

# **Non-Gluten Containing Ingredients Labelling: Insight from UK Consumers with Coeliac Disease**

A report for the Food Standards Agency by Basis Social and Bright Harbour

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# Executive Summary

## Introduction

This report presents the findings from qualitative research with coeliac consumers on experiences, interpretations and views of NCGI (non-gluten containing ingredients) notices. This research was conducted in tandem with wider research on precautionary allergen labelling (PAL) notices, but has been reported separately given the different information provided by PAL and NCGI.

NCGI notices are used by UK businesses to signal foods that do not include ingredients with gluten - but are not necessarily 'gluten free'. For example, a dish that did not include gluten via ingredients like wheat or barley may nonetheless include trace gluten via cross-contamination and is thus not entirely free of gluten exposure risk.

The FSA wanted to understand how coeliac consumers currently experience and interpret NCGI statements, and what their views are around NCGI usage.

## Method and sample

Qualitative research was undertaken with 15 coeliac consumers. All participants either had coeliac diagnoses themselves or cared for children who were diagnosed coeliac. All participants completed an online pre-task exploring initial views of NCGI statements and other gluten allergen communications. They then took part in group workshops of 1.5 hours each (4 groups of 4-5 consumers each).

### **Key Findings: Context in which consumers experience NCGI notices**

- Coeliac disease is experienced as a high-stakes, stressful disorder, linked to the need for constant monitoring of potential exposure risk and the potentially serious health consequences of accidental exposure.
- Coeliac disease often necessitates a high degree of self-advocacy. Many have experiences of not being 'believed' or having their exposure concerns taken seriously. Often, they feel that the burden of keeping themselves safe has been

placed unfairly on their shoulders, amidst relatively low public awareness that sometimes increases exposure risk.

- The learning curve of coeliac disorder is steep: coeliac consumers often find that it takes time to truly understand how to manage exposure risk, particularly in terms of cross-contamination risk. Initially, they 'don't know what they don't know' which increases risk.
- Experiences eating out are often stressful and uncomfortable, particularly for consumers who are more knowledgeable about proactive about managing potential cross-contamination risks. Many routinely experience stigma, embarrassment, and/or difficulty obtaining trustworthy information from food businesses about gluten exposure risk.
- Because of the ongoing cognitive load of exposure risk management, consumers are eager for 'short-cuts' that enable decision making about whether foods are safe for them. 'Gluten free' labelling is the 'gold standard' and highly valued by coeliac consumers.

### **Key Findings: Interpretation and use of NCGI notices**

- Coeliac consumers found NCGI statements highly confusing. The phrase 'non-gluten containing ingredients' was perceived as unclear across the sample, including by highly knowledgeable participants.
- Only some participants could remember having seen NCGI notices 'in real life – ' typically, in restaurant or catering environments, as part of 'No Gluten' or 'Non Gluten' menus.
- Although some coeliac consumers understood NCGI notices and menus as flagging potential cross-contamination risk, others mis-interpreted these as meaning 'gluten free.' This raised risk of harm for coeliac consumers, who may interpret NCGI notices as a 'green light' that foods are safe for them, without considering cross-contamination exposure risk.
- Upon understanding the intended meaning of NCGI statements, coeliac consumers often reacted strongly: with anger, frustration, and even a sense of betrayal. Less knowledgeable consumers in particular felt misled, initially thinking that NCGI menus included foods that were safe for them - only to be disappointed.

- Business use of attention-grabbing NCGI language in headings (e.g. NON GLUTEN MENU) and additional cross contamination detail in small print (e.g., PAL statements that restaurants could not guarantee foods were gluten free) contributed to this sense of being 'misled' for participants.
- However, coeliac consumers responded positively to 'additional information' around cross-contamination risk sometimes provided on NCGI menus. For example, they appreciated flagging of menu items prepared using fryers that also handled gluten-containing foods. This level of detail signalled care for coeliac consumers from the business and supported more informed decision making.
- These 'additional information' statements served two important functions. First, they disrupted incorrect understandings of NCGI as equivalent to 'gluten free' by calling attention to cross-contamination risk sources. Second, they served as useful sources of education around cross-contamination risk for less knowledgeable consumers.

## Conclusions

At present, NCGI notices do not support informed decision making or effective risk management for coeliac consumers. Consumers find NCGI statements unhelpful, confusing and sometimes actively misleading. At present, they may actually raise risk of exposure harm, particularly for less knowledgeable coeliac consumers. Additional information provision is considered far more useful - but at present, may be missed or perceived as contradictory to NCGI 'headings' on menus.

As NCGI regulation and guidance evolves, language should be adjusted to eliminate confusing 'non-gluten containing ingredients' phrasing, and businesses should be encouraged to provide additional detail about cross-contamination management in an accessible and readable format.

