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**ORIGINAL ARTICLE**

# Identifying key priorities for research to protect the consumer with food hypersensitivity: a UK Food Standards Agency Priority Setting Exercise

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**Author contribution statement :**

PJT developed the concept and initiated the Prioritisation Exercise (PSE) reported in this manuscript, on behalf of the UK Food Standards Agency. The PSE and related activities were coordinated by PJT, AB, CC, KC and JO'B. All authors participated in the PSE and subsequent workshops. PJT wrote the initial draft, which was subsequently reviewed, revised and the final version approved by all authors.

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**Abstract**

**Introduction**: Food hypersensitivity (FHS), including food allergy, coeliac disease and food intolerance, is a major public health issue. The Food Standards Agency (FSA), an independent Government department working to protect public health and consumers' wider interests in food, sought to identify research priorities in the area of FHS.

**Methods**: A Priority Setting Exercise was undertaken, using a methodology adapted from the James Lind Alliance – the first such exercise with respect to food hypersensitivity. A UK-wide public consultation was held to identify unanswered research questions. After excluding diagnostics, desensitisation treatment and other questions which were out of scope for FSA or where FSA was already commissioning research, 15 indicative questions were identified and prioritised by a range of stakeholders, representing food businesses, patient groups, healthcare and academia, local authorities and the FSA.

**Results**: 295 responses were received during the public consultation, which were categorised into 70 sub-questions and used to define 15 key evidence uncertainties ("indicative questions") for prioritisation. Using the JLA prioritisation framework, this resulted in 10 priority uncertainties in evidence, from which 16 research questions were developed. These could be summarised under the following 5 themes: communication of allergens both within the food supply chain and then to the end-consumer (ensuring trust in allergen communication); the impact of socioeconomic factors on consumers with FHS; drivers of severe reactions; mechanism(s) underlying loss of tolerance in FHS; and the risks posed by novel allergens/processing.

**Discussion**: In this first research prioritisation exercise for food allergy and FHS, key priorities identified to protect the food-allergic public were strategies to help allergic consumers to make confident food choices, prevention of FHS and increasing understanding of socioeconomic impacts. Diagnosis and treatment of FHS was not considered in this prioritisation.

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**Key messages**

- We undertook a food hypersensitivity research priority setting exercise for the UK Food Standards Agency.
- This was informed by a public consultation and multiple stakeholder input, but excluded diagnostics and treatment
- People with food hypersensitivity identified issues around making confident food choices as key research priorities.

**Key Words**

Allergen labelling; coeliac disease; food allergy; James Lind Alliance; research prioritisation.

**Data Availability**

The data that support the findings of this study are available from the corresponding author upon reasonable request. The data are not publicly available due to privacy restrictions.

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**Abbreviations**

| | |
|---|---|
| EU | European Union |
| FBO | Food business operator |
| FHS | Food hypersensitivity |
| FSA | Food Standards Agency |
| JLA | James Lind Alliance |
| PAL | Precautionary allergen labelling |
| PSE | Priority setting exercise |
| PSP | Priority setting partnership |

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## INTRODUCTION

Food hypersensitivity (FHS) - a term which encompasses food allergy (both IgE-mediated and non-IgE-mediated mechanisms), coeliac disease and food intolerances - continues to be a major issue in terms of the supply of safe food for consumers. According to the UK's Food Standards Agency, around 1 in 20 of the UK population report a FHS. Food allergy is the commonest cause of potentially life-threatening allergic reactions (anaphylaxis), a serious systemic hypersensitivity reaction that is usually rapid in onset and may cause death.[1] Hospital admissions due to food-anaphylaxis continue to increase in the UK and elsewhere, although reassuringly, the case fatality has not increased.[2,3]

The provision of safe food to consumers with FHS is a major priority for the UK Food Standards Agency (FSA), an independent Government department working to protect public health and consumers' wider interests in food. The FSA has been a significant funder of FHS-related research in the UK.[4] The FSA Board requested its Science Council, a group of independent scientific advisers, to undertake a review of its research programme on FHS in 2019 and help inform its future direction in terms of commissioning research.

Research priorities are often developed without wide and coordinated stakeholder contributions.[5] To address this concern, the James Lind Alliance (JLA) has developed a methodology for Priority Setting Partnerships (PSPs), which brings together patients, carers and clinicians to identify and prioritise the evidence uncertainties in any given topic area.[6] The aim of a PSP is to help ensure that those who fund health research are aware of what really matters to patients, carers and clinicians, the end users of research. The JLA uses an adapted nominal group technique; this prevents the domination of discussion by a single person and encourages the participation of less assertive members, including non-professionals. PSPs have been undertaken for numerous chronic diseases including asthma[7] and eczema[8] but not for food allergy or food hypersensitivity. Industry stakeholders and those with commercial interests are usually excluded from PSPs. However, in context of the FSA's remit to protect consumers with respect to risks posed by FHS, it was essential to include Food Business Operators and other stakeholders involved in the food supply chain. Therefore, in order to meet the

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requirements of the FSA, a research Priority Setting Exercise (PSE) was undertaken, adapting PSP principles with the inclusion of industry stakeholders, to identify research priorities for the FSA in the area of FHS.

