



Engaging food sensitive citizen scientists to understand the safety, efficacy, and practices of procuring ready to eat food online

Part of the Citizen Science for Food Standards Challenges Funding Call

March 2023

DOI: https://doi.org/10.46756/sci.fsa.zzx336

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Funders: Food Standards Agency (FSA) and UK Research and Innovation (UKRI)

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#### **Acronyms**

- CS: Citizen science or citizen scientist
- ECSA: European Citizen Science Association
- ELISA: Enzyme-linked immunosorbent assay
- FHS: Food hypersensitivity
- FSA: Food Standards Agency
- IFST: Institute for Food Science and Technology
- MS Forms: Microsoft Forms
- NGO: Non-governmental organisation(s)
- UKRI: UK Research and Innovation

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## **Executive Summary**

#### **Background**

Food allergies and intolerances are increasingly common in the UK, and 4% of population may be affected (FSA, 2023). These conditions range from mild to severe and can have a significant impact on a person's quality of life. Procurement of ready prepared meals, such as takeaways, is challenging for those with food hypersensitivity (FHS), with many opting to reduce the risk by avoiding them entirely when possible. How ready prepared meals are purchased has also changed, with the rise of online food delivery platforms, whose use during the global pandemic increased, particularly among younger consumers.

There is uncertainty about the degree to which businesses who sell ready prepared meals operate and meet the needs of people with food hypersensitivity, whilst still meeting regulatory labelling requirements to provide information at the point of selection and when the food is collected or delivered. It is also unknown if information provided meets the needs of the food hypersensitivity community with regards to safety.

This project aimed to improve understanding of the safety, efficacy, practices, and behaviours of FHS consumers when buying ready to eat food online. Both takeaway and delivered food were examined from the perspective of people with food hypersensitivities using a citizen science methodology. Citizen science is an increasingly popular and impactful methodology endorsed by the European Commission for Research, Science and Innovation that can offer large amounts of data that are geographically diverse.

#### Methodology

The project had four initial aims, a) to recruit 100 citizen scientists from the food hypersensitivity community, b) to understand safety, efficacy, practices, and behaviours of procuring ready to eat (takeaway and delivered) food online, c) to analyse 50 remotely purchased meals for the presence of milk, peanut or gluten d) to disseminate the information in innovative ways.

A total number of 279 eligible citizen scientists were recruited from across the UK from the hypersensitivity community using a combination of methods (newsletters, social media, personal contacts). Following a co-design meeting where the methodology was debated and finalised, citizen scientists were asked to complete 3 work items:

- Work item 1 was a perception and behaviour survey with 119 participants.
- Work item 2 was an exercise documenting perception of risk when navigating in online platforms with a buying intention (36 participants).
- Work item 3 was a sampling survey of purchased meals sent to an accredited laboratory.

More specifically, five citizen scientists based on England and Northern Ireland in this instance, acted as sample collectors for work item 3. They purchased a meal sold as gluten free or suitable for individuals with a milk or peanut allergy from different local food businesses, verifying its labelling communication and sending it on for laboratory analysis to confirm or not the presence of the target allergen in the meal. This exercise resulted in 11 meals procured, examined, and dispatched for analysis to an accredited laboratory. Analytical confirmation for the presence of milk, peanut or gluten was performed using a suite of recognised enzyme-linked immunosorbent assay (ELISA)-based methods.

#### **Key Findings**

In this pilot project we were able to demonstrate the effective application of citizen science methodology. Engagement with food hypersensitive citizens and others responsible for providing food advice and guidance to FHS individuals was demonstrated by the successful recruitment of citizen scientists and their participation in the three work items. The reason for the successful recruitment (300% higher than expected) was attributed to having the right partners for the promotional campaign and in the design of the information and relevance of the research (website and video). The research team has contact details for almost 100 well-characterised food hypersensitive citizen scientists who agreed to be contacted in future opportunities for research, indicating citizen scientists also found the experience valuable.

In addition to methodological learnings on how to successfully apply a citizen science methodology, the project also delivered some interesting findings on how consumers with food hypersensitivities approach buying ready prepared meals. These include the types of things consumers do at home to minimise the risk of cross contamination (e.g., eating along before others, physically separating gluten-containing from non-gluten-containing foods at the table, double checking the food order and the labels provided, following good food hygiene guidelines, and using their own senses), consumers perceptions of responsibility for managing their condition and associated risks and views on the clarity of information available when ordering food online.

Some key insights with resonate with the wider literature on food hypersensitivities were that:

- a) Younger consumers with a food hypersensitivity have more positive views about this new way of meal procurement and are more relaxed about the adequacy of food information provided in online meal ordering.
- b) Experiences of using online meal ordering platforms especially around communication and labelling can vary. It was found that there is room for improvement on the design of the interface and access to labelling information.
- c) Eleven samples were tested by an accredited laboratory for the presence of milk, peanut or gluten. The results showed that a level of peanut of < 1mg/kg was reported in two samples, milk between <0.4 and 0.5 mg/kg in four samples and gluten between <5 and 2365mg/kg in five samples.

#### **Outcomes of and Reflections on Citizen Science**

Engagement with food hypersensitive citizens was evidenced by the successful recruitment and participation in the projects' three work items, while the variation in participation levels across the three work items has provided important learnings for how to support participation when using citizen science approaches in the future.

One of the main learnings from the project has been of the importance of the early involvement of citizen scientists to project success. This is not limited to the co-design process but continued in the rest of the project phases.

Another learning was the benefit of clear and upfront communication of the work involved in each part of the project. Starting with less active/intensive activities before progressing to more active/intensive activities was found to be helpful in supporting participation and positive outcomes for citizen scientists as was communicating project findings. Results were disseminated at two different occasions during the project, via infographics and newsletters, and awareness within the food hypersensitive community and other stakeholders was increased. In the sampling survey (work item 3), both positive and negative results were disseminated to the citizen scientists. This was preferred to provide a balanced view and remove potential biases. Through this project, engaged citizen scientists have increased knowledge and built some experience of the scientific process and collaboration.

Were this project to progress beyond a pilot phase, there is an opportunity to rethink the design of the work items and to include more intelligent and rewarding activities with a learning angle so that the added value is instantly recognised. In addition, the research team learned that preparation of the research materials and methods require significant time and resources and therefore must be budgeted appropriately.

#### **Conclusions**

A key outcome of the project was the development of a comprehensive methodology for how to effectively apply citizen science methodology to issues relating to food effecting the FHS community in the UK. Apart from know-how, the project has developed training materials that can be used for other phases of the same or different projects and a recontact sample of approximately 100 citizen scientists who have expressed an interest in take part in similar activities in future. One of the pillars of the success was effective recruitment, which was facilitated by having the right partners in place and using a range of media in recruitment campaigns.

The project also generated data on the barriers and perception on procuring meals. An especially important finding is the influence of age in risk perception and key issues around the effectiveness of labelling in online food outlets.

A logical way forward for this work would be to grow the citizen science cohort by reaching new audiences, and to engage with additional partners such as some representation from the food sector for a balanced view.