## 1. Introduction

### 1.1. Background: Coeliac Consumers and Non-Gluten Containing Ingredients Labelling

Coeliac disease is a serious condition, in which ingestion of gluten results in an auto-immune reaction. Gluten exposure, even in trace amounts, can have serious ramifications for coeliac consumers, including short-term symptoms like stomach pain and inflammation, as well as longer-term and more systemic impacts including nutrient deficiencies, increased risk of other immune-mediated conditions, and cancer. It is estimated to affect at least 1 in 100 people.<sup>1</sup>

Transparent labelling of gluten in food is essential to the safe management of coeliac disease for UK consumers. Managing gluten exposure risk is particularly challenging given that reactions can and do occur from even very trace amounts. This means that eliminating gluten containing ingredients is not sufficient; gluten exposure occurring via cross-contamination, even in very small amounts, can cause real harm.

Amongst other categories of gluten communication, NGCI notices are provided by UK food businesses to signal foods that are made from 'non gluten containing ingredients'.

This category of information provision is used for foods that are made from ingredients that do not themselves contain gluten (for example, not including things like wheat or barley). NCGI statements do not convey that a product or food is 'gluten free' or completely free of gluten exposure risk, for example via cross-contamination. Such statements can only be used when a food business cannot guarantee that the foods are gluten free.

Previously, businesses could use NGCI statements to describe a single item of food, as well as a group of foods. However, the 'gluten-free regulations'<sup>2</sup>, which came into effect in 2016, only allow for the use of 'gluten-free' or 'very low gluten' statements when businesses want to provide information on the absence or reduced presence of gluten in food, thus outlawing NGCI and similar statements to describe single-food items. On the legal basis that the gluten free regulations only related to labelling of information for individual food items rather than grouped items, the FSA developed

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<sup>1</sup> <https://www.coeliac.org.uk/information-and-support/coeliac-disease/about-coeliac-disease/>

<sup>2</sup> EUR-Lex (2014) Regulation (EU) No 828/2014

the position that NCGI statements could be used to describe a group of food (e.g. a heading on a menu). This position, and associated FSA guidance<sup>3</sup>, applies to England only.

In the UK, NCGI statements are most commonly used in restaurant and catering environments, for example on 'non gluten containing ingredient' menus. These kinds of communications often also provide additional information to consumers about gluten cross-contamination risk, or clarify that foods on NCGI menus are not guaranteed to be free of gluten. However, there is currently no requirement for this kind of clarification to be provided.

## **1.2. Aims and objectives of this research**

Given the importance of transparent allergens communication for coeliac consumers, the FSA commissioned Basis Research, in partnership with Bright Harbour Research, to explore how NCGI statements are experienced and interpreted at present. Research focused on out-of-home eating experiences.

### **Key objectives for this research:**

- What experience do coeliac consumers have of NCGI statements?
- How do coeliac consumers understand, interpret and use NCGI statements?
- What do coeliac consumers think about the use of NCGI statements?

Research was conducted concurrently with a wider investigation of consumer experiences of precautionary allergen labelling (PAL). Given clear synergies in terms of consumer experiences across these two categories of labelling information, the same teams were used to conduct workshops and analyse project data.

Readers interested in the wider allergen communication context in which NCGI statements operated may find the report from this wider project useful, although it focuses on non-coeliac consumers.

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<sup>3</sup> FSA (no date) Changes to 'No Gluten Containing Ingredients' guidance

### **1.3. Research methods and sample**

See the Appendix for full sample and methodological details.

#### **Sample summary**

15 participants were included in research, consisting of a mix of adults diagnosed with coeliac disease (11 participants) and parents caring for dependents aged under 16 years old with coeliac disease (4 participants). The sample allowed for representation of a broad diversity of demographic factors in terms of gender, age, income, education and ethnicity. All participants had experience of occasionally eating out or ordering take-away.

All participants were recruited using a structured sample quota screener and provided formal written consent for their participation. Participants were provided with a thank-you payment for their time, in line with industry norms.

#### **Research methods**

Participants took part in group discussions of 1.5 hours each (3-4 participants per group, with each participant only taking part in one group), comprising of open discussion and guided exploration of NCGI menu stimuli (see Section 4.2 for details).

Workshops focused on understanding experiences around managing coeliac disease and gluten/allergen communications; impressions and experiences of NCGI communications specifically; and detailed exploration of interpretations and likely behavioural response in response to real-life NCGI statements.

Prior to participation in the workshops, participants completed a brief online pre-task in which they introduced themselves; spoke briefly about their experience managing coeliac disease; and gave some initial impressions of their understanding and use of NCGI statements. These pre-tasks helped shape the workshop discussions - for example via helping the research team identify relatively low understandings of what NCGI statements intended to convey.



