

FOOD ALLERGY AND INTOLERANCE PROGRAMME

Report by Steve Wearne, Director of Policy

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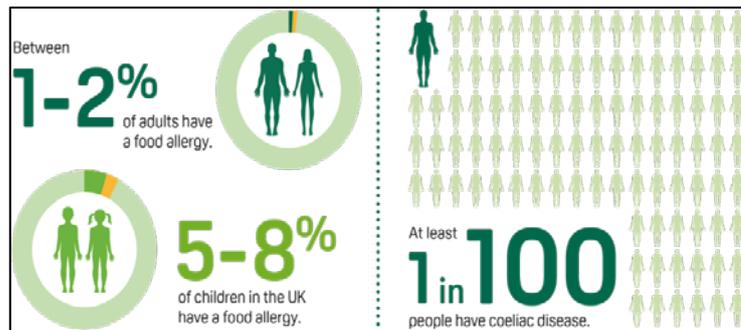
1. SUMMARY

1.1. The Board is asked to:

- a) Consider the recent outputs from world-leading research and their routes to impact, and
- b) Agree to the shift of emphasis of the research programme from food allergy in infants and children to adults.

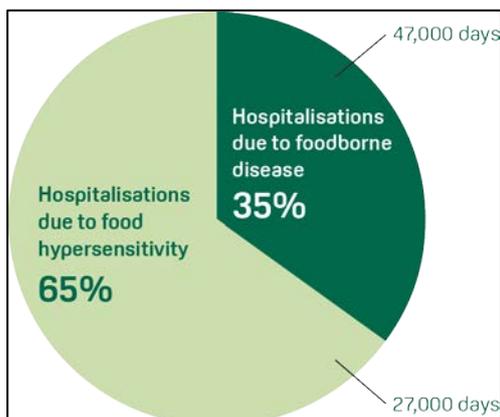
2. INTRODUCTION

2.1 Rates of food allergy and intolerance vary across the world. In the UK, an estimated 2 million people are living with a diagnosed food allergy, and 600,000 (1 in 100) with coeliac disease. These figures exclude those with food intolerances such as lactose intolerance.



2.2 There is no cure for food allergy or intolerance so the only way to manage the condition is to observe a strict avoidance diet. This puts a strain on the food allergic person, their family and friends. To avoid being the 'awkward one' who limits food choices or where to eat, the food allergic person often feels compelled to risk allergic reactions to fit in; this is especially true for young people.

2.3 Food allergy gets significant attention from interest groups and media. More



people per year are hospitalised due to food hypersensitivity (which includes allergic reactions) than through foodborne disease but for less time per patient as recovery is often shorter. Understanding the impact of what food allergic consumers need to manage their condition effectively has helped inform the regulatory and policy framework. The difficulties and impact of food allergy on the individual and their families has been detailed through FSA

funded quality of life research and supplemented through regular engagement through social media.

- 2.4 The number of deaths is thankfully low (average of 10 per year). The number of hospitalisations for allergic reactions gathered from hospital admissions data will not represent the total number of allergic reactions in the community as a large proportion of reactions are self-treated at home or by GPs. The most at risk are teenagers and those in their 20s who are starting to make independent food choices. These individuals can experience peer pressure or struggle with social acceptance and understanding and are more likely to take risks.

“I can tell immediately from eating, like just the back of my throat starts burning and itching, and my lip starts swelling up and stuff, but at the hospital they called it ‘very impressive facial swelling’, just kind of like all over the place.”

- 2.5 Access to allergen information is an important area of interest for allergic consumers; this covers what allergens are declared on prepacked foods and for non-prepacked foods. The unknown presence of an allergen can result in a severe reaction or death. The FSA’s Allergy and Intolerance Team has been at the forefront of food allergy developments, working closely with national and international organisations to influence research to develop policy for those with food allergy to help them make safe and informed food choices

“It was a box of cookies, and I had this tiny cookie, and my mouth and throat and tongue just swelled up. It was terrifying actually. I was trying to get water down my neck to make the swelling go down. I just didn’t know what was going on really.”

- 2.6 The Food Allergy and Intolerance Research Programme was established to investigate the causes and mechanisms underlying food allergy with the ultimate aim of reducing their incidence and severity. Significant progress has been made, with our research findings being used around the world in developing advice for food allergic people and for those with allergic infants and children. The knowledge of adult food allergy is less well-developed and is more anecdotal.