## **Background**

#### **Background**

Food hypersensitivity includes allergies, intolerances, and coeliac disease. It is estimated that in the UK two million people have a diagnosed food allergy which can lead to lifethreatening symptoms and 600,000 people are living with Coeliac Disease requiring them to avoid cereals containing gluten (FSA, 2023). Many more report different intolerances to a range of foods with different symptoms. These all require rigorous food avoidance of ingredients deliberately added to foods, and additional controls to prevent crosscontact of a non-ingredient allergen in the supply chain, preparation, or service / sales environment. These individuals, and those making food choices on their behalf, rely on correct information being provided by all food businesses – via labelling on the packaging, online information, printed menus and folders, or by asking staff. Food businesses also need to assess the risk and put controls in place to reduce allergen contamination and encourage informed dialogue with consumers. In response to high-profile fatalities in the recent years, and after consultation, legislation changed in October 2021 to require products prepacked for direct sale (made and packed on site for later sale) to carry the name of the food, and the full ingredients list highlighting any of the 14 regulated allergens present. Allergen information for meals or products made to order must be supplied to

customers on request by asking staff, and customers should be made aware that this is possible – on menus and signs on the premises and online. It is worth noting that in the UK, oral information is sufficient, in the Republic of Ireland, this information must be provided in writing.

Significant societal changes in the last decade hastened by the global pandemic have led to soaring demand for online food delivery including ready to consume meals, drinks, and snacks; one in four consumers now considers using such services on a regular basis (Edison Trends, 2021). In this developing online economy, there is uncertainty about how businesses operate and meet the needs of people with food hypersensitivity in their transition from in-person to remote service and then back to in-person service once again, whilst still meeting regulatory requirements to provide information at the point of selection and when the food is collected or delivered. They also need to ensure that their practices and procedures enable consumer requests for allergen avoidance to be recorded and managed, cross contamination controlled, and food prepared specially for such requests to be clearly identified when delivered. On the other hand, consumers at risk may encounter barriers discussing their needs with staff, enquiring online or via telephone, when making such purchases. As procedures and practices of both consumers and businesses are mostly unmapped and with a lack of literature evidence, a study is needed to answer emerging questions regarding food standards and allergen controls.

#### Aims and Objectives

This project aimed to improve understanding of the safety, efficacy, practices, and behaviours of procuring ready to eat (takeaway and delivered) food online from the perspective of people with food hypersensitivities. Participants following a food avoidance diet were recruited using social media, healthcare professionals and contacts in non-governmental organisations (NGOs) using an inclusive and diverse approach. The project linked with crowdsourcing initiatives led by UK NGOs and charities to promote recruitment. A Citizen Science portal was created and used as a hub for communication, training, and data collection.

The data collection methods were co-designed with a subgroup of the citizen scientists through an online pilot workshop. The core data collection involved documenting procedures and practices of individual food businesses offering online food delivery to collate evidence throughout the UK. This was achieved using screenshot captures from the participants' mobile phones. Data collected were both large-scale and highly localised as different services are available to different areas of the country. This gave the research team a valuable snapshot of business procedures and understanding of perception and

practices of hypersensitive consumers. It also allowed for UK wide reliable data collection with robust statistical significance; otherwise very difficult to access.

#### **Definition of citizen science**

Citizen science and food is part of a new programme of work to explore how Food Standards Agency (FSA) can involve the communities they serve when building the evidence-base on which policy decisions are made. The 'citizen science for food standards challenges' required projects to 'be a collaboration between researchers, a specific group of citizens and, where appropriate, relevant partners from outside academia' and for citizens and partners to be involved in co-creating the projects. The FSA and Research and Innovation (UKRI) provided the following documents as a guide:

- ECSA's ten principles of citizen science (PDF, 193KB)
- ECSA characteristics of citizen science
- the recent FSA publication <u>citizen science and food: a review</u>.

The FSA has identified food hypersensitivity as a research priority (Priority 1). No direct FSA studies have previously been commissioned using citizen science methods. Citizen science can help research into allergies and intolerances in several ways. For example, people with allergies or intolerances can participate in online surveys or studies to provide information on their food choices, and experiences or in the case of a food hypersensitivity reaction, their symptoms, and triggers. This can help researchers better understand the barriers they are facing in food choices, conditions and develop either evidence to inform policy or new strategies for managing them.

In this project, citizen science methodology was used to improve understanding of the safety, efficacy, practices, and behaviours of procuring ready to eat (takeaway and delivered) food online. The citizen scientists participating, the voice of this project, were exclusively people with a food hypersensitivity. Citizen science methodology was the appropriate way to deliver the large-scale data collection required because the project involved a) localised information about food labelling efficiency of UK food outlets across the country and b) a small survey of food meals sampled for analysis from different geographic locations. In addition, the citizen science methodology was appropriate to develop the sampling protocol for large scale and diverse sample survey. This was achieved through the co-design process at the centre of this project.

## Methodology

#### Methodology related to Citizen Science

#### Citizen Scientist profile and recruitment

Recruitment took place between May and July 2022 using a combination of methods: social media self-promotion, personal contact of the research team, advertising via the FSA's social media channel, the Coeliac UK and the Institute of Food Science & Technology (IFST, UK) mailing lists and a promotional YouTube clip (Video 1) produced by the research team. Respondents to FSA surveys who had opt-ed in to be recontacted about research and who had food hypersensitivities were also invited to participate. Interested members of the public were invited to undertake the screening questionnaire hosted in MS Forms (see Annex) that was used to recruit eligible citizen scientists. The key parameters for acceptance were a) UK residency and b) to have a food hypersensitivity or be a carer for someone with a food hypersensitivity. Responses to the screening questionnaire relating to socio-demographics and type of food hypersensitivity condition were used to construct the profile of the citizen scientists.

#### **Preparation of research materials**

Before the citizen scientists joined the project, three preparatory research activities were designed. Each Work Item was implemented, and pilot tested to meet quality and ethics research criteria.

Work item 1: an online survey to capture perceptions and practices of citizen scientists (Survey 1). Key aspects of this MS Forms-hosted survey were perceptions of food hypersensitivities and relative food risks and practices as well as existing food allergen avoidance behaviour and practices. For further information see Annex.

Work item 2: an MS Forms-hosted survey, following the structure of a short scientific report, to be completed by the citizen scientists after navigating various online food delivery platforms with an intention to buy (Survey 2). Key aspects of this survey were availability and accessibility of information on the presence of allergens in food available as well as barriers encountered. For further information see Annex.

Work item 3: training materials including a video to describe the meal procurement exercise (see below) as well as itemised step-by-step instructions to guide the citizen scientists through the process. This was presented in the form of a 'wizard' using user

prompts (see Annex). The training materials were hosted and embedded on the project's website linked to YouTube (Video #2) and MS Forms (Survey 3). The meal procurement exercise is described in the Analytical Methodology below. It is important to note that the protocol followed by the citizen scientistic was designed for this specific study and it does not reflect the FSA protocol used for internal sampling surveys.

#### **Communication and information portal**

Communication with the CS was through the following routes:

- A project website (<u>www.foodsensitive.science</u>) that served as a portal for public information about the project (including the scientific team, the project aims, the partners). The website also included specific sections accessible to citizen scientists with the Work Items required to meet the objectives of the study.
- An email-based communication tool (Mailchimp) that was used to keep the citizen scientists up to date with developments of the project, inviting them to take on new Work Items as they became available and communicating early findings of the project (Infographics, see Supplementary Material).

#### The co-design meeting

During the development of the research materials, a core group of citizen scientists was formed to represent diversity with regards to geography, gender representation and food hypersensitivity conditions. This was possible due to the screening questionnaire information. The purpose of the core group was to act as an advisory panel, to feedback on the Work Items of the study and to discuss progress. On the 13<sup>th</sup> of June 2022, two (2) co-design meetings with the research team and the citizen scientists core group took place in the form of focus group discussion. In these meetings, the research team briefly presented early feedback of piloting Survey 1 and 2 internally and the focus was directed in working collaboratively with the citizen scientists to shape the final version of the research protocol. An evaluation form was sent to the participants after the meeting and meeting minutes were shared with all citizen scientists on the project.

