able to engage with customers about the detail of these if required.
- 8) Seek to identify ways in which the venue can actively and visibly signal that staff are attentive to the requirements of those that wish to avoid allergens. It should be made clear that those with a food allergy or intolerance have an invitation to ask questions and that these will be clearly, confidently and correctly answered in a timely manner.
- 9) There is considerable value in proactive information provision relevant to allergens. For example, when the server first goes to a table, as part of the opening dialogue diners might be invited to let the server know if they have particular preferences or requirements around allergens.
- 10) Consumers value the provision of relevant alternatives where suitable meals are not available. Similarly, being able to mix and match simple components of a meal in order to build one's own meal from identified ingredients is also valued.
- 11) Recognise that when returning to a venue in which they have eaten a particular dish before customers often assume that the meal ingredients are the same. They may assume this similarity too when eating in different branches of the same chain. Chains of venues need to bear this in mind either in terms of ensuring consistency or signaling to customers that consistency cannot be guaranteed.
- 12) Customers wanted to see consistency in universal symbols for the presence or absence of allergens in menus or other information sources in the UK and across Europe. Clarity and consistency was also required in whether the symbol indicates the presence or absence of the allergen.

- 13) There are risks to the credibility of those responsible for enacting the legislation and potential for a growth in scepticism or cynicism on the part of those with food allergy or intolerance if information provision about allergens is not meaningfully and sustainably implemented.
- 14) Increased menu options particularly for those seeking to avoid cereals containing gluten or nuts are welcome. Increased provision of options for customers with different requirements especially those seeking to avoid milk are required.
- 15) Though not covered by the legislation it is important to recognise ongoing consumer concerns about cross contamination when eating out. Associated may contain statements are generally considered to be unhelpful when seeking to manage a food allergy or intolerance.