

## UPDATE ON SCIENCE COUNCIL WORKING GROUP 5 ON FOOD HYPER-SENSITIVITY

### Report by Alisha Barfield

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#### 1. Summary

1.1 The Board is asked to:

- **Consider and comment** on the progress of the Working Group to date; and
- **Accept** the recommendations in the attached interim report to the Board arising from the review to date.

#### 2. Introduction

2.1 In May 2019, the Science Council was asked by the Board to:

- a) Conduct a review of the science and evidence base for addressing food hypersensitivity
- b) Consider and advise on future research priorities and direction in respect to food hypersensitivity.
- c) Advise on the role the FSA should play to enhancing scientific knowledge.

2.2 This paper outlines progress against the work plan (Annex 1) as well as the mitigations due to COVID-19 for the Science Council's Working Group 5 on food hypersensitivity as agreed by the Council in December 2019.

2.3 In addition, the Board is asked to consider the Science Council's recommendations arising from the Working Group's review into previous and existing FSA research activities in food hypersensitivity, that can be found in the Council's interim report (Annex 2).

### 3. Methodology

3.1 At the Science Council's open plenary meeting of June 2019, it was agreed to establish a new Working Group 5 to assess food hypersensitivity (FHS) issues in response to the request from the Board. The Working Group agreed the following workplan at the December 2019 Science Council meeting (Annex 1):

- a) **WG5.1: Review into the FSA's existing Food Allergy and Intolerance Research (FAIR) programme:** An independent expert, Dr Alisdair Wotherspoon, was commissioned to undertake a desk study relating to the FAIR programme. Findings were shared with internal FSA staff and discussed with Prof. Ian Kimber (Emeritus Professor of Toxicology, University of Manchester) in his role as the External Programme Advisor to the FAIR programme.
  
- b) **WG5.2: Priority Setting Exercise (WP5.2)** The FSA and Working Group 5 have developed a Priority Setting Exercise (PSE) process inspired by the James Lind Alliance Priority Setting Partnership methodology. The PSE is comprised of 3 stages:
  - Public Survey: "Improving life for people with Food Hypersensitivity" was launched on 20<sup>th</sup> February and was communicated to over 250 organisations *via* social media channels, targeting the general public, food businesses, patient groups/charities, healthcare sector, academia, local authorities and professional bodies. The survey asked respondents to help identify knowledge gaps relating to food hypersensitivity in the following 5 theme areas: Eating out, Pre-packed food, Handling and understanding food, Changes in how we interact with food, Improving what we know about food allergy and food hypersensitivity (Annex 3). Over 300 responses were received when the survey closed (a month earlier than anticipated due to COVID-19) on 26<sup>th</sup> March.

- Ipsos MORI were commissioned to analyse the responses received, following which the working group streamlined responses into 15 research themes.
  - These 15 themes were prioritised during a 2-day workshop, originally planned for July but moved to 7<sup>th</sup>/8<sup>th</sup> September due to COVID-19 (virtual meeting). A range of stakeholders representing food businesses, patient groups, healthcare and academia, local authorities and the FSA were present. The outputs of this event will be discussed within the final report of the Working Group.
- c) **WG5.3: A review of existing working practices within of the FSA working practices in the broader commissioning and use of research on food hypersensitivity.** Interviews with previous and existing FSA staff were held throughout February and March, as outlined in Annex 2. In parallel, case studies on 3 projects commissioned within the FAIR programme were reviewed. The findings were discussed by the Science Council, culminating in the Interim Report to the Board (Annex 2).
- d) **WG5.4: Review of the existing evidence underpinning the Top 10 priority areas in food hypersensitivity identified in WG5.2.** To be undertaken by external contractor.
- e) **WG5.5: Horizon scanning workshop** to identify future priorities in commissioning research in the area of food hypersensitivity (5-15-year timeframe). This was planned for 19<sup>th</sup> October 2020 but will now take place in early 2021 due to COVID-19.
- 3.2 The attached interim report represents the final recommendations to the FSA Board arising from WG5.1 and WG5.3.
- 3.3 This interim report has been considered and accepted by the executive in both the Science and Policy directorates.

3.4 A final report will be presented to the FSA Board in June 2021 (delayed from March 2021 due to mitigations arising from COVID19).