#### **Analysis of survey data**

The citizen science cohort (n=119) was divided into 3 classes (age, type of food hypersensitivity and frequency of ordering online) so that comparisons could be made (Table 1). Clustering was a product of a) consultation with the citizen scientists, b) knowhow and scientific hypothesis (see later), as well as c) statistical requirements for balanced class size and normality of the data. For Survey 1 "Perception and practices" related to Work Item 1, fifteen questions relating to perception of risk and behaviour containing a 3 or 5-point quantitative Likert scale were considered and scale-assigned a

value from minus 2 to 2. For Survey 2, "Navigating the online ordering platforms", related to Work Item 2 results, five questions relating to clarity, sufficiency, accessibility of information and trust in the food outlet were considered. As before a 3 or 5-point quantitative Likert scale was used and scale-assigned a value from -2 to 2. The citizen science cohort (n=36) was broken into the same 3 classes as before (age, type of condition, frequency of ordering online) according to the table below. The mean scores of each question for each class were compared using one-way ANOVA using SPSS v.28 (IBM, Massachusetts, USA) to establish if there are significant difference at 95% probability level and identify it using the Duncan's post hoc test.

**Table 1** Groups considered for citizen scientists in the Surveys 1 and 2.

Factors	Group	Survey 1	Survey 2
Age	Less than 24	6 (5%)	2 (6%)
Age	25-44	64 (54%)	12 (33%)
Age	More than 44	49 (41%)	22 (61%)
Condition	Food allergies	21 (18%)	5 (14%)
Condition	Gluten sensitivity	66 (55%)	21 (58%)
Condition	Other sensitivities	32 (27%)	10 (28%)
Frequency	Weekly	66 (55%)	13 (36%)
Frequency	A few times a month or more	53 (45%)	23 (64%)

#### **Ethics**

An ethics application was submitted to the Ethics Committee of Faculty of Medicine, Health & Life Sciences of Queen's University Belfast (MHLS Faculty REC) and after minor corrections, received final approval on the 8th of March 2022, into the 3<sup>rd</sup> month of the project. The inclusion of 16-18 year olds was allowable under the ethics approval and the consent to take part in the study was recorded.

#### **Project evaluation**

A Project Evaluation Framework was prepared collaboratively by the research team and an external assessor (Libby Oakden) and was regularly updated as the project progressed. Main themes included practices to ensure citizen scientist engagement and capturing of metrics to measure engagement with each stage of the project. Examples of metrics included participation rate per Work Item, total visits and time spent on the project website, number of clicks and opening of emails sent to the citizen scientists, and number of views and impressions per post for the project account on Twitter. The framework also included a section on project outputs and output indicators for engaging food hypersensitive communities with citizen science.

#### Alignment with citizen science principles

In this project, hundreds of members of the public acted as contributors, active collaborators and had a meaningful role in the project (alignment with #1 of the ESCA's 10 principles of citizen science). They were asked to collect evidence to answer a series of valid research questions ("How safe it is to procure food online for people with food hypersensitivities?", "What are the perceptions and barriers identified when procured food online"?, "Can we validate allergens present in a food through laboratory analysis and if yes, how?", "Can we prepare samples for analysis while minimising the risk of cross contamination?"), which aligned with #2 and #4 ESCA's principles. For the researchers, this project allowed for large scale data collection otherwise not possible due to both numbers and geographical restrictions. Leading to an improved understanding of the challenges facing consumers and food businesses, and connection with the larger audience, enhancing the pathway between evidence and societal impact (principle #3). Participants achieved a good understanding of the work of the research team through real time data access and the ability to comment on draft design documents, as well as mid project "Infographic" reports which aligned with #5 principle) in multiple stages of the project (principle #4) in including them in the co-design process. They also received training in the process of sampling for allergen analysis (principle #3). The researchers are committed to make the dataset and the research paper available open access format (principle #7) with the citizen science participants acknowledged in the publication (principle #8).

#### Sampling and analytical testing

Samples (ready-to-eat meals) were procured from local restaurants in England and Northern Ireland by the citizen scientists. The protocol, that was co-developed with citizen

scientists, included a) selecting local restaurants or take-aways, b) the citizen scientists contacting and visiting the restaurant and specifically asking for either a milk-free, peanut-free, or gluten-free meal, c) authentic transactions as the citizen scientists are purchasing for themselves, i.e., declaring milk, peanut or gluten sensitivity, and d) the citizen scientists not consuming the food that was purchased. These 3 allergens were part of the initial design of the project but were discussed and confirmed in the co-design meeting after consultation with the citizen scientists. The argument for selecting these are that they are, together with 'eggs', the most prevalent conditions in the UK (NHS, 2023). In addition, limiting to a few allergens would allow the production of meaningful results with some level of statistical confidence. The citizen scientists were reimbursed for the cost of the meals and received training to prevent cross-contact during sample handling. Training was provided by the research team in the form of a video tutorial that was specifically developed for the project (Video 3, see Annex G).

The sample procurement exercise (Work Item 3) took place between July-September 2022 after the citizen scientist training material was developed. The training was incorporated into the sampling protocol survey (Survey 3) to ensure that all citizen scientists were trained before sample handling. Once bought, delivered, or collected, the meals were briefly inspected by the citizen scientists to confirm the order, photographed, and airtight packed. After overnight freezer storage, they were sent to the laboratory partner ROMER LABS UK (The Heath Business & Technical Park, Runcorn, Cheshire WA7 4NH), an experienced global supplier of diagnostic solutions for food safety and allergen detection.

The samples were analysed by our laboratory partner ROMER LABS UK for the presence of peanut, milk and gluten . Samples arriving at ROMER were opened, photographed, homogenised using a stomacher and subjected to analysis.

Standard in-house ELISA test kits were used, for which the company is accredited by the United Kingdom Accreditation Service (UKAS) to the international standard 'ISO/IEC 17025:2017: General requirements for the competence of testing and calibration laboratories.

## Research Findings

#### Profile of the CS recruited in the project

#### Citizen Scientist profile and recruitment

This study recruited a total number of 297 participants, of which 36 males (12%) and 259 (87%) females, aged from 16 to 75+, the majority aged 35-44, (30% with only one individual between 16-18 years old. Most participants lived in England (n=219, 73%), followed by Scotland (n=33, 11%), Wales (n=14, 4.7%) and Northern Ireland (13, 4.3%). From all that expressed their interest, 279 reportedly had a food hypersensitivity (including food allergy, food intolerance, or coeliac disease) (94%), and qualified for this study as citizen scientists. Among them, 24% were also caring for someone with a food hypersensitivity. Most of the citizen scientists were females (87%), between 35-44 years old (29.3%), followed by the 45-54 age group (22.9%), while 0.3% were adolescent (16-18 years old). The age group <24 (11.2%, n=31) i.e., young adults and adolescents, were intentionally included in the study because social behaviour and perception of risk might change in this life period with many food allergy and intolerance incidents occurring during those years. The participants reported familiarity and engagement with the remote meal ordering using mobile phone or PC online applications. They also reported frequency of ordering ready-to-eat food online: 42% monthly, 30% weekly, and 1.3% daily.