The aim of the PSE was to identify and prioritise the current knowledge gaps in providing safe food to individuals with FHS in the UK from key stakeholder perspectives, including (but not limited to) consumers (both allergic and non-allergic), healthcare professionals, regulators, industry and wider stakeholders. The scope of the PSE included: enabling safe food choices for consumers with FHS; practises to handle and produce food safely for those with FHS; behaviours surrounding food safety with specific reference to FHS. Although the scope of the PSE did not include underlying health delivery (including access to diagnosis and treatment of FHS) as these are not within the FSA's remit, information regarding these issues were collected and reported here, although not included in the prioritisation exercise. In reporting this exercise, we have referred to the REPRISE Reporting guideline for priority setting of health research.[9]

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## METHODS

There were 5 stages to the PSE, outlined as follows and in Figure 1:

i. *Initiation and identification of potential stakeholders*: a Steering Group made up of members of the FSA Science Council and Secretariat was established to write a protocol,[10] oversee the PSE activity and identify potential stakeholders. The protocol was aligned with JLA methodology as per the JLA Guidebook,[6] and finalised in December 2019.

ii. *Identifying knowledge gaps*: A UK-wide, online consultation of public stakeholders was undertaken to identify "unanswered questions" and knowledge gaps (referred to as "evidence uncertainties") relating to the provision of safe food to consumers with FHS.

iii. *Analysis and formulation of research questions*: refinement of responses generated in (ii) to formulate summary questions. This work was contracted to Ipsos MORI and overseen by the PSE Steering Group.

iv. *Prioritisation workshop*, where the summary questions identified in (iii) were prioritised through consensus, with the input from representatives of the various stakeholder groups, held in September 2020.

v. *Development of research questions* based on the identified priorities, to help the FSA understand the existing evidence base and thus the need for future research.

### *Identification of knowledge gaps and public consultation*

Five themes were identified by the Steering Group to provide structure to the PSE:

i. *Eating out*: the consumption of food prepared and served away from home, especially at a restaurant, café or take away establishment.

ii. *Buying prepacked food* i.e. food that has been prepared in advance of sale e.g. ready meals, packaged sandwiches etc.

iii. *Handling and Understanding Food* – helping consumers to make informed choices about buying safe food, which involves: food preparation, labelling, food/ingredients supply, preventing cross-contamination, effective cleaning, testing and monitoring to ensure food safety.

iv. *How we interact with food*, including changes in how and where consumers obtain food today e.g. new foods and novel allergens, food banks, food business

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practices, new, reusable and biodegradable packaging, online purchasing through the internet etc.

v. *Improving knowledge* including, for example, questions about the numbers of people in the UK affected by food hypersensitivity; or why some people develop food hypersensitivity but then outgrow their allergy or sensitivity.

An online public consultation "Improving life for people with Food Hypersensitivity" was created using Microsoft Teams and launched on 20th February 2020 (see supporting information). The public consultation was communicated to over 250 organisations *via* social media channels, targeting the general public, food businesses, patient groups/charities, religious and cultural organisations, the healthcare sector, academia, local authorities and professional bodies. Respondents were asked to help identify knowledge gaps relating to FHS in each of the above 5 themes. Responses from the UK were automatically collected in Microsoft Excel, cleaned and then transferred to Ipsos MORI who were commissioned to analyse the responses received, using a 4-stage process as shown in Figure 2.

After excluding out-of-scope questions or those areas in which FSA is currently commissioning research, the Steering Group developed 15 indicative questions to capture the key themes and concerns raised in the public consultation. These were then taken to a two-day prioritisation workshop in September 2020 (virtual meeting, postponed from early 2020 due to COVID) conducted according to the JLA guidebook.[6] Thirty-two stakeholders, representing food businesses, patient groups, healthcare professionals and academia, local authorities and the FSA were present. The workshop followed the standard JLA workshop method, drawing on an adapted version of Nominal Group Technique, and consisting of a rounds of mixed-stakeholder group discussions and ranking exercises. The workshop was facilitated by independent facilitators with experience in the JLA priority setting method. Relevant research questions relating to the identified priority indicative uncertainties were then developed by the same attendees at a subsequent workshop. A standard pro forma, based on a PICO format (Participants, Intervention, Comparator, Outcome), was used to guide discussions. No reimbursement was provided for participation.

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## RESULTS

The public consultation received 295 responses by the time the survey closed (a month earlier than anticipated, due to COVID-19) on 26th March 2020, representing a broad group of stakeholders (Figure 3), 96% of whom were based in the UK. Responses were categorised according to "tags" (Table 1) which were then used to identify more specific sub-questions. In total, 17 broad themes were generated, with 70 sub-questions within these themes (see Supporting information: Table S1; further details appear in the Ipsos MORI report available online[11]). Very broadly the questions and issues identified by different stakeholders were similar, although specific types of respondents had slightly greater interest in certain issues.

- Healthcare professionals – allergen contamination (e.g. due to use of shared production lines); communication of (potential) allergen presence to consumers, including through labelling and precautionary allergen ("may contain") labels; knowledge and understanding of FHS; science underlying the development or loss of tolerance resulting in FHS.
- Food business operators (FBOs) – knowledge and understanding of FHS; provision of allergen information between FBOs within the supply chain, and to the end-consumer.
- Patients with FHS and their carers – diagnosis and treatment of FHS; making safe food choices, including when eating out; measures to minimise contamination during production; communication of allergen information including precautionary allergen labels.

The Steering Group then reviewed these sub-questions, and after excluding out-of-scope questions or those areas in which FSA is currently commissioning research (Table 2), 15 indicative questions were developed (see supporting information, Table S2) and taken forwards for prioritisation at the PSE workshop in September 2020 (virtual meeting, postponed from early 2020 due to COVID). Using the JLA prioritisation framework, this resulted in 10 priority indicative uncertainties, from which 16 research questions were developed (Table 3).

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## DISCUSSION

The JLA methodology was originally developed to bring patients and clinicians together in a non-hierarchical manner to identify and address the most important uncertainties with respect to the effects of care and treatments.[12] It has since been used to prioritise questions for research in over 100 clinical areas internationally. We report the outputs from a prioritisation exercise using this methodology to highlight priority unanswered questions in terms of providing safe food to consumers with FHS. This is the first research prioritisation exercise ever conducted for food allergy and FHS. A major strength is the very significant and comprehensive input from patients/consumers achieved as a result of the initial public consultation. Although the focus was on UK consumers, it is likely that many (if not all) of the identified indicative uncertainties would apply elsewhere. The research questions proposed are not intended to be exhaustive, but rather, reflect the views of the workshop participants in terms of areas where addressing the underlying evidence uncertainties could help better provide for consumers with FHS. The traditional JLA PSP approach ends with the identification of priorities. These tend to be broad topic areas which require interpretation and development to become tractable propositions for research. We have built on this process by incorporating that additional step into the project, to identify specific research questions from the priorities, involving multiple stakeholders to ensure those questions genuinely reflect the concerns of the evidence users.