All interviews were recorded and anonymised data were documented and analysed using a structured pro-forma. The research team, including FSA partners, also conducted two more creative analytical brainstorms to identify key themes and findings.

## **2. The consumer context: living with coeliac diagnosis and managing gluten risk**

Coeliac consumers' approach and response to NCGI labels are highly influenced by wider factors such as their overall experiences around coeliac diagnosis and management; their risk orientation around gluten exposure; and their general levels of knowledge around cross-contamination risks.

Below, we briefly explore general consumer experience and drivers of audience difference, and how these factors shape the consumer context in which NCGI operate.

### **2.1. Coeliac is experienced as a high-stakes, stressful disease**

Across our participant sample, there was a pervasive sense of stress and anxiety associated with coeliac disease. This was in relation to often difficult pathways to diagnosis, the seriousness of potential harm involved and the constant worry around exposure management.

Most of our coeliac participants had been diagnosed following periods of extended and sometimes serious ill-health – often, after multiple 'false starts' or mis-diagnoses. Their eventual coeliac diagnosis often came as a relief, providing an explanation for the symptoms they had been experiencing and a simple, if frustrating, treatment plan: strictly avoid gluten. However, the diagnosis was a double-edged sword: it gave them a pathway to manage their health but also made them aware of how much damage continued exposure might cause, including risk of harms like cancer, Crone's disease, and so on.

“I’m 54 now and I had bowel disease since my mid-twenties that was diagnosed as ulcerative colitis, and for ten years after I had lots of surgery. I have always had quite bad diarrhea due to UC, and I was also getting ill so much, and I just thought it was the colitis. But then my GP did some tests and I had some markers for it.” Recent coeliac diagnosis

“I already have osteoporosis in my hips and I’m worried about the cancer risk.” – Recent coeliac diagnosis

Similarly, parents of coeliac children expressed a strong sense of pressure to ‘get it right ’and protect their children from harm, often with notable impact on their own wellbeing and mental health. Parents of younger children seemed particularly stressed about eliminating all risk of exposure, but also felt this was difficult if not impossible to achieve within a wider social context in which not everyone understood exposure risk (e.g., families, schools, restaurants) – with children not yet old enough to advocate for themselves.

During a projective exercise in which participants were asked to choose an image from the [‘blob tree’](#) to describe how they felt about managing coeliac disease, one parent chose an image of one person clinging to the branches of a tree, trying but failing to catch someone who had already fallen off. She became visibly upset about how difficult it was to manage risk on her daughter’s behalf, always trying but never quite able to eliminate risk of harm.

Participants also reported many experiences of not being ‘believed ’during their coeliac journeys, which made managing their health more difficult and stressful. For example, many spoke of having needed to ‘push ’doctors to believe that their health was suffering, and that investigation was needed, or felt judged by friends and family for being ‘dramatic. ’Participants said it was often hard to get others to understand the seriousness of the problem, which often increased their exposure risk.

“At the time I was diagnosed, as a child, they thought I was just being over-sensitive... teachers and relatives didn’t always believe my mum and sometimes just gave me a biscuit here and there.” – Longer-term coeliac diagnosis

## **2.2. The learning curve is steep, and confusion is high**

Participants often reported a steep learning curve upon first being diagnosed in terms of managing exposure risk when food shopping or preparing food at home.

Often, those newly diagnosed found understanding what to do hugely confusing and taxing: figuring out whether relied upon ingredients, meals and restaurants were 'safe'; changing their diet; learning to read labels; even changing supermarkets; and so on. Although sources like the Coeliac Society were highly regarded and considered useful, it took time to digest and assimilate the information that they provided.

The difficulty of learning to safely manage exposure risk was particularly evident in relation to cross-contamination management. Some had simply been given advice to 'eliminate gluten' at point of diagnosis. They understood that they should check labels and menus but were not aware of the ways that gluten cross-contamination most commonly occurs, or how to avoid it.

This difference in knowledge and approach was very clear across the sample. Some participants were highly knowledgeable about the various types of gluten risk communication and how to interpret them; others had a more tenuous grasp or only questions.

There was also a sense that knowledge about 'what is safe' mostly results from a process of trial and error plus community learning. Coeliac consumers made the best decisions they could with the information they had, and then learned from how their bodies responded, or via discussions with others. Over time, as participants reacted to foods that 'should have been' gluten free - or learned more from other people living with coeliac disease - they often realised that completely eliminating cross contamination risk was harder than it seemed.