3. STRATEGIC AIMS

- 3.1. The programme of work for food allergy has been driven by putting the consumer first throughout its development. With the planning required to avoid such risks, the consumer needs to be empowered through a regulatory framework to promote information provision and that is what the FSA has been working to ensure.
- 3.2. Outputs from the research programme and implementation of legislation have led to guidance for those with food allergy and also for the food industry, who we have worked in partnership with for mutual benefit of those with food allergy. Many businesses have increased their range of ‘free from’ foods, increasing

consumer choice and improving further the quality of life for those with food allergy, in line with FSA strategic aims.

4. DISCUSSION

Priorities informed by the research programme

4.1 Since its establishment, the FSA has invested in research and collaborated with others to understand the important issues consumers with food allergy and intolerance face, and to investigate the causes and mechanisms of these conditions. The research programme is currently funding work under a number of key themes, namely:

- Development of management thresholds for allergenic foods
- Route and timing of exposure to food allergens in early life
- Immunological aspects of food allergy
- Prevalence and characteristics of child food allergy
- Food allergen labelling and consumer choice.

4.2 The programme has had a significant global impact and reach, with FSA-funded research being published in prominent international scientific journals. Highly cited findings have been used in Europe, America and Australia to revise guidelines and advice to the public. Progress with this world-leading allergy research was recently summarised in a Chief Scientific Advisor’s report¹. The outputs from these projects help with risk management efforts.



4.3 Significant progress has been made in recent years in understanding why children develop food allergy and how this may be prevented. The FSA funded and supported two large trials, the Enquiring About Tolerance

“Going to places... We just can’t do sort of random adventures here, there and everywhere. We plan things quite meticulously from that perspective, even down to where’s the nearest hospital. Generally, we know where the nearest hospital is, so if there’s something up, we know where to go.”

¹ <https://www.food.gov.uk/sites/default/files/fifth-csa-report-allergy.pdf>

(EAT) study and the Learning Early About Peanut Allergy (LEAP) study respectively. To follow-up this research, the FSA commissioned a systematic review of the evidence base, which has been assessed by the Committee on Toxicity and was published in September 2016.

- 4.4 A sub-committee of the Committee on Toxicity and the Scientific Advisory Committee on Nutrition is producing a risk benefit assessment of when peanut and egg might be introduced into the diet of infants. This work uses findings from EAT, LEAP and other studies and will form the basis of integrated advice to the Department of Health to ensure advice reflects the best available evidence and considers all aspects of infant nutrition. This guidance will be especially important to parents of infants at risk of food allergy and the health professionals involved in their care.

Regulatory framework to empower food allergic consumers

- 4.5 The mandatory provision of food allergen information was first introduced in legislation in 1996. Research at that time found that those with food allergy required more time to shop as food labels needed to be checked for the presence of allergenic ingredients and for the unintentional presence of allergens due to unavoidable cross contamination (precautionary allergen labelling (PAL)). Feedback from social research showed that consumers with a food allergy found shopping for food was complicated as there were inconsistent approaches to how allergen information was disclosed. So, they also wanted better labelling, emphasising the presence of allergens in prepacked foods and to get clear and accurate advice from food businesses on food allergens when eating out as many consumers avoided doing so, faced with the risk of an allergic reaction.
- 4.6 Following these findings, the FSA was prominent in negotiating on an EU regulatory labelling framework that would promote a consistent approach to declaring food allergens on prepacked foods and to ensure access to allergen information for non-prepacked foods.
- 4.7 A significant improvement came with the introduction of the Food Information to Consumers Regulation in December 2014. It introduced a requirement to emphasise the presence of 14 food allergens when used as ingredients in prepacked foods and to ensure allergen information was made available to customers for non-prepacked foods such as meals from restaurants or takeaways.
- 4.8 Baseline views on consumer perception of allergen information were taken before the introduction of the legislation and a follow-up survey is being conducted; this is part of the on-going assessment to ensure the regulatory approach remains fit for purpose.
- 4.9 'Fit for purpose' in the context of non-prepacked foods includes continuing to develop the culture where allergic consumers feel empowered to ask for allergen information from food businesses and for the FBO to be able to provide this. Increased awareness in FBOs is only possible through continued partner work towards these goals.