Healthcare delivery, including therapeutics, are outside the FSA's remit and were therefore considered out of scope. However, the public consultation demonstrated that these remain priorities for consumers with FHS, and we therefore list these unanswered questions in Table 2. A need to improve diagnostics (accuracy, accessibility) and develop new therapeutics for FHS (including, but not limited to allergen desensitisation and interventions targeting the microbiome) are highlighted. Given that respondents were encouraged not to consider issues relating to healthcare provision when completing the public consultation, the list of out-of-scope priorities should not be considered exhaustive, and a future PSP focussed on food allergy management and treatment is justified. We attempted as broad a public consultation as possible, using specific targeting of community charities and religious organisations to capture the inclusion of consumers

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who might otherwise be excluded e.g. children/young people, minority groups. Despite this, it is possible that some groups may have been under-represented. In this respect, it will be interesting to compare the outputs of the ongoing COMFA (Core Outcome Measures for Food Allergy) project which seeks to develop a set of Core Outcomes for evaluating new treatments for food allergy.[13]

The priorities identified fit into 5 themes. First, communication of allergens both within the food supply chain (between different FBOs) and then to the end-consumer (ensuring trust in the allergen information available); (ii) the impact of socioeconomic factors on both the development of FHS and then the risk of more severe reactions; (iii) other drivers of severity; (iv) the mechanism(s) by which individuals can develop FHS to a previously tolerated food (something which is increasingly reported with respect to adult-onset FHS); and (v) the risks posed by novel allergens/processing, something which is becoming more important given the increasing global population and the desire towards sustainability. There are many similarities between these themes, and those identified by PSPs for other related conditions, including asthma, eczema and coeliac disease.[7,8,14] For coeliac disease, risk communication by FBOs (including allergen labelling), diagnostic accuracy, increased awareness amongst the general public have also been highlighted as priority areas.[14]

Some of these unanswered questions can be addressed through improving the surveillance of FHS reactions occurring in the community, to inform both current policy but also allow the detection of new allergen risks (either arising from novel allergens/processes, or changes in the consumption patterns of existing allergens) which pose a hazard to consumers with FHS. In this respect, the FSA is funding the establishment of a UK-wide Anaphylaxis Registry to report allergic reactions, and developing a Food Allergic Reaction Reporting Mechanism to better capture food incidents from FBOs and the general public.[15]

The communication of allergen risk through the food supply chain and to the end-consumer is partly informed by legislation. The public consultation was undertaken prior to the COVID-19 epidemic, which impacted upon the food supply chain; changes in the

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availability of ingredients and the increased use of online ordering and dark kitchens has demonstrated potential vulnerabilities which could impact on the efficacy of allergen communication. The interpretation of precautionary allergen ("may contain") labels (PAL) remains a concern to consumers, FBOs and regulators alike.[16] PAL are not specifically informed by legislation at the current time (although the use of PAL should not be misleading under the General Food Law). Work is currently ongoing at a global level to reassess the evidence base for use of PAL.[17] This should improve scientific rigour and transparency to the communication of risk posed by unintended allergen presence (for example, due to cross-contamination during food production), allowing consumers with FHS to make more informed and safer food choices.

There is a clear impact of socioeconomic factors on food allergy in the USA[18] but the extent to which this may be true in the UK is unclear. A London-based study reported a relatively greater increase in children diagnosed with peanut allergy over a 14 year period (1990-2004) from non-white backgrounds, compared to egg allergy, which could not be explained by improved awareness.[19] Another study has reported a significantly higher incidence of anaphylaxis among British South Asians compared with those from a White Caucasian background.[20] In the EAT study, authors noted a much higher rate of food allergy in non-white participants, from 5.3% in those from a white background to 19.3% in Asian/black/Chinese participants.[21] The EAT study also indicated that cultural norms and communication may be a factor, with adherence to advice lower in those from a non-white background.[22] The relationship between ethnicity and socioeconomic class can be difficult to unpick, and can also impact on access to healthcare and communication (which is important in terms of dietary advice and risk avoidance). The PSE has identified this as a major knowledge gap which should be addressed to help resolve the disparities that appear to exist with respect to ethnicity and FHS.

Creating a research agenda involves many different drivers: for many chronic diseases, research direction is affected by commercial interests and the "patient voice" is something which may not figure prominently; it is this inequality that the JLA methodology for PSPs was designed to address.[5] At the same time, the absence of "treatments" for FHS (with management focussed more on avoidance of the trigger and rescue

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medication in the event of accidental reactions) creates different drivers compared to other chronic conditions. Legislation and regulation set a minimum standard for FBOs to adhere to, but consumers may not have confidence and trust that their needs are being provided for, for instance with respect to the purchase of foods from a catering outlet or the use PAL. An FBO can be fully compliant with legislation and guidance, yet consumers may not feel confident that the FBO can provide them with "safe" food, for example, due to poor communication. Improving this requires a combination of "science push" and "policy pull", with clear and transparent communication to consumers so that they can develop trust in FBOs providing food for them. In undertaking this exercise, we hope to have identified key areas where further research and funding should be targeted, from the perspectives of the various stakeholders who will be the beneficiaries and end users of FHS research. The hope is that this will better provide for the significant proportion of the population with FHS and reduce the day-to-day impact of a diagnosis of FHS on patients.