#### 4. Interim report recommendations

4.1 **The Science Council has approved the interim report to the FSA Board, which outlines** recommendations for the FSA to consider across both Science and Policy (Annex 2). While these relate to the work undertaken by FSA in the area of food hypersensitivity, many of the recommendations are likely to be applicable to other areas of FSA practice.

4.2 The key recommendations are summarised as follows:

- a) **Overall strategy and direction:** Historically, the FSA has funded a significant amount of research into FHS in the UK. More recently, there has also been a focus on adult food allergy; the FSA Board requested at the March 2017 meeting that funding research on adult food allergy should not be at the expense of other FSA research activities in FHS. There has been a decrease in investment in the FAIR programme since 2010. In addition, the reduction and turnover in personnel, together with the cessation of annual stakeholder meetings, may have limited the ability of FSA to identify and launch new research activities. The FSA has funded research that provides less direct impact to protecting consumers with FHS (e.g. by reducing the prevalence of FHS through primary prevention strategies). The success of this work was acknowledged at the March 2017 FSA Board meeting. **With the introduction of cross-governmental ARIs, the FSA Board should again provide a steer as to the role FSA should play in commissioning broader research into FHS** (for example, whether research into the treatment of food allergy or potential environmental causes of food intolerances falls within the FSA remit).
  
- b) **Food Hypersensitivity Programme Board:** A new Programme Board was established by the FSA in Summer 2018 to bring together FSA work in the area of FHS under the direct oversight of the Executive Management Team. The process by which science and data are brought to the Programme

Board needs to be made more resilient. **We recommend a more structured approach with the necessary staff resourcing to facilitate this, without compromising the benefits of the informal horizontal system currently in place. This could take the form of a multi-disciplinary forum alongside the Programme Board to provide “science push” while the Programme Board creates “policy pull”.**

- c) ***Maximising outputs from existing data:*** The FSA should consider allocating additional resource to maximise use of routinely-collected data across the FSA (e.g. post-incident analyses) and avoid the current situation where operational and analysis roles may be combined resulting in limited capacity for data analysis. This has been previously flagged by the Science Council as a recommendation to the FSA Board (Science Council Report on Capability and Assurance, July 2018).
- d) ***Capturing best practice, supporting staff and building resilience:*** There is a critical reliance on “lynchpin” individuals. **This must be addressed through adequate internal resources, succession planning, handover checklists and strategies to capture best practice and protect institutional knowledge.** Thought should be given to the use of expert Project Managers who may be better qualified than FSA scientists to undertake this work.
- e) ***Regular external reviews:*** The FSA should reinstate regular stakeholder and quinquennial external reviews to ensure ongoing evolution and external monitoring of the FHS research environment. This would also facilitate:
- more structured (and regular) horizon scanning
  - wider dissemination of research programme outputs and impact
  - development of more strategic relationships with other funders/stakeholders to maximise potential for early identification of collaborative working/funding and sourcing of high-quality proposals, particularly in new/complex areas.

- reassurance to FSA with respect to the quality of the programme, its future direction and that the necessary oversight is in place.
- f) ***Tendering process for contracted research:*** The FSA should consider complementary methods to develop tender calls relating to more complex areas of future research e.g. sandpits. Guidance on the tender process should be developed for the non-commercial sector, emphasising the differences in process of FSA-funded contracted research and that funded through UKRI. A data management plan should be required as part of the tender process, to incorporate details on data flow to facilitate compliance with GDPR and associated legislation.
- g) ***Maximising impact:*** Improving the internal and external visibility of previous and existing outputs and impacts will help the FSA build a compelling narrative to inform future business case planning. **A clear process should be developed for data sharing, allowing monitoring by FSA of secondary outputs and impacts. Monitoring of impact should be an integral part of the regular external reviews, which ceased in 2012 due to resource constraints.**
- h) **In response to this report, the Science Council requests that:**
- The FSA develop a strategy setting out how it will address the recommendations from the WG, with clear responsibilities, timelines and resources.
  - The FSA provides a report to the FSA Board and then the Science Council on implementation of the WG's recommendations, within 12 months of submission of the WG's final report.