Working with and through others to improve lives of those with food allergy

- 4.10 The Food Allergy and Intolerance Team cover both the science and policy of food allergy as well as leading on risk assessment and risk management for allergy incidents. Through this work and through engagement via social media we have gained the trust of a range of groups interested in food allergy issues. We have developed strong collaborative approaches to raise awareness of food allergy issues with academia, food industry, food allergic consumers, allergy groups, healthcare professionals, and policy makers in the EU and internationally.
- 4.11 Improved awareness, checks and consumer reporting are likely to have been the cause of an increase of food allergy incidents noted since the introduction of the regulations in 2014. The numbers of allergy incident notifications received increased from 127 in 2014 to 206 in 2015, with the number of allergy alerts issued increased from 73 in 2014 to 92 in 2015. The majority were due to the wrong product in the wrong packaging or the labelling not being in English. To disseminate allergy alerts in a targeted manner, we work with allergy groups who pass them to their members, with over 18,000 registered for bespoke alerts and a further 3,000+ for general food allergy alerts. Management of these incidents, with a proportionate but important use of recalls and withdrawals, also creates opportunities to raise awareness of allergen management across industry and the enforcement community.
- 4.12 Raising knowledge of food allergy with all citizens is a positive step so we continue to be involved in initiatives like Allergy Awareness Week, working with the allergy support organisations. For instance, in 2016 we supported the campaign which focussed on consumer confidence when eating out and why good handling of food allergy issues can be a benefit for food businesses. Evaluation showed the week was a success, with significant media impact.
- 4.13 Working closely with Coeliac UK has maintained momentum on delivering the latest changes to the EU regulations on gluten labelling. There are no significant changes to controls so the re-housing of the regulations is a legal technicality but given its importance to Coeliac UK and its members they have provided advice and support to the FSA throughout the process.
- 4.14 With the transient nature of the workforce in some sectors of the food industry, maintaining food safety knowledge such as food allergy within a business can be challenging. The FSA has produced a library of free e-learning, guidance, posters, videos and tools to support the enforcement community and food industry to learn about the requirements and how to comply with them. Over 175,000 have visited our e-learning website (food.gov.uk/allergy-training) in the last 12 months. Advice is also disseminated to local authority representatives via a FSA training programme. Our e-learning course has already trained over 70,000 enforcement officers and food business operators.

- 4.15 To supplement this, we have worked with the food industry in their development of best practice guidance documents which promotes further information consistency.
- 4.16 Publicity from a report by the Royal Society for Public Health, although somewhat critical of the penetration of allergen information provision in certain sectors of the food service sector (such as chicken shops and ethnic restaurants/takeaways), continues to raise awareness of the subject. We also resourced an appearance on the BBC's 'Rip off Britain' to further the messaging. A challenge is to ensure all new and existing businesses, especially those with a high staff turnover, take responsibility for putting the correct processes in place.
- 4.17 Many people with food allergy do not like emphasising their condition, especially teenagers who do not want to be seen to be different in social groups, so may feel inhibited from asking for information. Consumer groups like the Anaphylaxis Campaign, Allergy UK and Coeliac UK run campaigns to de-stigmatise food allergy to encourage conversations between the consumer and the food business and we endorse and support these initiatives.