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**Competing interests**

All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare competing interests as follows: PJT reports grants from the Food Standards Agency, JM Charitable Foundation, Medical Research Council, NIHR/Imperial Biomedical Research Centre and End Allergies Together, outside the submitted work; personal fees from UK Food Standards Agency, Aimmune Therapeutics, Allergenis and ILSI Europe outside the submitted work. JB reports personal fees and grants from Food Standards Agency, outside the submitted work. SC reports financial activities with Unilever, outside the submitted work. KC is an independent facilitator and senior adviser to the James Lind Alliance. She is co-author/editor of the JLA Guidebook and supports the JLA Secretariat and team of JLA advisers. She was an independently contracted adviser for this work. MF reports personal fees from Aimmune Therapeutics and Danone outside the submitted work. ATF is current President of the British Society for Allergy & Clinical Immunology (BSACI) and Chair of the Health Advisory Board of Allergy UK, both of which receive corporate sponsorship from companies involved in food allergy. He also reports consultancy work with Aimmune, without receiving a personal fee. MHG reports personal fees from Food Standards Agency (as a subcontractor), outside the submitted work. IK reports personal fees from Food Standards Agency, outside the submitted work. J'OB John O'Brien is a trustee of the Institute of Food Science & Technology, a member of the non-executive board of Campden BRI, and Director of the Food Observatory; personal fees from Food Standards Agency, outside the submitted work. GR reports grants from European Union and Food Standards Agency outside the submitted work; he is also President Elect of the BSACI. CV reports grants from National Peanut Board; grants and personal fees from Reckitt Benckiser; personal fees from Nestle Nutrition Institute, Danone, Abbott Nutrition, INTENT Study, and Else Nutrition, outside the submitted work. The other authors do not report any conflicts of interest.

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**Table 1**: Main themes identified during the public consultation

| Themes | Mentions (n) | Examples of tags in each theme |
|---|---|---|
| **Packaging and labelling** | 658 | Comprehensive, clear, disclaimers, packaging, allergens, gluten |
| **Allergic consumers** | 631 | Reactions, hypersensitivity, number, frustrations, diagnosis, treatment, Irritable Bowel Syndrome, Coeliac disease |
| **Cross contamination** | 397 | Manufacturing, processing, products on display, staff behaviour |
| **Information** | 364 | Ingredient lists, digital info, clarity, allergen list |
| **Knowledge / education** | 306 | Better training, guidance, understanding, take it serious, allergy vs. intolerance |
| **Safety** | 325 | Tolerance levels, levels of risk, trust |
| **Allergens** | 311 | 14 EU Priority allergens, rapeseed, additives, egg, cow's milk (dairy), nuts |
| **Food** | 258 | Prepacked, more choice, novel food, vegan, vegetarian |
| **Legislation / standardisation** | 239 | Ratings, testing, reporting, FSA |
| **Eating out** | 202 | Food preparation, menus, staff knowledge |

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**Table 2**: Excluded evidence uncertainties due to out of scope or through being addressed by ongoing FSA-contracted research

| Out of scope | Addressed by current FSA research |
|---|---|
| What is the difference between an allergy and an intolerance? | How many people are affected by FHS? |
| Why do healthy eating options include so many allergens? | How many hospital/GP visits are due to FHS? |
| Gluten-free foods: Why do they cost more? Are they "better" for you? | What are the most common food allergies/intolerances? Is this changing? |
| Diagnostics: Waiting times, accuracy, access, novel diagnostics and genetics | National register or database for allergy incidents/people with FHS |
| Desensitisation treatment for food allergy, including interventions targeting the microbiome | Are food allergies/intolerances increasing? |
| Are staff in food establishments trained in how to use adrenaline autoinjector devices? | Is there a link between childhood eczema and food allergy? |
| Are food allergies in adults treated with the same seriousness as those in children? | Thresholds for clinical reactivity i.e. how much allergen is needed to trigger reactions |
| Is there a link between food poisoning and the development of FHS? | |
| What is the defined safe level of lead in game birds? | |

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**Table 3**: "Top 10" Research questions identified by the PSE

| **Indicative uncertainty** | Suggested **research** q**uestion**(s) | **Notes** |
|---|---|---|
| **Risks posed to people with FHS by new/novel foods and/or processes** | In consumers with FHS, what measures are needed to monitor for reactions due to:<br>• new uses of known allergens?<br>• novel proteins which might induce sensitisation and thus clinical reactivity?<br><br>What protocols should the FSA use when assessing the risk to consumers with FHS posed by novel foods/processes/packaging?<br><br>What data exist as to the likelihood of allergenic proteins in biobased food contact materials migrating into foods? | e.g. the use of pea protein in protein concentrates, which is often declared only as "vegetable protein" in ingredients listing.<br><br>e.g. wheat-based starch in packaging, latex-based binders in packaging and sustainable cutlery. |
| **Improving traceability of allergens in the food supply chain** | How should information be communicated (through the food supply chain) to consumers with FHS, to:<br>• improve consumer confidence in terms of possible allergen content?<br>• reduce the incidence of unintended allergen exposure? | The sensitivity and reliability of analytical tests was also discussed, but development of these and the responsibility to ensure such tools are used appropriately was felt to be outside the FSA's research remit. |
| **Risks posed due to shared production of foods, and how can these be mitigated** | What are the health risks to consumers with FHS due to allergen cross-contamination during food production?<br><br>How effective are different control options (such as cleaning protocols) in reducing these health risks? | e.g. Use of shared ovens (e.g. gluten-free foods cooked in the same oven as gluten-containing foods) |
| **Communicating risk, so that consumers with FHS can be** | What are the most effective ways for FBOs to communicate a level of competence (with respect to allergen risk management) to consumers? | |