Of the responders, 279 reportedly had either an allergy or a food hypersensitivity (94%), and with 24% also carers of someone with a food hypersensitivity, such as young children in the family. Of those who participated, 79% have medically diagnosed conditions - either allergy or intolerance, which is quite a high number and indicates that the participants are the right demographic for this study.

The prevalence of allergies and intolerances was as follows: cereals containing gluten (such as barley and oats), 36.5%, Tree nuts (such as almonds, hazelnuts, walnuts, Brazil nuts, cashews, pecans, pistachios, and Macadamia nuts) 11.5%, milk 11.5%, peanuts 11.3%, crustaceans (such as prawns, crabs, and lobsters) 4.6%, eggs 4.4%, soyabean 2.7%, sesame 2.5%, molluscs (such as mussels and oysters) 2.3%, fish 1.7%, sulphur dioxide and sulphites 1.1%, lupin 1%, mustard 0.4%, with the rest others 8.8%. Some of the participants declared allergies or intolerances to more than one food.

#### **Perception and Practices survey (Work Item 1)**

119 citizen scientists participated in this survey out of the total CS population recruited in the project. Most of these were females (87:13 female: male ratio); most were from England (79%). Broader groups for age, type of condition and frequency of ordering online are presented in Table 1.

Several concerns were raised by citizen scientists about ordering food online including:

- cross contamination during preparation or serving, (20% frequency).
- restaurant staff awareness and/or language barriers (12% frequency).
- allergens or intolerances not among the 14 UK regulated allergens. (12% frequency)
- outdated information presented. (8 % frequency)
- unlisted, unknown, or not trustworthy ingredients; incomplete labelling (5% frequency).
- information. (5% frequency).
- errors in delivery (5% frequency).

These were in open text options of the survey; subjects expressed a variety of responses about trust or dissatisfaction with food businesses. In general, respondents expressed more trust in nationwide food chains due to their perceived resources, updated information, menu consistency and/or accreditation by a UK allergy charity, such as Allergy UK or Coeliac UK. While large food outlets may be more trusted, some simply don't take any orders online due to the perceived litigation risk.

There are discrepancies and some polarisation about trust in smaller restaurant outlets, which is natural given the number of different food outlets and variety in the type of service. Usually, local restaurants are trusted when there is some personal relationship with the staff, e.g., when the person is a regular customer. Some respondents expressed greater trust in food businesses providing certain types of cuisine (e.g., Indian cuisine, Chinese cuisine), although this could be due to perceptions/assumptions about how commonly different ingredients are used. In any case, there is no statistical difference or large sample size or statistical comparisons possible to confirm this.

The citizen scientists revealed some of their in-house practices to minimise the risk of contamination including a) taking food alone, before or after the family or work meal; b) physically separating gluten-containing from non-gluten-containing foods at the table; c) double checking the food order and the labels provided, d) following good food hygiene guidelines, and e) using their own senses.

Table 2 contains 15 mean values for Perception and Practice parameters corresponding to specific questions that were quantified and statistically compared. Information on the scoring is described above.

Briefly, the range -2 to 2 represents the positive (+2) or negative (-2) opinion citizen scientist have for these statements with zero (indicated in orange) being the neutral opinion. On average, CS feel that they understand and accept their responsibility in relation to managing their condition, and the potential risk involved and are moderately satisfied with the effort that food outlets are putting into effective labelling. They acknowledge some compassion from family and friends for their condition but little compassion or care from co-workers or the food outlets/restaurants. They perceive ordering online as very risky and labelling and packaging for online food orders highly important (+1.39, +1.63, +1.71 respectively, Table 2). In previous encounters with online platforms, they have mixed views about effectively communicating their condition and some satisfaction with labelling information provided in ordered meals.

Age (3 groups), food hypersensitivity condition (3 groups), and frequency of ordering (two groups) were the 3 factors that were considered when clustering the citizen scientist cohort (Table 1). The scientific hypotheses, associated with this clustering are:

- 1) That the younger generation might have different perceptions or behaviour with online orders due to their familiarity with technology (Hernández *et al.*, 2011)
- 2) The condition, being e.g. an allergy with a possible anaphylactic response or an intolerance (e.g., to lactose) will command different views and practices simply due to different health implications involved (Lomer *et al.*, 2007)
- 3) The frequency of using these services might create a habit or distraction which might, in time, cause a more relaxed view of the risk involved and thus, lead to riskier behaviour (Versluis *et al.*, 2015)

It should be noted that although these hypotheses are not exhaustive or universally accepted by the scientific community, they formed the basis for discussion of the results in this study because they were also genuine questions of the citizen scientists participated and meaningful for the communication of findings between the CS and the research team and by extension, the wider public.

**Table 2** Recorded Perception and Practices of the CS when ordering food online (Survey 1 related to Work Item 1).

Perception and practice parameters	Scoring	Mean ± sd	Perception
General effectiveness of food labelling (not limited to online)	-2 to 2	0.69 ± 1.08	Positive
Response to food appeal <i>vs</i> risk	-2 to 2	-1.70 ± 0.57	Negative
Perceived risk	-2 to 2	1.70 ± 0.73	Positive
Personal responsibility	-2 to 2	1.74 ± 0.54	Positive
Food business responsibility	-2 to 2	0.60 ± 0.96	Positive
Authorities' responsibility	-2 to 2	1.05 ± 1.27	Positive
Compassion from family re condition	-2 to 2	1.51 ± 1.01	Positive
Compassion from friends re condition	-2 to 2	1.25 ± 1.04	Positive
Compassion from co-workers re condition	-2 to 2	0.41 ± 1.30	Neutral
Compassion from food businesses re condition	-2 to 2	0.30 ± 1.09	Neutral
Perception of actual labelling of ordered meals	-2 to 2	0.00 ± 1.80	Neutral
Efficiency of communication of your condition (online)	-2 to 2	-0.30 ± 1.12	Neutral
Perceived risk ordering online	-2 to 2	1.39 ± 0.85	Positive
Importance of labelling (online purchases)	-2 to 2	1.63 ± 0.79	Positive
Importance of packaging (online purchases)	-2 to 2	1.71 ± 0.68	Positive

Note: Scores in the range of [-0.5, 0.5] were considered neutral.

Table 3 shows the four (4) parameters that showed statistically significant differences in perception and practices of citizen scientists as captured in Survey 1. In the interest of clarity, the non-significant parameters are indicated using "n.s". As suggested before, age (>44) plays an important role in the perception of food appeal *versus* risk ("How likely are you to try a food product which may cause you a reaction if it looks appealing to you?") and the perception of effective labelling on ordered meals ('How effective do you think that food labelling -including website and menu information, or provided by staff- is in controlling food allergen risks?'). In both cases, those over the age of 44 perceive more negatively both these issues (Hypothesis 1 confirmed for some cases).

Interestingly, perception of risk, personal and business responsibility and all the other parameters except 'compassion with family re condition' were found not influenced by the condition that the person has (allergy vs gluten sensitivity vs other sensitivities), which is a net positive outcome and perhaps shows that the general awareness is high among the hypersensitive population independent of the exact condition (hypothesis 2 not confirmed). The only statistically significant result was the reduced "compassion" the citizen scientists allegedly receive from family if they have a gluten intolerance compared to the other two conditions ("How much do you think that other family cares about your food hypersensitivity?"), which can be explained by the non-anaphylactic nature of the condition. When frequency was factored in the CS cohort, weekly users were less worried in their perception of general effectiveness of food labelling ("How effective do you think that food labelling - including website and menu information, or provided by staff - is in controlling food allergen risks?") compared to monthly users (twice a month or less frequent). On its own this is not important finding because in the 'Perceived risk ordering online' both groups answered positively and with non-statistical differences (hypothesis 3 not confirmed).