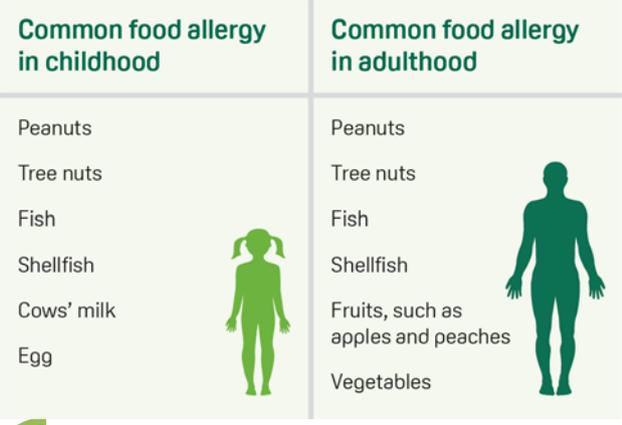
Future work

- 4.18 Precautionary allergen labelling (PAL), such as 'may contain', remains an obstacle to some for adequate choice of foods due to their food allergy. Inappropriate use can result in distrust in the statement, unnecessarily limiting food choices to some allergic consumers whilst others indulge in risk taking behaviour and choose to ignore the claim risking an allergic reaction.
- 4.19 The use of PAL statements are voluntary and are used to warn allergic consumers when allergen cross contamination is unavoidable. The provision of PAL is not defined specifically in legislation and this has resulted in an inconsistent approach to how it is applied on prepacked foods. Some food businesses and Member States opt for a zero tolerance approach as it is not always clear how much allergen being present is considered to be unsafe, which can result in the application of PAL where the risk is remote.
- 4.20 The FSA has been working on the development of standardised PAL for some years and as a consequence of our work, this has been picked up by the food industry and the European Commission. The FSA published guidance for food businesses in 2006; to help develop allergen management protocols so that PAL was used only where there was a real risk of allergen contamination in the finished product. However, this guidance was qualitative not quantitative and did not define what amount of allergenic protein was construed to be unsafe. Allergic consumers and the industry would welcome greater transparency on risk assessment as it will give more meaningful and risk based PAL for consumers. The FSA continues to engage with experts across the EU and internationally to develop PAL as quantitative guidance.

Proposed refocus of evidence work to adult allergy

4.21 Food allergy in adults is an emerging area of interest. Reports from experts and consumers indicate that more adults are becoming allergic to foods and that the types of foods which adults are experiencing issues with are more diverse. Initial scoping data suggest that fruits and vegetables and seafood are causing reactions in adults. The evidence base in this area is very limited and we have been utilising innovative approaches to help us to understand the problem, such as analysis of social media.

Common food allergy in childhood	Common food allergy in adulthood
Peanuts	Peanuts
Tree nuts	Tree nuts
Fish	Fish
Shellfish	Shellfish
Cows' milk	Fruits, such as apples and peaches
Egg	Vegetables



Taken from Anaphylaxis Campaign's "2017 Year of the Adult"

'I had my first allergic reaction and full anaphylactic shock in 1993 to peanuts at the age of 26. I believe I was the first patient that the Old Blackburn Royal Infirmary had dealt with. I carry an EpiPen at all times. Since then I have become allergic to more foods. Sometimes I can trace it other times I never know what it is that has set me off. Luckily I only get itching, hives, swelling and a bit of wheeziness and antihistamines see it off. I see it as lucky because it is not the full shock. Most people around me don't. I find my local GP unsympathetic probably because they have little experience.'

4.22 We propose to work collaboratively with research groups, health professionals and consumer groups to gain robust data on the prevalence of adult food allergy, their characteristics and the barriers they face in being able to choose safe and healthy food. This area of work will also allow us to respond to changes in the prevalence of food allergy

which may be related to increased dietary diversity.

4.23 A collaborative approach which utilises existing cohort studies will allow us to invest in research projects which will maintain and build on the FSA's reputation as a key funder of research and deliver excellent value for money.

4.24 Before we take this further, it would be beneficial to have the Board's agreement on whether this is an area the FSA should seek to understand further with potential for future policy interventions and advice.

5. CONCLUSION

5.1 The Board is asked to:

a) Consider the recent outputs from world-leading research and their routes to impact, and,

b) Agree to the shift of emphasis of the research programme from food allergy in infants and children to adults.