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| | | |
|---|---|---|
| **confident that the food they are provided is safe** | | |
| **Allergen labelling, including Precautionary Allergen ("may contain") labels.** | What forms of allergen labelling are effective in order for consumers to make informed decisions as to whether a food is "safe" for purchase/consumption? | Labelling to inform both what is present, what might be present (through cross-contamination), and what is not present (whether or not a "free-from" claim is made). |
| **Informing the FSA as to incidents involving food hypersensitivity.** | What evidence is there for different reporting systems to deliver useful data to regulators that can impact on reducing the risk of unintended allergen consumption?<br><br>What are the barriers that prevent reporting of near misses and other incidents to official bodies? | Reporting systems might include:<br>• Mandatory/voluntary reporting by healthcare professionals.<br>• Direct reporting by FBOs and the public<br>• Surveillance of serious incidents e.g. coronial system |
| **Impact of co-factors on reaction severity** | In consumers with FHS, what are the factors which can increase the risk of a severe reaction?<br><br>How should risk posed by co-factors be communicated to those affected by FHS? | Incorporates both general advice to all consumers with FHS, and individualised advice provided by healthcare professionals |
| **Impact of socioeconomic factors (including race/ethnicity) on FHS** | What are the socioeconomic factors which impact on risk in consumers with FHS?<br><br>How do cultural attitudes impact on the management of FHS? | Includes:<br>• understanding the impact of ethnicity/race as confounders<br>• language impacting on access to effective advice and |

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| | | |
|---|---|---|
| | | communication of consumer needs<br>• impact on affordability/ accessibility/availability to safe foods for those with FHS |
| **Impact of environmental exposures on risk of developing FHS** | What are the factors that drive a loss of immune-tolerance to food allergens?<br><br>(Discussion was also held with respect to the impact of disturbances in the microbiome affecting risk of FHS, but it was considered that funding research in this area would be beyond the scope of the FSA) | Applies to both childhood- and adult-onset allergy e.g. how common is loss of prior tolerance? |
| **Current knowledge of FHS amongst the general public** | What are the current gaps/inaccuracies in knowledge with respect to FHS amongst the general public? | Focus on general public, but also applies to specific stakeholders e.g. FBOs, healthcare |

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## Figure Legends

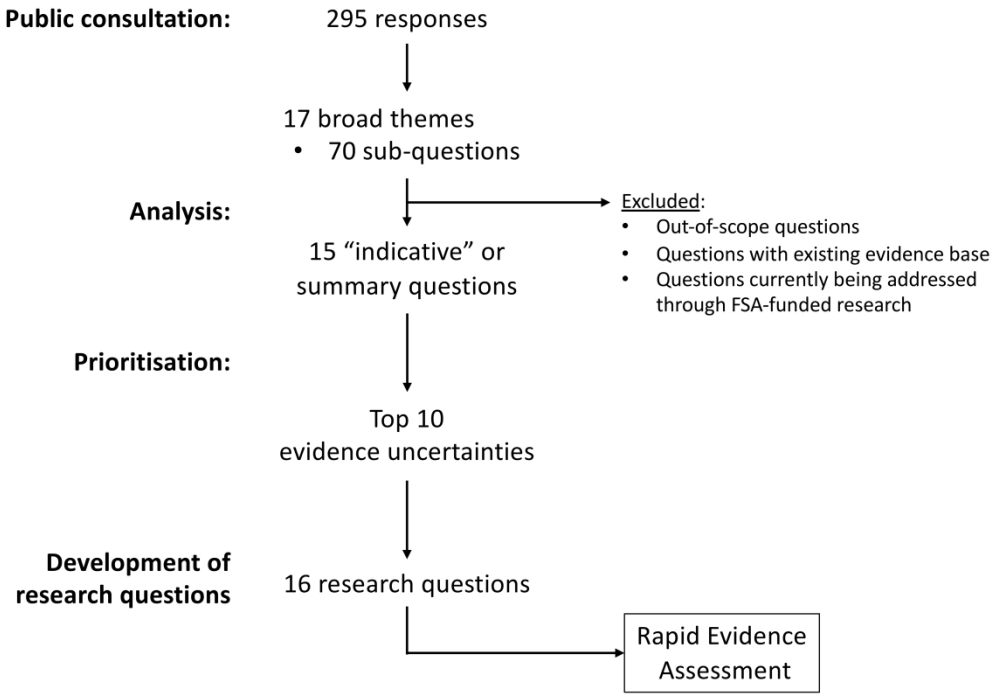
**Figure 1**: Outline of methodology

**Figure 2**: Analysis of responses to the public consultation into indicative questions for the PSE. Further details available in the Ipsos MORI report[10]