For example, participants spoke of having 'A-ha' moments when they realised that the same fryers were often used for gluten-containing and gluten-free foods – or that their gluten free toast probably arrived at their plate covered in crumbs from other customers' standard bread. Many discovered that gluten was often 'hiding' in

seemingly innocuous foods that they wouldn't have expected to carry any exposure risk, like ketchup, mustard, or soy sauce and stock-cubes.

Often, the research discussions became learning moments for newly diagnosed or less knowledgeable participants, as they swapped tips and stories with others.

### **2.3. Less knowledgeable consumers are more risk exposed**

Although all participants viewed coeliac disease as serious and important to manage as well as they could, as discussed above, their ability to manage exposure risk safely varied enormously.

In general, those with longer times since diagnoses and more experience on the 'learning curve' took a stricter approach and were more confident that they knew how to keep themselves safe – although they didn't always trust food businesses to help them do so. For some of these participants, avoiding gluten exposure was managed via strict risk reduction systems that seriously limited their diets and social lives. They simplified risk decision making by simply not eating anything they couldn't guarantee was '100% safe'.

For example, some participants essentially didn't eat out at all, simply missing out on social events like birthdays or work-dos, or bringing their own food along. Others scrutinised labels and interrogated restaurant staff religiously, even if they had been to the restaurant before and had a positive experience.

However, less experienced coeliac participants often took a slightly more relaxed approach, particularly in terms of management of cross-contamination risk. For example, these consumers might check labels and speak to staff and ask which dishes were gluten-free, but weren't asking any specific details about things like cross-contamination management. For some this reflected a lack of understanding about how commonly cross-contamination can occur. For others, the risk of cross contamination really hadn't been considered at all.

In general, as we explored in detail these less experienced participants' interpretation of NCGI labels, this more relaxed approach left them more risk exposed, particularly when eating out. They were generally more prone to error when interpreting various gluten risk messaging, and less likely to seek clarity about risk levels to enable informed decision-making.

## **2.4. Implications for NCGI labelling**

Although all coeliac consumers are conscious of the importance of managing gluten exposure risk, they have varying levels of confidence and knowledge to support this, which poses a challenge for NCGI labelling. They are eager for 'short cut' labels that help simplify decision making and make it easier to manage risk.

Less experienced consumers may have limited awareness of cross-contamination risks. This means that they are more likely to interpret 'non-gluten containing ingredients' messaging as signalling that NCGI-labelled foods are 'totally safe', raising risk of exposure harm. NCGI and other gluten risk communication messaging serve as an important touchpoint of consumer education and protection for this group.

Conversely, more knowledgeable coeliac consumers are likely to understand that NCGI statements mean something different than 'gluten free', and to have additional questions to confirm safety when they encounter NCGI labels. A simple statement alone is unlikely to provide reassurance for this group. As explored in more detail in Chapter 4, they are also not immune to misinterpretation risks, particularly given that they are more likely to experience risk management fatigue, and to encounter NCGI statements in moments of high cognitive load.

Reliance on the simplicity of 'gluten free' labelling as a 'green flag' shortcut also raises risks that other similar statements – like NCGI – are interpreted in the same fashion.

### **3. Experiences using non-NCGI communications to manage exposure risk**

NCGI labels are only one of many ways that gluten risk is communicated in order to help coeliac consumers manage exposure risk. How consumers understand and interpret NCGI information is affected by this wider communications context.

Below, we explore how coeliac consumers interpret other types of gluten risk communications, and their general pain points in managing gluten exposure risk both in-home and out-of-home.

In general, coeliac customers find cross-contamination risk management quite difficult, particularly in out-of-home contexts. The context in which they are making gluten exposure risk decisions makes mis-interpretations and errors more likely, meaning clear NCGI communications are critical.

#### **3.1. 'Gluten free' is the benchmark for all gluten communications**

Because of the high cognitive load involved in managing exposure risk and deciding what is safe to eat, coeliac consumers are generally very appreciative of labels which provide 'short cut' signs of safety.

Whether in-home or out-of-home, three kinds of gluten communications tended to be considered most helpful to cut through the confusion:

- 'gluten free' labels/wording
- 'free from' labels/wording
- coeliac-safe stickers (wheat and 'X' symbol)

Participants spoke about the ways in which these kinds of labels had made their lives easier, because they were something that they could simply 'scan' for rather than have to read detailed information or engage in complex decision making.

“Gluten free and things like that – they have a legal obligation to make sure that it is safe, so things like that are the best to trust.” – Longer-term coeliac diagnosis

In particular, ‘Gluten Free ’was the label that was most commonly seen and used, serving as a benchmark reference against which other labels and notices were often compared. Participants appreciated that the same language was often used both in-home and out-of-home, and that the language didn’t vary across brands.