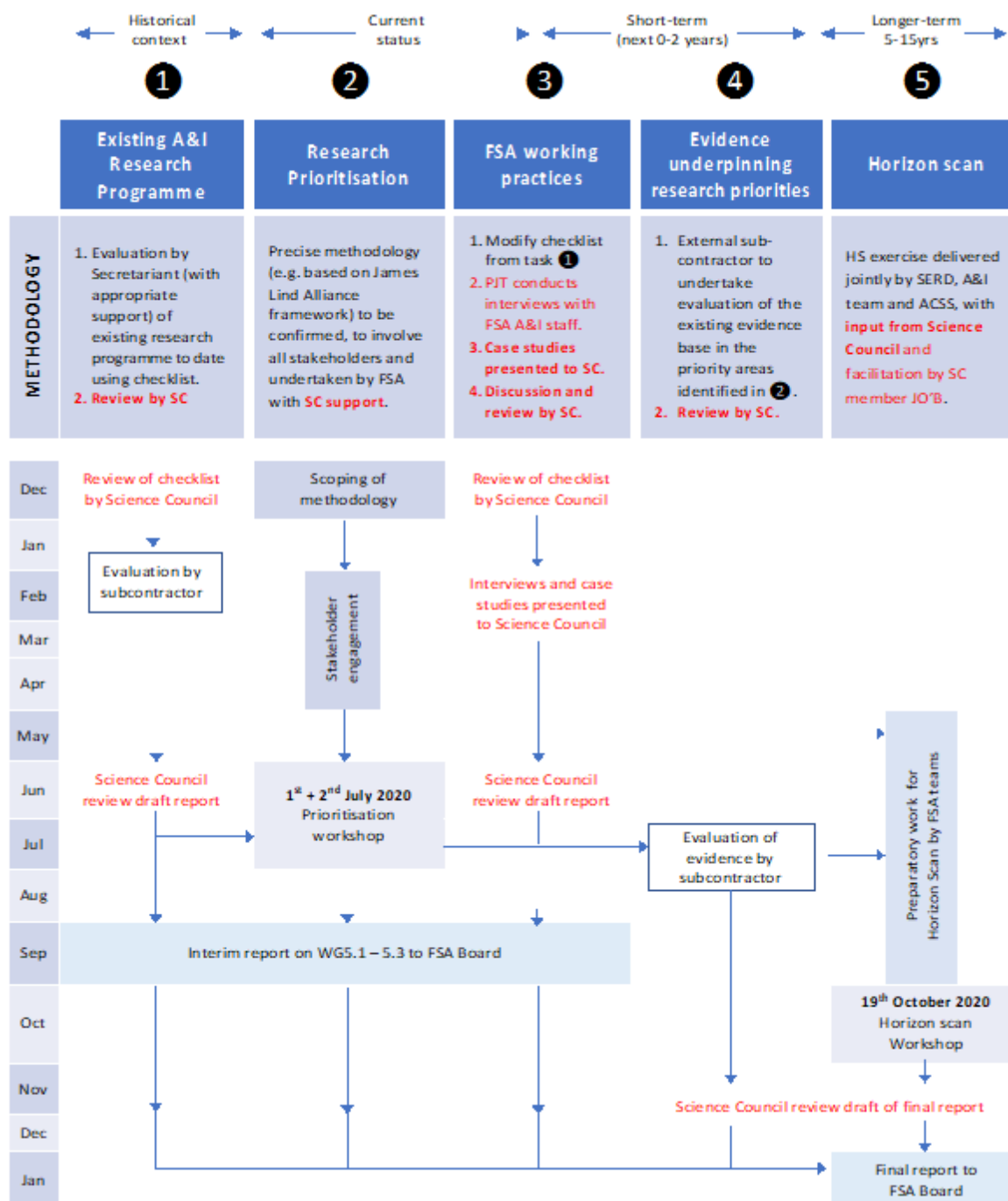
## 5. Conclusions

5.1 The Board is asked to:

- **Consider and comment** on the progress of the Working Group to date;  
and
- **Accept** the recommendations presented in the interim report from the review (WG5.1 and 3).

ANNEX

Annex 1 – Original Working Group 5 Workplan overview (without CV19 mitigations).





**Annex 2 – Working Group 5 Interim Report and annexes**  
Both are attached as separate documents.

### **Annex 3 – Priority Setting Exercise Survey**

#### **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% 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
- 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](mailto: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+