**Figure 3**: Respondents to the public consultation

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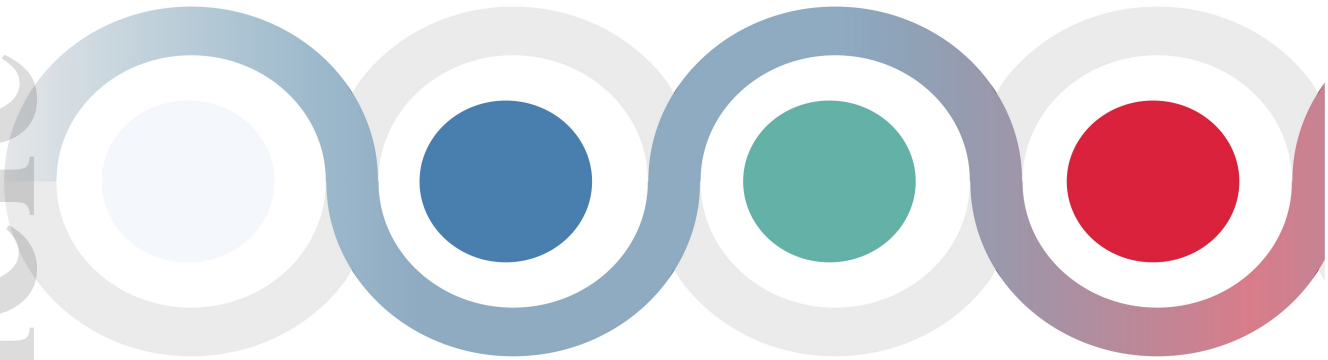
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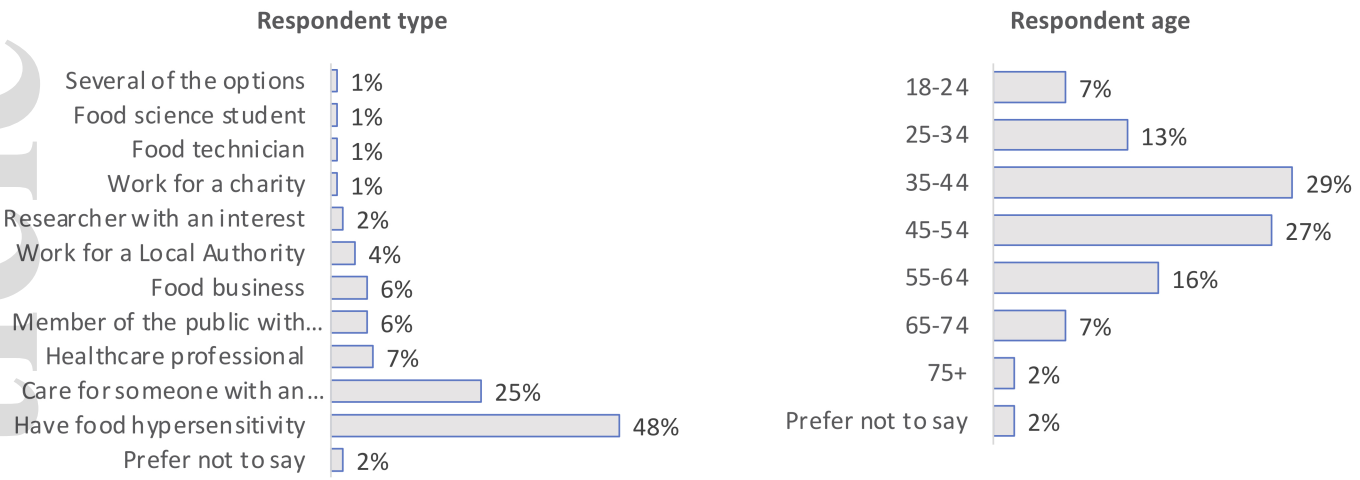
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**Identifying key priorities for research to protect the consumer with food hypersensitivity: a UK Food Standards Agency Priority Setting Exercise**

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# SUPPORTING INFORMATION

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**Public stakeholder survey for Research Prioritisation Exercise**

**FSA Survey: Improving life for people with Food Hypersensitivity**

The FSA is an independent Government department working to protect public health and consumers' wider interests in food. We make sure that food is safe and what it says it is.

We want the UK to become the best place in the world for people living with food hypersensitivities.

Do you have big questions that we could answer through research, to make things better for people with food hypersensitivity? Tell us your thoughts and help us to make a difference.

**Why is the Food Standards Agency (FSA) carrying out this survey?**

Around 2-3% of adults and 8% of children in the UK have a food hypersensitivity. This includes:

- food allergies (which involve the immune system, and can cause severe allergic reactions (anaphylaxis)
- coeliac disease, which affects about 1% of the UK population
- food intolerances (e.g. lactose intolerance) which do not involve the immune system).

We are carrying out this survey to get a better understanding about the key questions and issues the FSA needs to address through research, in order to better provide safe food for people with food hypersensitivities.

**Who is the survey for?**

- You can complete the survey if you are aged 18 years or over and you are:
- a member of the public with an interest in food hypersensitivity
- affected by food hypersensitivity yourself, or care for someone else with a food hypersensitivity
- a food business operator, representative or member of staff who has an interest in food hypersensitivity
- a charity representative or worker with an interest in food hypersensitivity
- a healthcare worker or researcher with an interest in food hypersensitivity
- a local authority or professional body with an interest in food hypersensitivity

This survey is funded by the Food Standards Agency. The survey is voluntary, and you are free to exit at any point - you don’t need to answer all the questions.

**What will the survey involve?**

This survey asks about your experiences and how you think the FSA can help people affected by food hypersensitivity to make safe food choices. Note that the FSA is not responsible for the diagnosis or management of food hypersensitivity.

We will use your responses to help the FSA define and prioritise its research activities in the area of food hypersensitivity. It will take approximately 10 minutes to complete. If you have any problems completing this survey, please email fsadigital@food.gov.uk. We will not ask you for any personal data;

The only personal details that we will be collecting are: your age range; whether you live in the UK; and your general demographic i.e. consumer, business, charity etc. This is so we can ensure we hear from a broad range of people. You will not be identifiable from this information. Please do not include any other personal details in your answers.

For further information on how FSA handles the information you have shared with us, please see our privacy policy on our website https://www.food.gov.uk/about-us/privacy-policy

## Questions

### Theme: Eating Out

Eating out describes the consumption of food away from home, especially at a restaurant, café or take away establishment.

Thinking about the experience of eating out, what unanswered questions and/or issues should the FSA try to answer in order to help people with food hypersensitivity?

### Theme: Buying Prepacked Food

Prepacked food describes food that has been prepared in advance of sale e.g. ready meals, packaged sandwiches etc.

Thinking about the experience of buying prepacked food from shops, what unanswered questions and/or issues should the FSA try to answer in order to help people with food hypersensitivity?

### Theme: Handling and Understanding Food

Handling and understanding food means being able to make informed choices about buying safe food, which involves: food preparation, labelling, food/ingredients supply, preventing cross-contamination, effective cleaning, testing and monitoring to ensure food safety.

Thinking about the experience of handling and understanding food, what unanswered questions and/or issues should the FSA try to answer in order to help people with food hypersensitivity?

### Theme: Changes in how we interact with food

This relates to changes in how and where we obtain food today e.g. new foods and novel allergens, food banks, food business practices, new and reusable packaging, online purchasing through the internet etc.

Thinking about changes in the food we eat and where we get it from, what unanswered questions and/or issues should the FSA try to answer in order to help people with food hypersensitivity?