The remaining parameters (perceived risk, personal responsibility, food business responsibility, authorities' responsibility as well as compassion from friends, co-workers, and food businesses regarding the hypersensitivity condition) did not show any significant difference when perception was compared in groups factoring to condition, and frequency of ordering and in most cases, age. In other words, the perception of risk and the ordering behaviour were not influenced by how old you are (apart from a few notable exceptions), what allergy or intolerance you have or how often you choose the online food ordering platform, beside the 3 cases mentioned.

**Table 3:** Statistically significant factors affecting Perception and Practices when ordering food online. (Survey 1 related to Work Item 1)

Factors	Groups	General effectiveness of food labelling	Response to food appeal vs risk	Compassion from Family on condition	Perception of labelling on ordered meals
Age	Less than 24	n.s.	-1.67 ± 0.52 <sup>a</sup> (negative)	n.s.	0.83 ± 0.41 <sup>a</sup> (positive)
Age	25-44	n.s.	-1.55 ± 0.85 <sup>a</sup> (negative)	n.s.	0.02 ± 0.92 <sup>a</sup> (neutral)
Age	More than 44	n.s.	-1.88 ± 0.33 <sup>b</sup> (negative)	n.s.	-0.12 ± 0.88 <sup>b</sup> (neutral)
Condition	Allergies	n.s.	n.s.	1.57 ± 1.08 <sup>a</sup> (positive)	n.s.
Condition	Gluten sensitivity	n.s.	n.s.	1.73 ± 0.62 <sup>a</sup> (positive)	n.s.
Condition	Other sensitivities	n.s.	n.s.	1.03 ± 1.40 <sup>b</sup> (positive)	n.s.
Frequency	Weekly	0.48 ± 1.19 <sup>a</sup> (neutral)	n.s.	n.s.	n.s.
Frequency	2 weeks or over	0.89 ± 0.97 <sup>b</sup> (positive)	n.s.	n.s.	n.s.

*Note*: Score ranges from -2 to 2. Scores in the range of [-0.5, 0.5] were considered neutral.

#### Navigating through online food ordering platforms (Work Item 2)

36 people participated in this activity - a subsection of the citizen scientist's population, and their demographics were: 94:6 female: male ratio, based in England (86%), with mainly a gluten sensitivity condition (58%, see Table 1). Table 1 also indicates the age of the participants in this exercise. With regards to food ordering patterns, the ordering platform of choice was Just Eat' (35%) followed by 'Deliveroo' (32%), and 'Uber Eats' (10%). The rest of the participants choose another platform (22%). The most accessible method of communication when ordering was: telephone (46%), the restaurant's website (31%), and other (22%).

Following the Work Item 2, the citizen scientists navigated in various online food ordering platforms (up to 3 each) and had a buying intention. Results showed that were cautious and sceptical about information provided when visiting various online restaurants or aggregator platforms. Five (5) parameters were systematically recorded and quantified, as seen in Table 4.

**Table 4** Recorded Perception and Practices of the citizen scientists when exploring different options for ordering food online (Survey 2 or Work Item 2)

Perception and practice parameters	Scoring	Mean ± sd	Perception
Clarity of information	-2 to 2	-0.62 ± 1.42	Negative
Accessibility of information	-2 to 2	-0.50 ± 1.32	Neutral
Sufficiency of information	-2 to 2	-0.58 ± 1.34	Negative
Opinion shift after this exercise	-2 to 2	-0.32 ± 0.73	Neutral
Confidence to complete order	-2 to 2	-0.18 ± 1.35	Neutral

*Note*: bold font and subscripts indicates significant differences. Score ranges from -2 to 2. Scores in the range of [-0.5, 0.5] were considered neutral.

Most of the citizen scientists agreed that the clarity of information given and the perception of risk when meeting their order were lower than expected. They maintained a reserved or neutral attitude towards completing the online order and their ability to influence awareness of the subject area after conducting this exercise (Work Item 2).

Following on the hypotheses set out in the previous section related to age, hypersensitivity condition, and frequency of using online meal ordering services, a similar statistical analysis was conducted factoring the same groups. Although, the sample size was different, the same pattern showing influence of age in Perceptions and Practices was identified in this survey. As seen in Table 5, people of age 44 or over, (61% of the participants) appeared having different perceptions than other younger people with regards to 3 out of 5 parameters recorded (accessibility, sufficiency, and confidence to complete order), scoring lower than all other groups.

Notably, clarity of information was found marginally not significantly different among people of different ages (p=0.063). On the other hand, all recorded perception parameters ('clarity', 'accessibility', 'sufficiency of information', 'opinion shift' and 'confidence to order') were not influenced by the other two factors examined, namely hypersensitivity condition and frequency of ordering.

In other words, the perception of risk was not influenced by what allergy or intolerance you might have (the testing hypothesis was that people with allergies will be more cautious than those with intolerances both in terms of expected clarity of information and perception of risk) or how often you choose the online food ordering platform (the testing hypothesis here was that the more frequent user you are, the more confident you become and the more riskier are your next choices). However, statistical differences were found between older and younger individuals with regards to expected accessibility ('How accessible was information about the food(s) you need to avoid?') and sufficiency of information ('Was the information you found sufficient about the foods you need to avoid?), which is provided at the point of online ordering, as well as with regards to the overall confidence in completing the order (Would you complete this order?). Again, the younger the individual, the more confident they were following the order through and being satisfied with their accessibility and adequacy of the information provided by the vendor.

**Table 5** Statistically significant factors affecting perception and practice when navigating online outlets for ordering food online (Survey 2)

Factors	Groups	Accessibility of information	Sufficiency of information	Confidence to complete order
Age	Less than 24	-0.17 ± 0.71 <sup>a</sup> (neutral)	-0.33 ± 0.94 <sup>a</sup> (neutral)	0.17 ± 0.71 <sup>a</sup> (neutral)
Age	25-44	-0.14 ± 1.23 <sup>a</sup> (neutral)	-0.19 ± 1.33 <sup>a</sup> (neutral)	0.11 ± 0.60 <sup>a</sup> (neutral)
Age	More than 44	-1.25 ± 1.31 <sup>b</sup> (negative)	-1.36 ± 1.11 <sup>b</sup> (negative)	-0.53 ± 0.66 <sup>b</sup> (negative)
Condition	Allergies	n.s.	n.s.	n.s.
Condition	Gluten sensitivity	n.s.	n.s.	n.s.
Condition	Other sensitivities	n.s.	n.s.	n.s.
Frequency	Weekly	n.s.	n.s.	n.s.
Frequency	2 weeks or over	n.s.	n.s.	n.s.

Note: Score ranges from -2 to 2. Scores in the range of [-0.5, 0.5] were considered neutral.

## Sample procurement and laboratory analysis (Work Item 3)

Eleven meals were analysed by our accredited laboratory (Table 6) purchased by five citizen scientists. Two samples were tested for peanut and the results showed a level of < 1mg/kg. Two samples tested for milk reported a level of protein between <0.4 and 0.5 mg/kg. Five samples tested for cereals containing gluten reported a level of gluten between <5 and 2365 mg/kg.

More specifically, the 'sausage and chips sample reported a level of gluten of 2365 mg/kg which is above the regulated limit of 20 ppm. The product is therefore considered unsafe for people with FHS to gluten. There are no regulated threshold levels for peanut and milk.