### 3.2. Navigating food labels for in-home risk management

Although the ‘learning curve ’of adjusting to reading labels before purchase was often uncomfortable, most participants felt fairly confident in terms of their ability to manage risk when shopping for in-home use.

Once they knew what to look for, participants generally found it fairly straightforward to interpret gluten exposure risk from labelling - eased by the bolded allergen notices on labels, and by ‘gluten free ’branded products. The challenge then became avoiding the risks of complacency and remembering to ‘keep it up’. Several people also mentioned that brands sometimes changed formulations without notice, requiring constant vigilance.

Precautionary allergen labelling (PAL) – for example, ‘may contain ’and ‘produced in a factory which ’labels that signal cross-contamination risk, was the only area of labelling that consumers found difficult. They found this category of information ‘confusing ’and ‘unclear’.<sup>4</sup> Participants reported they were often unsure whether foods marked as ‘may contain ’gluten were safe for them to eat or not, often simply opting to avoid them. They also found it frustrating to have to look at two areas of labelling information: the ingredients list itself plus the PAL notice.

Over time, coeliac consumers had generally used the allergens information on food labels to develop a list of ‘safe ’foods that they could count on and return to over time. Some had also found tools like the Coeliac Society’s bar scanner app useful

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<sup>4</sup> Further details on consumers’ experiences of PAL labelling was explored separately as part of this research piece. Please see the full report for more.

during their early adjustment process: it helped minimise the 'guess work' and totally confirmed the safety of a given food for them.

### 3.3. Managing exposure risk out-of-home

In contrast, eating out experiences were highly uncomfortable for those managing coeliac risk, particularly for participants who were more experienced and/or risk conscious. When trying to find 'safe' foods to eat when out-of-home, coeliac participants reported that:

- they felt embarrassed and singled out when having to ask for gluten and/or cross-contamination information
- staff often didn't have the information they needed, or didn't seem to know enough about coeliac disease to communicate or manage risk safely
- staff didn't always take their needs seriously, assuming they were avoiding gluten for lifestyle rather than serious health reasons.
- gluten labelling on menus was often absent or inconsistent

"Sometimes I think that chefs have no idea what coeliac even is... they start asking questions that don't make any sense like 'can you have yoghurt', etc." – Longer-term coeliac diagnosis

"Often, people just don't understand what you have to worry about when you are coeliac, especially now that you have so many people eating 'gluten free'." – Longer-term coeliac diagnosis

These experiences often made eating out highly unpleasant and anxiety-producing for many coeliac consumers, particularly for those more knowledgeable about cross-contamination risk. They also reduced consumers' trust in food businesses and in allergen management in the food system more generally.

Participants' strategies for managing risk varied, but most relied on a mix of menu checking, discussions with staff (often having to involve managers or kitchen staff to double-check handling procedures) and simply not eating food where uncertain about safety. Contextual cues also played a strong role, with consumers making



assumptions about allergen and cross-contamination management based on things like staff friendliness, overall cleanliness and look and feel, or business reputation.

The line that consumers drew around what 'felt safe' varied according to their general risk orientation: for some, very few businesses passed the test and out-of-home eating was extremely minimal. Others were often happy to rely on general contextual cues to inform their decisions and then leave the outcome partly to chance.

Many of the more risk-conscious participants felt that the burden of managing their disease was falling unfairly on their shoulders, and that more needed to be done to ensure that businesses were providing equitable, safe eating opportunities for coeliac customers. They were eager for more staff awareness and stricter regulation of cross-contamination management in kitchens to help keep them safe.

However, participants also acknowledged the challenges of ensuring that staff knew enough to keep them truly safe: if they had found the learning curve around gluten management steep themselves, how could they expect restaurants to ensure all staff knew enough to manage risk well? In light of this, some participants had come to a very practical, if isolating conclusion: it's better just to assume most food out-of-home is not safe, and to adapt accordingly.

Conversely, where food businesses were perceived as 'making the extra effort' by coeliac consumers this was hugely appreciated and improved experiences.

Participants spoke warmly of businesses which had developed separate labels for coeliac customers or had made customers feel welcome and supported when they asked questions about ingredients or cross-contamination risks. These businesses often gained customer trust and repeat business.

"I've been places where the chef actually does come out and they talk about how they're handling it and what they're doing, and that really does fill me with confidence. If they do that, I know they are taking it seriously." – Longer term diagnosis

### **3.4. Implications for NCGI labelling**

Out of home, coeliac consumers have low trust that they can rely on food businesses to adequately manage risk on their behalf and are eager for signs that businesses understand the seriousness of coeliac disease and the importance of good quality risk management information.