**Theme: Improving what we know about food allergy and food hypersensitivity**
What unanswered questions and/or issues about food hypersensitivity should the FSA try to answer, in order to help ensure that food is safe for people with food hypersensitivity?

For example, your questions could be about the numbers of people in the UK affected by food hypersensitivity; or why some people develop food hypersensitivity but then outgrow their allergy or sensitivity.

## Demographic Questions

**Do any of the following apply to you?**

- I am a member of the general public with an interest in food hypersensitivity
- I have a food hypersensitivity myself
- I care for someone with a food hypersensitivity and /or I am completing this survey on behalf of someone else affected by food hypersensitivity e.g. my child
- I am a food business operator, representative or work for a food business
- I work or volunteer for a charity who helps provide for people with food hypersensitivities
- I work for a local authority or professional body with an interest in food hypersensitivity
- I am a healthcare professional (e.g. doctor, nurse, dietitian etc)
- I am a researcher with an interest in food hypersensitivity
- Other (free text)
- Prefer not to say

Do you currently live in the UK?

- Yes
- No

What age are you?

- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75+

**Table S1: Indicative themes and sub-questions**

| **1. What is the type and prevalence of food hypersensitivity?** |
|---|
| How many people are affected by FHS? |
| How many hospital and/or doctors visits are caused by FHS incidents? |
| Is FHS increasing? |
| What are the most common allergies/intolerances? |
| What is the difference between an allergy and intolerance? (risk communication to public) |
| Are people being treated for symptoms of an allergy and not the cause? |
| **2. How and why do people develop food hypersensitivity?** |
| Why do people develop FHS? |
| Microbiome/microbiota and allergy development |
| Why do you get more allergies as you get older? |
| What factors make it more likely that you will get FHS? |
| Can you grow out of FHS? / does sensitivity/severity change with age? |
| Are allergies changing as our foods change? |
| Impact of behaviours on reaction severity |
| Impact of co-factors on reaction severity (in scope) |
| What is known about the link between development of FHS and their environment? (a lot of research has been carried out on this topic) |
| Is there a link between eczema in childhood and developing an allergy? (research has been conducted/is this fully addressed?) |
| Is there a link people who have food poisoning and then getting allergies/FHS? (interesting links to intolerance) |
| **3. Is it necessary to review the regulatory allergens list?** |
| What other allergenic ingredients exist? |
| Should the allergen list go beyond the EU 14? |
| What foods are cross reactive with other allergens/intolerance? |
| What is the risk of ingredients derived from allergens? |
| Is it possible to legislate/regulate for unexpected ingredients e.g. pea protein? |
| Do novel food processing techniques make foods more allergenic? |
| Can products used during growing of foods cause FHS? (only in scope if related to pesticides/residues left on food) |
| **4. What is the role of FODMAPS in trigging IBS?** |
| What is known about the role of FODMAPS in triggering IBS? |
| **5. What do the general public understand about FHS** |
| What do the general public know about FHS? |
| Should educate children so they understand FHS |
| How can we increase understanding of FHS amongst the general public? |
| **6. What information do consumers with FHS need to make choices about food?** |
| Do consumers feel safe to eat out? |
| How confident are consumers about traceability of food and integrity of supply chain? |
| Would more regulation satisfy consumers' concerns about eating out choices? |

| |
|---|
| How do people with FHS know if staff are properly trained in managing/responding to FHS? |
| **7. What is the most effective way of communicating information?** |
| What would be the most effective way to communicate with consumers with FHS? |
| How can people report a food allergen incident? |
| How can consumers report breaches? |
| **8. What do businesses understand about FHS?** |
| Do food businesses understand FHS? |
| How do businesses reduce cross contamination? |
| How do businesses manage traceability, how confident are they in the accuracy of that information? |
| **9. How effective is monitoring and enforcement?** |
| Is it possible to combine hygiene ratings with a standard rating for allergies? |
| Can competence be measured via food safety/HACCP? |
| What testing is done on establishments to monitor processes to avoid cross contamination? |
| What testing is done to measure levels of knowledge of FHS amongst business operations? |
| Can there be a certification for businesses trained in FHS? |
| How many novel/online takeaways/street vendors have allergy information, can there be better regulation of businesses? |
| How to improve staff training? |
| What testing is done to ensure compliance with food regulations? |
| **10. How effective are existing measures/guidance on reducing cross contamination?** |
| What controls are needed to cook gluten free and gluten-containing foods in the same oven without cross contamination? |
| What food preparation needs to be in place to reduce cross contamination and guarantee something is free from a FHS ingredient? |
| Risk of cross contamination for coeliac disease e.g. fried food and how to mitigate |
| How can traceability be improved to monitor cross contamination? / How do businesses monitor traceability? |
| Could assessments be introduced so cross contamination is accurately assessed? |
| Risk posed by latex gloves |
| **11. How effective is guidance on producing gluten free food?** |
| Is there centralised guidance for manufacturers to ensure they are producing gluten free food? (work is being done on this) |
| **12. What improvements are required to current labelling of prepacked food?** |
| Is labelling clear enough? Use of symbols/icons rather than (or in addition to) words? How to display ingredients clearly on mixed/multipack foods |
| Is listing of allergen traces in prepacked food helpful? |
| Could similar labelling be in place for FHS as there are for allergens? |
| Can E-numbers be translated to allergens e.g.E322 soya? (possibly relates to lack of consumer understanding) |
| Can labels highlight when ingredients change? |
| How many people rely on information other than the food packaging label? |
| Labelling to highlight actual risk of cross contamination (ingredients/packaging) |