**Table 6** The results of the laboratory analysis for the 11 meals purchased by the citizen scientists (Work Item 3)

Sample	Food tested	Target allergen	Results (mg/kg)*
1	Vegetable spring roll	Peanut	<1
2	Mix vegetable curry	Peanut	<1
3	Plain chop suey	Milk	<0.4
4	Vegan sausage roll	Milk	0.5
5	Sausage and chips	Gluten	2365
6	Margarita pizza	Gluten	<5
7	Cod and chips	Gluten	7
8	Curry sauce	Gluten	<5
9	Sausage and Chips	Milk	<0.4
10	Burger	Milk	<0.4
11	Margarita pizza	Gluten	<5

\*Values of 'results mg/kg' refer to kg of food.



Figure 1 "Sausage and chips" meal (sample #5) purchased by the citizen scientist

# Outcomes of and Reflections on Community

This was the first Citizen Science project for the research team and the first project for Queen's University Belfast (QUB) in the area of food science/safety. Although there was a steep learning curve it was undoubtedly a positive experience for the QUB research group. In documented email communication, the team discussed 'instant access to vast amount of data', 'delegation of the research work', 'creating societal impact', 'gaining valuable insights on how the public, in particular the food hypersensitive community, engages with research'.

The citizen science approach was facilitated by a) the technologies available for recruitment, communication, engagement that led to automation and economy of resources in administering the project, b) the contacts of the research group, and especially the knowledge and experience of the collaborators, Hazel Gowland (Allergy Action) and Michael Walker (QUB) who provided specialist expertise that helped in various aspects of the project, and c) the naturally more engaged and more vocal food hypersensitivity community.

The project attracted almost 300 citizen scientists from the FHS community. Although highly motivated to participate in research the community might not be so familiar with the citizen science aspect, which goes quite beyond survey participation and involves a more active role (in this case, group meetings, co-design elements, dataset, or infographic review etc). All this might appear quite new and alienate the collaborating citizen scientists. Other barriers we identified to citizens remaining engaged throughout included timing of the key activity of the project (Work Item 3, the laboratory survey) in the middle of the cost-of-living crisis (Spring -Summer 2022). This was intensified by the initial decision on the level of reimbursement of the citizen scientists' incurred costs when taking part in the more demanding task. The time taken to identify and correct this meant that fewer participants were involved with this activity. As a result of the lower levels of engagement toward the end of the project further adjustments were made in the planned work items: 'Work Item 4 'Simple Data Analysis of the Survey Findings' and Work Item 5:' 'Dissemination of the project findings by the CS' were cancelled and priority has been given to Work Item 3 (laboratory survey).

#### Learnings for the researchers

- 1. Ensure the materials and methods are straightforward to use that reflect the experience of citizen scientists and are ready at the outset of the study phase.
- 2. Inclusion of the citizen scientists from the start of the activities design process. The co-design meeting could be scheduled earlier in the project, as will influence better the direction of the outcomes. Whereas a focus group discussion would be good to be replicated, a workshop organisation, with an element of a small talk by someone with authority in the community should be more suitable to maximise participation in the co-design meeting. All these were suggested by the citizen scientists of the co-design meeting (post hoc feedback form).
- 3. Design citizen science activities to strike a better balance between ease of use and research depth in a way that maximises engagement. Time demanding or cost demanding tasks involving food sensitivities and allergies (even if partially or fully reimbursed) are more likely to create stress and reduce engagement. Refinement, clear communication and where appropriate, simplicity, are the key.
- 4. Understanding the time needed to prepare research materials (website information, training document, videos, survey design). Explicitly including the time and resources for this in the project plan.
- 5. Provide clearer information about what is expected in related to various work items and how in depth they are to support the decision of the citizen scientist will make and the level commitments associated. To facilitate understanding, various visual or narrative ques can be given (an 'effort' score, task hierarchy according to complexity, technical difficulty, or time commitment, creating, essentially, various levels on a ladder of participation). To be fair, such levels existed in the project, but they were not hierarchically listed or communicated in the manner described above.

#### **Learnings for the citizen scientists**

The main learning for the citizen scientists could be to identify differences between survey participation and citizen science work. This should be communicated to them at the recruitment stage in a more efficient way.

#### Project evaluation by the citizen scientists

The citizen scientists that took part in the co-design meeting received an evaluation questionnaire shortly after. From those responded (n=3), they mentioned that a meeting with a longer duration (than 1h that was scheduled) would have been more useful and

that a more 'a little more explicit on what will happen next' at the very end of the meeting would help'. This prompted us to replace the 1-hour meeting with a workshop in the future, as previously indicated.

There was also overall project evaluation at the end (December 2022). There were 25 responses to the online questionnaire sent to all 279 citizen scientists. The majority of those who responded heard about the project from social media (52%), participated mostly on the first survey (Work Item 1), 61% and were moderately happy with the number of activities offered (63%), with the rest perhaps expecting less overall workload or less complexity to the work involved (see Annex, Table 9 for the quotes). However, citizen scientists appreciated the instructions given to support them in the Work Items of the project (63% fully agree). This included, the website, the videos developed and the regular email communication (12 project updates in 6 months). There seems to be room for improvement for communication of the work of the academic researcher and their contribution to society, since only 22% admitted that the participation in this project allowed them to 'change their perspective for the work of scientists'. The overall satisfaction for participating in the project was quite high at 7.40/10, marked in an appropriate quantitative scale. Some quotes that were provided by the citizen scientists are presented in Table 8 after permission.

#### **Future plans**

Plans include further developing on the CS methodology and seeking opportunities to apply it in other research projects conducted at QUB. In this research area, the QUB researchers will think on how to construct even more interesting and engaging follow up studies and ponder on the design "simpler to do" and more enjoyable activities with the right research depth. At the same time, it is important to keep some level of contact with the CS involved in the project. The direction agreed so far is to start a biannual email newsletter and distribute it via the existing communication platform to update on activities of the research team in the area, especially around the writing up of the research article of the present work, although other sections will be included (any new laboratory surveys conducted by others, any updates on the legislation front in the UK and beyond).

## **Conclusions and Implications**

This project has delivered a comprehensive methodology on how to effectively apply citizen science methodology in the area of food safety and policy information working with the UK hypersensitivity community. This includes specific parameters for large scale CS recruitment (production of recruitment video, building an accessible, supportive and informative website, partnering with NGOs for promotion through novel media, e.g., social media and private groups), the communication tools (a large-scale email platform such as MailChimp and a survey tool such as MS Forms) as well as important learnings for the design of project activities to maximise engagement.

This project commissioned several CS activities, ('Work Items') and from analysis of parameters involving engagement (surveys, and sample procurement exercises, laboratory analysis, dissemination of findings) there is new learning on how best to do this (e.g., to co-design the project activities, to simplify sample procurement for analysis, to involve the right level of compensation for the CS's time).

Apart from the methodology know-how, the project has:

- a) developed training materials that can be used for other phases of the same or different projects.
- b) gathered contact details for 91 well-characterised food hypersensitive citizen scientists who agreed to be contacted in future opportunities for research.
- c) generated insights on the barriers and perception of procuring food, particularly on the influence of age in risk perception and key issues around the effectiveness of labelling in online food outlets.
- d) delivered results from a small CS-led survey conducted to confirm the absence of milk, peanut, and gluten in online and walk-in food restaurants.