This makes NCGI information an important element of supportive risk communication for coeliac consumers if well delivered and correctly interpreted. However, in the environments in which consumers are most likely to view NCGI notices (i.e., in restaurants or catering environments), they are likely to be eager to make a decision fairly quickly. All of these factors lower cognitive bandwidth, raising the risk of misinterpretation or confusion.

Wider customer experience will also influence how NCGI labels are interpreted and acted on in context. Coeliac consumers rely on cues like customer treatment and cleanliness that may or may not align with actual allergen and cross-contamination risk.

## **4. Understanding and interpretation of NCGI labels**

In this section we explore participants interpretations of a variety of NCGI communications, primarily in the form of on-menu communications.

In general, although coeliac consumers welcome additional information about gluten cross-contamination risk, current NCGI notices often confuse them rather than provide clarity. Terminology used, level of detail provided, and confusions between NCGI and other gluten communications often results in potentially dangerous misinterpretations - for some consumers, potentially enhancing exposure risk.

Below we explore drivers and impact of common (mis)interpretations, plus factors that need to be considered as NCGI labels are adjusted and improved.

### **4.1. Spontaneous recall of NCGI exposure and usage**

Discussions about NCGI statements began with fairly open exploration of where coeliac participants had seen these kinds of communications in the past and how they had interpreted them.

Upon viewing the examples of NCGI information provided in the pre-task, only some participants could remember having seen similar notices 'in real life – 'typically, in restaurant or catering environments. Participants who were more experienced in gluten exposure risk management (usually, those with longer time since diagnosis) and those who were more risk-averse were more likely to report having seen them.

“I've never seen that before. Is it about how things are handled? Is that different than gluten-free?” – Recent coeliac diagnosis

A few more knowledgeable participants understood that NCGI notices were a way of distinguishing dishes which did not include gluten 'in the dish 'but did not necessarily mean there was no risk of gluten exposure. Others were less sure about exactly what level of risk was being communicated – but were nonetheless grateful that businesses were making an effort to inform consumers managing gluten risks.

“I saw a notice like that for the first time recently, and it made me so happy to know that coeliac is finally being taken seriously. I'd triple check anyway, but it's good to know that someone has really looked at whether the food on that menu is safe for me.” – Recent coeliac diagnosis

“If you see something like that, you should still be cautious. It's good when you see this because you are often on a hunt to find something that *might* be suitable for you, but still you do end up with the occasion where you have a reaction because it wasn't totally without gluten.” – Longer-term coeliac diagnosis

However, in general participants 'interpretations and understandings of what NCGI notices were trying to communicate were mixed – and many were confused. This seemed largely driven by uncertainty about how NCGI notices related to other allergen and gluten labelling that participants were more familiar with, such as

'Gluten Free' menus or markings. The language itself, which also felt quite 'formal' and academic, contributed to the confusion for many (see Section 4.3).

For example, some assumed that NCGI notices in some way had to do with risk of cross-contamination – but then struggled to answer other participants' questions about how a product without gluten in the ingredients could nonetheless contain some gluten exposure risk. Others assumed that (or queried whether) NCGI notices meant the same thing as 'gluten free'.

"I would prefer 'gluten free' as it means it's all gone; 'non-gluten', I don't know what exactly that means. I'm guessing it might mean some cross-contamination? 'Gluten free' is the finished product that has been checked and I'm confident to eat it." – Recent coeliac diagnosis

Some expressed gratitude for this category of gluten communication, welcoming it as a sign that cross-contamination issues 'were being taken seriously.'

"I saw one of those for the first time recently, and I was really pleased that coeliac people are starting to be taken seriously." – Longer term coeliac diagnosis

## **4.2. Prompted, detailed exploration of NCGI communications**

Following spontaneous discussions around NCGI experiences, we presented participants with a range of stimuli, each showing different versions and wording options of NCGI communications.

In order to explore consumer reactions to NCGI statements in a similar context in which they would be using and interpreting them, examples from real-life menus were used as stimuli for discussion. Participants' reactions, interpretations and (reported) likely behaviour were explored to understand the impact of NCGI statements on coeliac consumers' understanding of gluten exposure risk and decision-making process.

The below table summarises the language used in research stimuli. Identifying company detail (like branding and business name) have been removed.