Annex

Food information to consumers regulation

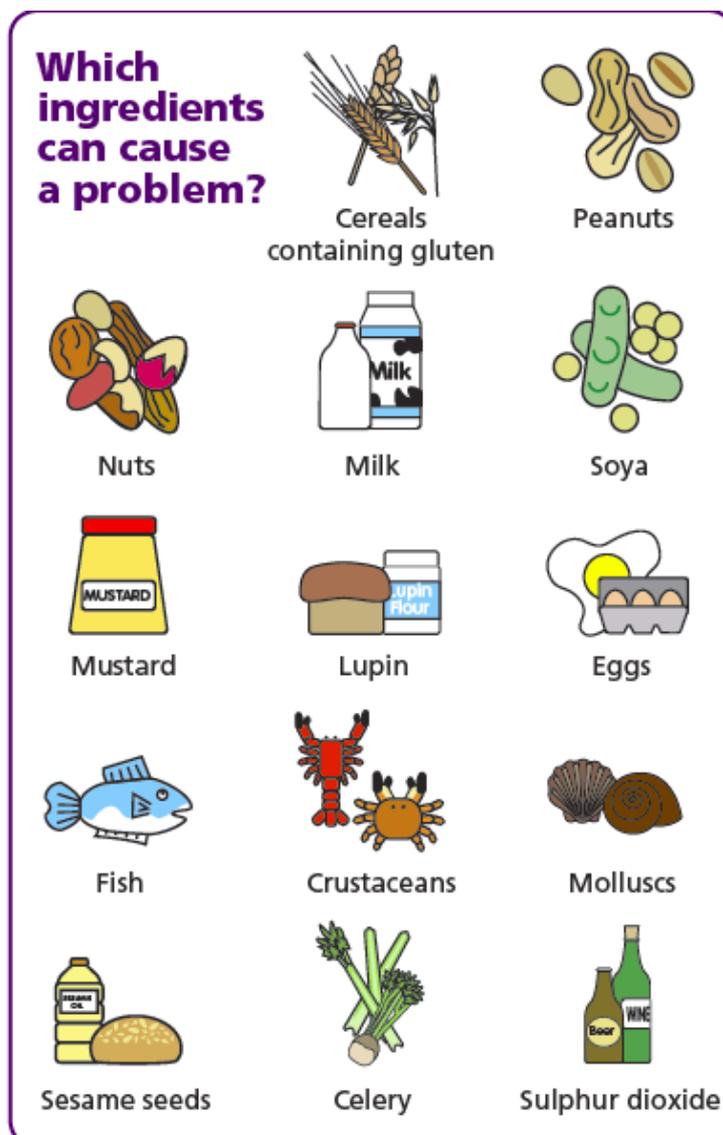
In December 2011, rules on food allergen information were published and detailed in EU Food Information for Consumers Regulation (1169/2011) introducing improved declarations for prepacked foods through:

- the emphasis of allergenic ingredients within the ingredients list, and
- a new requirement to provide allergenic ingredients information for foods sold non-prepacked such as meals provided in restaurants, schools and hospitals.

On December 2014, these rules were enforced across the UK and the EU, bringing better consistency in the provision of allergen information for consumers.

Allergens to be declared

These regulations require the declaration of 14 food allergens, namely:



Gluten labelling regulations

Gluten labelling was housed for legislative purposes under the PARNUTS framework. This has now ended and the gluten rules are housed in a different legislative framework. Scotland, Wales and Northern Ireland have all implemented secondary legislation. Controls for England were delayed due to changes to plans on which legislation the gluten regulations were to be linked with. It proved best to produce a standalone SI and the consultation on the draft legislation closed in December with production of the finalised England SI aiming for April. There is no major change in the specific controls with the transfer to this SI but a consequence of this process led to clarification that the expression “no gluten-containing ingredients” could no longer be used on individual meals or food products. Definitions for when ‘gluten free’ and ‘very low gluten’ voluntary claims can be used for foods remain as before.

Food Allergy Campaign 2016

In 2015, media articles and reports suggested that compliance with allergen rules was not as high as would be desired. The information came from small local surveys and while they did not reflect the national picture they indicated that small businesses were not aware of the rules and/or struggled to understand them. The FSA worked in partnership with local authorities and online take away food aggregators to reach out to small businesses to improve awareness and compliance.

The FSA delivered its second allergy campaign during Allergy Awareness Week (25 April- 1 May 2016) in partnership with Allergy UK, Anaphylaxis Campaign and Coeliac UK. The focus of this campaign was for food businesses why food allergies were important to them and how providing allergen information could aid business. More often than not, those with food allergy chose not to eat out or stuck to places they trusted. Eating out as a person with food allergy required organisation (e.g. checking website, calling the restaurant) and is often faced with prejudice when asking for allergen information.

The campaign was facilitated by traditional and social media channels as well as a Twitter forum with an FSA spokesperson during the #AllergyHour – a popular online forum for influencers and the allergy community.

The total circulation of allergy campaign via traditional media was calculated to have a reach of over 100 million and on social media it had an estimated reach in excess of 7 million. Overall the level of engagement and reach of the campaign was excellent.

References

Quotes (unless otherwise given) are taken from *Understanding the food choice reasoning of nut allergic consumers*, Final Technical Report T07058, commissioned by FSA in 2009