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## **Annex**

# A. Survey 1 - "Food Sensitive Citizen Scientists Survey"

Question		Option
•	First name	Open question
•	Family name	Open question
•	Email address	Open question
•	What is your age group? Please remember that in order to take part in the study you must be 16 years old or older.	Under 18  18-24 years old  25-34 years old
		35-44 years old
		45-54 years old
		55-64 years old
		65-74 years old
		75 or older years old
•	What is your gender?	Woman
		Man
		Non-binary
		Prefer not to say
•	What is your ethnic group?	Asian or Asian British
		Black, Black British, Caribbean or African
		Mixed or multiple ethic groups
		White
		Other ethnic group
		Prefer not to say
•	Where do you live in the UK?	England

	Northern Ireland
	Scotland
	Wales
Postcode	Open question
<ul> <li>How would you describe in your own words your food hypersensitivity (including allergy, intolerance, coeliac disease)?</li> </ul>	Open question
<ul> <li>Please tell us how you perceive the following occasions related to food hypersensitivities.</li> </ul>	Not at all
related to lood hypersensitivities.	Very little
	Somewhat
	Very much
	Not sure
<ul> <li>In your opinion, how risky can your food hypersensitivity be for you after consuming the food that is a problem for you?</li> </ul>	Open question
<ul> <li>How much do you think each individual is personally responsible for avoiding the food that gives them problems?</li> </ul>	Open question
<ul> <li>How much do you trust claims by food businesses that say their foods are safe to be consumed by hypersensitive individuals?</li> </ul>	Open question
<ul> <li>In your opinion, how responsible are environmental health and trading standards authorities for protecting food hypersensitive consumers from having reactions?</li> </ul>	Open question
<ul> <li>How effective do you think that food labelling (including website and menu information, or provided by a staff) is in controlling food allergen risks?</li> </ul>	Open question
<ul> <li>How likely are you to try a food product which may cause you a reaction if it looks appealing to you?</li> </ul>	Open question
How much do you think that other people care about your food hypersensitivity?	Not at all
, 3 % 1 1 3 % 1 1 1 1 1 1 1 1 1 1 1 1 1 1	Very little
	Somewhat
	Very much
	Not sure
o Family	Open question
o Friends	Open question
o Colleagues	Open question

o Caterers	Open question
Please let us know how you prefer to order takeaway meals	Online by their own (branded) application
	Online by an application used by
	many businesses (eg Just Eat, Uber Eats, Deliveroo)
	By ringing the restaurant
	By visiting the take-away
	Other, please specify
	I never order takeaway meals
	Other
<ul> <li>If you chose 'Other' in the previous question, please specify</li> </ul>	Open question
When you order a takeaway meal	You tend to try something different each time
	You prefer an option you have tried in the past
	Depends how you feel each time you order
	Other, please specify
<ul> <li>If you chose the option 'Other' in the previous question, please specify</li> </ul>	Open question
How would you rate your experience on informing the restaurant about your food hypersensitivity when you order through their online applications?	Rate from 0 to 5
Have you noticed labelling on ready-to-eat takeaway meals?	Yes, No, Maybe
Please let us know how you feel about the following occasions.	Not at all
0000310113.	Very little
	Somewhat
	Very much
	Not sure
<ul> <li>How concerned are you about food safety when you order ready-to-eat food online?</li> </ul>	Open question

<ul> <li>How important is the labelling on ready-to-eat food when you order a ready-to-eat takeaway meal?</li> </ul>	Open question
<ul> <li>How important is it for you that the packaging preserves the safety for you of the food you have ordered?</li> </ul>	Open question
<ul> <li>Please tell us your concern(s) about ordering ready-to- eat food from a local takeaway</li> </ul>	Open question
<ul> <li>Are there particular businesses which you trust when ordering ready-to-eat food online?</li> <li>Could you mention why you prefer some businesses and not others?</li> </ul>	Open question
<ul> <li>Are there any businesses you avoid when ordering ready-to-eat food online?</li> <li>Could you please mention what discourages you to order from certain places?</li> </ul>	Open question
Please describe your actions after you receive a ready- to-eat meal order to avoid food risks related to food allergens, if any.	Open question

## **B:** Survey 2 - "Food Sensitive Citizen Scientists Navigating through online food platforms"

Quest	ion	Option
•	First name	Open question
•	Last name	Open question
•	Email address	Open question
•	Name of the restaurant	Open question
•	Location of the restaurant	Open question
•	Food aggregator	* Just Eat, Uber eats, Deliveroo, Other
•	If you answered 'Other' in the previous question, please specify.	Open question
•	Were you able to find the necessary information about the food(s) you need to avoid?	* Yes, No, Maybe
•	Please tell us your opinion about the following.	<ul> <li>Not at all</li> <li>Very little</li> <li>Somewhat</li> <li>Very much</li> <li>Not sure</li> </ul>
0	In your opinion, how accessible was information about the food(s) you need to avoid?	Open question
0	In your opinion, was the information you food sufficient about the food(s) you need to avoid?	Open question
•	How did the restaurant offer to provide information on the food(s) you need to avoid?	<ul> <li>* Phone the restaurant</li> <li>* Access the restaurant's website</li> <li>* Other</li> </ul>
•	If you answered 'Other' in the previous question, please specify.2	Open question
•	Please mention anything else you found helpful in accessing information about the food(s) you need to avoid?	Open question
•	Please mention any barriers to accessing information regarding the food(s) you need to avoid?	Open question
•	Please leave any comments about your experience.	Open question
•	Has your opinion about this restaurant changed after this exercise?	I still have the same opinion about this restaurant     I think this restaurant is better at providing information than I thought     I think this restaurant is worse at providing information than I thought     Not sure
•	Would you complete this order?	* Yes * No * Maybe
•	If you answered 'Maybe' or 'No' in the previous question, please specify why.	Open question

## C: Survey 3 - "Food Sensitive Citizen Scientists: Ordering and handling of a takeaway meal"

Question	Option
First Name	Open question
Last Name	Open question
Email address	Open question
Please let us know which of the following best describes you	I am a food hypersensitive individual     I am a carer for someone with a food hypersensitivity     I have a food hypersensitivity and I am a carer of someone with a food hypersensitivity     None of the above
IMPORTANT: which allergen(s) you will declare when you place your order	<ul> <li>* I will ask for the meal to be "peanut free"</li> <li>* I will ask for the meal to be "milk free"</li> <li>* I will ask for the meal to be "gluten free"</li> <li>* I will ask for the meal to be BOTH "peanut and milk free"</li> <li>* I will ask for the meal to be BOTH "peanut and gluten free"</li> <li>* I will ask for the meal to be BOTH "milk and gluten free"</li> <li>* I will ask them for something else</li> </ul>
Please let us know how you are planning to place your order	* Online through a Food Delivery     Platform (eg Just Eat, Uber Eats,     Deliveroo app or website)     * Online through Restaurant's app or     website     * By ringing the restaurant directly     * By visiting the take-away restaurant
Name of the restaurant you visited	Open question
Location of the restaurant (address, postcode)2	Open question
Please let us know if the restaurant picked up your call?	* Yes     * No, please try again with another restaurant
Please let us know what you ordered. (eg Pad Thai with chicken, free from peanut)2	Open question
If applicable, please type the ingredient list that the restaurant gave to you during the telephone order	Open question
If you chose 'something else' in the previous question, please specify	Open question
Please confirm that you declared or tried to declare your food hypersensitivity while you were ordering your meal	* Yes * No
<ul> <li>Please answer the following questions about your experience placing the order</li> </ul>	Open question