#	Menu heading	Additional detail(s)	Dish markings
1	NON-GLUTEN MENU	<p>Dishes marked with an asterisk (*) include a component which is cooked in a fryer/oils with other gluten containing ingredients.</p> <p>When placing your order, please specify that you'd like the non-gluten option of this dish to your waiter to avoid confusion.</p>	NON-GLUTEN
2	NON-GLUTEN CONTAINING INGREDIENTS	When placing your order, please let your waiter know that you would like the non-gluten dish.	N/A
3	NON-GLUTEN	<p>This menu has been designed for a non-gluten diet. It's a selection of dishes that do not contain gluten in their ingredients.</p> <p>All the taste but no gluten.</p>	N/A
4	NO-GLUTEN-CONTAINING MENU	<p>Please be aware that all our dishes are prepared in kitchens where wheat, nuts and gluten are present, as well as other allergens, therefore we cannot guarantee that any food item is completely "free from" traces of allergens.</p> <p>Please ask your server if you are concerned about the presence of allergens in your food.</p>	N/A
5	Summer Free From Menu	All dishes are free from gluten-containing ingredients and refined sugar.	N/A

The combined insights of these discussions are as follows.

#### **4.1.1 'Non-gluten containing ingredients is misunderstood in ways that raise risk of harm**

The phrase 'non-gluten containing ingredient' was highly confusing for most participants. The terminology felt 'heavy', 'formal' and hard to interpret – particularly when contrasted to phrases that participants were more familiar with, like 'gluten free.' That meant that it took time and effort for participants to understand, raising cognitive load.

As discussed previously, within the context in which participants are likely to encounter NCGI notices – stressed and/or anxious, and trying to understand what they can eat, quickly – the risk of misinterpretation is high. The effort to understand what is meant by NCGI, as currently phrased, clearly further increased this risk.

Encountering difficult language, participants often made 'best guesses' about what NCGI notices were attempting to communicate, and these guesses were often wrong. Concerningly, the assumption that NCGI notices are essentially equivalent to 'gluten free' were common – including amongst some more knowledgeable and experienced coeliac consumers.

“Does that mean that all of the ingredients here are alternatives to gluten? Like this menu is made of things like gluten free lasagna? It doesn't feel like they would use this to talk about things that normally don't have gluten in them anyway.” – Longer-term coeliac diagnosis

This confusion was particularly pronounced when NCGI statements were included in separate menu information. In one group, 4/5 people assumed that an NCGI menu statement meant that the menu included only dishes that were entirely gluten free. This had the effect of acting as a false 'short cut' for coeliac consumers eager for simple risk decision making: 'they have flagged this as safe, and I can eat it.'

Less knowledgeable coeliac consumers were at particular risk from harm from this kind of mis-interpretation. They had a more trusting approach to gluten risk decision making in general, and a less established frame of reference for the kinds of questions they might need to ask to assess cross-contamination risk. For many, NCGI statements were perceived as a 'green flag' that actually reduced the likelihood that they would ask further clarifying questions that might help them make more informed decisions.

"This would be so amazing. There are so many dishes on this list that I've been told I can't eat, but actually there's loads here. This is really reassuring that all of these are ok for coeliacs." – Recent coeliac diagnosis

#### **4.1.2 Additional detail about cross-contamination risk management is critical**

Some menus included additional detail about how cross-contamination risks are actively managed by the food business, beyond the general NCGI 'heading'.

For example, this included notices which included asterisks flagging which dishes might use fryers that are also used for gluten-containing ingredients (#1), and notices which made mention of how allergens were handled in the kitchen or by staff. Participants also reported other menus that provided information about how the staff were made aware of allergen needs, or that reassured customers that dishes for gluten-free customers would be flagged and held separately.

In the context of widespread confusion about the exact meaning of NCGI statements, these additional details served an important role: drawing consumers' attention to how their food would actually be handled and prepared and disrupting assumptions that NCGI menus were equivalent to 'gluten free.'

In general, coeliac consumers highly appreciated these additional details, particularly those who were more risk conscious. Additional information provision made them feel that the business cared enough to take the time and effort to provide more information so that they could make a more informed choice. In a context in which participants often felt too much responsibility had been put on their shoulders to manage exposure risk, they appreciated a sign that businesses took the issue

seriously. It often made them more hopeful that they could trust information the business provided to make their decisions.

“I would be thrilled to bits to get a menu like this as it is quite extensive and there’s a lot that I might be able to eat, but I can also see what might be ok for someone not choosing to eat gluten, but not ok for someone like me. The menu shows us items that are gluten-free but they become contaminated if they are cooked in a fryer/boiler etc.” – Longer term coeliac diagnosis

It was notable that once participants had seen more detailed NCGI notices, those that took a more minimalist approach and did not provide this kind of additional cross contamination detail were perceived as lacking. The contrast made it feel that those who did not offer additional information weren’t as safe, or even had something to hide.

"This menu doesn’t have the extra warning like the previous one had. This one doesn’t feel as safe, does it?" - Recent coeliac diagnosis

However, for less knowledgeable and more trusting coeliac consumers, these ‘additional details ’often had the opposite effect – precisely because it disrupted their incorrect assumptions that ‘NCGI ’was probably equivalent to ‘gluten free. ’Seeing additional notices that prompted consideration of cross-contamination risk was uncomfortable, even scary. Sometimes, coeliac consumers began asking other participants questions about cross-contamination risks at this stage and were not happy about what they discovered.