| |
|---|
| What is the risk from trace levels? |
| **13. What improvements are required to current labelling of non-prepacked food?** |
| Full allergens should be listed on the menu |
| Menus include advice about whether food can be adapted to exclude allergens |
| Regulation forcing FBOs (inc. street vendors/takeaways) to label foods correctly |
| Labelling to highlight actual risk of cross contamination (ingredients/packaging) |
| **14. What role can digital technology play in providing information to consumers/businesses in the future?** |
| Can digital technology be used as a better means of displaying allergen info? |
| How reliable are food apps for providing information? |
| What level of detail is needed to communicate allergen risk? |
| **15. What regulations/guidance is needed for novel packaging?** |
| What testing is being done on novel packaging? |
| **16. What regulations/guidance is needed for package free shopping and reusable packaging?** |
| What impact will package free shopping have on those with FH? (relates to labelling and cross contamination) |
| **17. Is there an advantageous commercial value to providing safe food to consumers with FHS?** |
| Is there any evidence that businesses benefit economically when they cater for consumers with FHS? |
| Could food producers be incentivised to exclude FHS ingredients to increase consumer choice? |
| What impact does socio-economic factors have on consumers with FHS? (e.g. availability of gluten-free food/allergen free food in food banks) |

## Table S2: Indicative uncertainties identified by IPSOS MORI analysis

| Initial indicative question | Questions for prioritisation | Rationale |
|---|---|---|
| **What is the type and prevalence of food hypersensitivity?** | none | Existing FSA-commissioned research is examining this:<br>• PAFA study (adults)<br>• Anaphylaxis (all ages) |
| **How and why do people develop food hypersensitivity?** | What are the environmental exposures which increase the risk of developing food hypersensitivity?<br><br>How do socio-economic factors impact on individuals with food hypersensitivity?<br><br>What co-factors (other than exercise and sleep deprivation) increase the risk of a severe allergic reaction? | Responses highlighted whether individuals from some SE backgrounds are at greater risk of severe FHS reactions |
| **Is it necessary to review the regulatory allergen list?** | none | Existing FSA-commissioned research is examining this (anaphylaxis register) |
| **What is the role of FODMAPS in triggering IBS?** | none | Not in FSA remit |
| **What do the general public understand about food hypersensitivity?** | What is the current level of existing knowledge of food hypersensitivity in the general public (including consumers and food business operators), and how can this be improved? | |
| **What information do consumers with food hypersensitivity need, to make choices about food?** | What is the most effective way to alert consumers as to changes in ingredients?<br><br>What are the best ways to communicate risk and appropriate mitigating actions to consumers and food business operators (including, but not limited to, online food | |

| | | |
|---|---|---|
| **What is the most effective way of communicating information to consumers with food hypersensitivity?** | business operators/street vendors / food banks)?<br><br>What are the risks posed due to shared production (e.g. cooking) of foods to individuals with food hypersensitivity, and how can these be mitigated?<br><br>What are the best ways for consumers to be confident that the food they are provided with is safe with regard to food hypersensitivity?<br><br>How can food business owners improve traceability of allergens in the food supply chain | |
| **What do businesses understand about food hypersensitivity?** | What is the current level of existing knowledge of food hypersensitivity in the general public (including consumers and food business operators), and how can this be improved?<br><br>What are the risks posed due to shared production (e.g. cooking) of foods to individuals with food hypersensitivity, and how can these be mitigated?<br><br>What risk is posed to health by "derived" ingredients such as plant oils /fats, starches (other than those foods for which legal exemptions currently exist)?<br><br>How can food business owners improve traceability of allergens in the food supply chain | The sensitivity and reliability of analytical tests was also discussed, but research/development of these and the responsibility to ensure such tools are used appropriately was felt to be outside the FSA's research remit. |
| **How effective is monitoring and enforcement?** | What is the best way to alert the FSA as to incidents involving food hypersensitivity (and increase awareness of how to do this amongst the general public)? | This is captured through existing incidents data |

| | | |
|---|---|---|
| **How effective are existing measures/guidelines on reducing cross contamination?** | What are the risks posed due to shared production (e.g. cooking) of foods to individuals with food hypersensitivity, and how can these be mitigated?<br><br>What is the risk to latex-sensitive consumers from latex cross-contact (both via packaging and during food handling)? | |
| **How effective is guidance on producing gluten free food?** | What are the risks posed due to shared production (e.g. cooking) of foods to individuals with food hypersensitivity, and how can these be mitigated? | Food and Drink Federation and Coeliac UK produced evidence-informed guidance to the food industry in 2019. Coeliac UK has undertaken research on risks of gluten cross-contamination in the kitchen environment. |
| **What improvements are required to current labelling on prepacked food?** | What are the best ways to communicate risk and appropriate mitigating actions to consumers and food business operators (including, but not limited to, online food business operators/street vendors / food banks)?<br><br>What do consumers want from allergen labelling, including Precautionary Allergen (e.g. “may contain”) Labelling)? | |
| **What improvements are required to current labelling of non-prepacked foods sold via food business operators?** | What are the best ways to communicate risk and appropriate mitigating actions to consumers and food business operators (including, but not limited to, online food business operators/street vendors / food banks)?<br><br>What do consumers want from allergen labelling, including Precautionary Allergen (e.g. “may contain”) Labelling)? | |

| | | |
|---|---|---|
| **What role can digital technology play in providing information to consumers and FBOs?** | What is the best way to alert the FSA as to incidents involving FHS (and increase awareness of how to do this amongst the general public)?<br><br>How can food business owners improve traceability of allergens in the food supply chain?<br><br>What are the best ways to communicate risk and appropriate mitigating actions to consumers and food business operators (including, but not limited to, online food business operators/street vendors / food banks)? | |
| **What regulation/ guidance is needed for novel packaging?** | What risk is posed to people with food hypersensitivity by new/novel foods and/or processes (including packaging and other food contact materials)? | |
| **What regulation/ guidance is needed for package free and reusable packaging?** | | |
| **Is there commercial advantage to providing for consumers with food hypersensitivity?** | Are there economic benefits to providing for individuals with food hypersensitivity, which can be used to encourage food business operators to go beyond the letter-of-the-law? | |