la verm eninion, herry informated were staff	Onen sucesties
<ul> <li>In your opinion, how informed were staff about food hypersensitivities?</li> </ul>	Open question
<ul> <li>In your opinion, how willing were staff to</li> </ul>	Open question
discuss your food hypersensitivity and the	
precautions they take to reduce risk?	
<ul> <li>In your opinion, how accommodating were</li> </ul>	Open question
staff?	
Once you mentioned your food hypersensitivity, let us know how the staff reacted to you	<ul> <li>* The staff said that they will check with the chef what has the allergen you avoid, then the staff told you what you can or cannot eat</li> <li>* The staff asked how severe your food hypersensitivity is and if you have your medication with you</li> <li>* The staff said that they cannot guarantee there won't be the allergen you avoid in the food as there may be a risk of cross</li> </ul>
	contamination so the risk is up to you     * The staff explained the procedures     they take to reduce risk (eg clean     area, clean equipment, etc)     * Other
If you chose 'Other' in the previous question, please specify	Open question
How did the phone call end?	* They agreed to take my order and I felt confident to place my order     * They would have taken my order but I didn't feel confident to place my order     * No, they refused to serve me
Let us know about any barriers you encountered while placing your order, if any.	Open question
Briefly tell us why you preferred this way of placing your order (direct communication, understanding, feeling safer etc)	Open question
Have you placed your order?	Yes, I am awaiting for my order to arrive      No, I was not able to place this order

# D: Recruitment - "Food Hypersensitive Citizen Scientists Expression of Interest Form"

Quest	ion	Option
•	First Name	Open question
•	Family name	Open question
•	Email address	Open question
•	What is your age?	<ul> <li>* Under 18</li> <li>* 18-24 years old</li> <li>* 25-34 years old</li> <li>* 35-44 years old</li> <li>* 45-54 years old</li> <li>* 55-64 years old</li> <li>* 65-74 years old</li> <li>* 75 or older years old</li> </ul>
•	Gender	<ul><li>* Woman</li><li>* Man</li><li>* Non-binary</li><li>* Prefer not to say</li></ul>
•	Postcode	Open question
•	Do you have a food hypersensitivity?	<ul><li>* Yes,</li><li>* No</li><li>* Maybe</li></ul>
•	Are you a carer of someone with a food	* Yes
	hypersensitivity (such as a parent or partner)?	* No * Celery
•	Which foods do you or the person you care for needs to avoid? (Please select any options which apply to you)	<ul> <li>* Cereals containing gluten (such as barley and oats)</li> <li>* Crustaceans (such as prawns, crabs, and lobsters)</li> <li>* Eggs</li> <li>* Fish</li> <li>* Lupin</li> <li>* Milk</li> <li>* Molluscs (such as mussels and oysters)</li> <li>* Mustard</li> <li>* Peanuts</li> <li>* Sesame</li> <li>* Soybeans</li> <li>* Sulphur dioxide and sulphites (at a concentration of more than ten parts per million)</li> <li>* Tree nuts (such as almonds, hazelnuts, walnuts, Brazil nuts, cashews, pecans, pistachios, and Macademia nuts)</li> <li>* Others</li> </ul>
•	Has the food hypersensitivity of your or the	<ul><li>Yes, all of them</li></ul>
	person you care for been medically diagnosed?	* No

	Some of them medically diagnosed
	* Daily
- How often do you order ready to get food or	* Weekly
How often do you order ready-to-eat food or dript online?	* Monthly
drink online?	* Seasonal
	* Never
	* This week
When was the last time you ordered ready-to-eat	* A week ago
food online?	<ul><li>* A month ago</li></ul>
	<ul><li>More than a month ago</li></ul>
Can you download Epicollect5 to your mobile	* Yes
device?	* No

# E: Post hoc survey: "Food Sensitive Citizen Scientists – project evaluation"

Question	Option
How did you hear about us and our citizen science project in the first place?	Social Media campaign     Friends or colleagues     Other
In the project we had different contribution levels, in which levels were you involved as a citizen scientists?	<ul> <li>Level 1: Told us what you think through an online survey</li> <li>Level 2: Navigated through the online platforms and write a short scientific report</li> <li>Level 3: Shaped the design of the study finalising the study's acquisition protocols</li> <li>Level 4: Placed your order and record several parameters</li> <li>Level 5: Posted the food order to our lab for allergen analysis</li> <li>Level 6: Helped with data organisation and analysis</li> <li>Level 7: Helped with dissemination (video, posters, social media posts)</li> </ul>
What was your favourite experience of the project? Something positive such as the survey, the promise of the results etc.	Open question
Where there any barriers in participating in this project?	Open question
Were you satisfied with the amount of activities offered?	Yes, there was choice     No, they were too complicated or too few     other (please explain)
Were you satisfied with the instructions or support given to participate? (webpage, videos etc)	* Yes * No * Maybe
What have you learned or seen in a new light because of your participation?	Open question
Did your participation change, even slightly, your perspective for the work of academic scientists?	* Yes * No * Maybe
How satisfied were you with the project as a whole?	* Rate from 0-10
Please share any additional comments, thoughts or suggestions for this or future Citizen Science projects.	Open question
If you identified any barriers to participation, please suggest what might we change or do differently next time?	Open question
Can we contact you in the future for a similar study? we will always keep your details private as per our commitments to UKRI, our funding body.	* Yes * No * Maybe

## F: Infographic from Work Item 1 produced with the Citizen Scientists



## **G:** Video recruitment and training materials produced for this project

Recruitment video - <a href="https://www.youtube.com/watch?v=YNJhDD9ObG4">https://www.youtube.com/watch?v=YNJhDD9ObG4</a>



 <u>Instructions video produced to train the citizen scientists</u> which is also narrated by one of the citizen scientists of this project



### H: Quotes for the evaluation questionnaire responses from the citizen scientists

#### What was your favourite experience of the project?

- Someone taking the consequences of food cross-contamination on Coeliacs seriously.
- Promise of results in an important issue
- That someone is doing research into food sensitivity.
- working with other CS to see what matters to them and shaping the next stages
- Great to see research being done in this area and supporting it.
- Excitement to be able to change the narrative/raise awareness/influence and to see the final results.
- The survey was a good experience because it gave me the opportunity to contribute to a study with meaning.

#### Where there any barriers in participating in this project?

- Not really, just my allergy was too rare to take it forward
- I struggled with "work item 3" (sample procurement exercise) so I never finished completing this phase which I am disappointed about
- The ordering and posting of food was not reimbursed or sent a label to stick on the food so I struggled to get it done as I don't have time to go to the post office as there is no post office near me.
- Don't like placing orders for delivery online when you have to go through all the hassle of asking about gluten free options first
- The barrier I had was that there were not any gluten free take-aways in my area,
   so I was of limited use.

### What have you learned or seen in a new light because of your participation?

- Takeaways may be safe from the right food business
- It was interesting to see how study and research are completed.
- It just confirmed what a lottery it is to order safe gluten free food from takeaways!
- Just reiterated how poor some places still are in relation to allergies.

### If you identified any barriers to participation, please suggest what might we change or do differently next time?

- The main barrier was cost the cost of the meal and then the cost of the postage.
- I guess it's all a learning curve for all of us, but I strongly believe the allergens should have been looked at separately as the level of avoidance and crosscontamination risks are different
- Post label to be printed by people who order food so I don't have to go to the post office as there is none near anymore
- Better cost awareness



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