#### **4.1.3 Coeliac consumers lost trust if feeling ‘misled’ by NCGI**

Where coeliac consumers felt that NCGI notices were confusing and not providing adequate clarity about cross-contamination risk for the coeliac audience, it tended to result in strong feelings: anger, frustration and for some even a sense of betrayal.

This was particularly true for less knowledgeable consumers who had made initial (incorrect) judgements about the safety levels implied by NCGI menu headings – only to be let down as they understood more about the actual level of risk involved.



For these participants, the net effect was of feeling that a treat had been offered ('I can eat this!') and then taken away ('No, I can't!') – with the added heartbreak of becoming more aware of all the other cross-contamination risks they might now need to monitor in the future.

This frustration and sense of being 'misled' was exacerbated by the formatting approach taken by many NCGI menus. The perceived misleading 'non-gluten containing ingredient' headings were often large print and attention grabbing. In contrast, the additional detail that often made cross-contamination risk clearer was often in 'fine print' and likely to be missed.

This mis-match in ease of access for cross-contamination information on menus felt misleading and unfair. Coeliac consumers felt that you had to 'know to look for it', and judged that outside the confines of a research session where a moderator was actively prompting them to look for it, they probably wouldn't have seen it at all.

#### **4.1.4 Coeliac consumers' interpretations are sensitive to tone and wording**

Food businesses' NCGI notices were often embedded in wider branded communications, and/or had been tailored to fit the brand's feel in terms of the tone and language used. Often, interpretations of NCGI information were highly influenced by these variations in style and wording.

For example, participants discussed many different versions of statements which encouraged consumers with allergen needs to have discussions with staff (both from our stimuli and from real-life experiences).

Participants tended to be frustrated by versions of these notices which felt like businesses were simply making a blanket statement about their inability to manage cross-contamination risk (e.g. #4). This frustration tended to spark a wider loss of trust in the business and their ability to protect coeliac consumers.

“It really does feel that businesses are just trying to cover their backsides with notices like this. ‘There’s a chance, that’s not our fault.’ There’s no sense of care.” – Longer-term coeliac diagnosis

Conversely, where the tone of these kinds of statements felt warmer and more consumer focused, that tended to increase trust, in ways that weren’t always helpful. For example, in some cases language signalled ‘safety ’to participants – meaning that they then downgraded their assessment of the cross-contamination risks involved. Warmer language, or language that generally appealed to the particular participant involved, made them less wary and increased the risk that NCGI statements would be interpreted as a blanket ‘green flag’.

“I like that this example says, ‘these dishes are designed for a non-gluten diet.’ That feels so much safer to me.” – Recent coeliac diagnosis

Here as elsewhere, the exact language that made consumers take NCGI statements more/less seriously varied. This seemed to be influenced by their experience and knowledge levels (as discussed) but also general brand and language ‘fit ’for the given consumer. For example, for some, more formal language provided reassurance that gluten exposure risks were being taken seriously. For others, warmer language served as a sign of care for customers and a suggestion that the business would look after them well.

Either way, when participants perceived signs of general ‘safety ’they were prone to errors about the actual risk being communicated, for example interpreting NCGI language as meaning ‘safe for me and my coeliac disease’.

Ensuring the clarity of core NCGI messaging, including any additional information detail, becomes particularly important in this context. Brand tone and imagery send powerful safety signals, and customers are likely to be choosing to spend their money with brands that are a good fit for their particular style and taste.

These signals make it even harder to interpret NCGI statements and assess risk correctly, particularly if NCGI statements themselves are confusing or hard to interpret.

### **4.3. Implications for NCGI labelling**

It was clear that coeliac consumers are not currently well served by NCGI notices, which are often missed or experienced as unclear and confusing, and which do not consistently support informed decision making. The wording in particular drives confusion - but context and format (on-menu) can also contribute to misunderstandings.

Most concerning is the risk of misinterpretation by less experienced coeliac consumers, who may currently interpret NCGI statements as equivalent to 'gluten free', thus leading to gluten exposure risk.

## **5. What would make NCGI statements clearer for coeliac consumers?**

The findings of this research clearly show that at present, NCGI notices are not working well for coeliac consumers. In many cases, particularly when used by coeliac consumers who are less knowledgeable (e.g., those recently diagnosed), NCGI statements may actually introduce risk of harm given common misinterpretations that they signal food is 'safe to eat'.

It was notable that many of the confusion and frustration points that participants raised about NCGI statements aligned with frustration points raised about PAL more widely in the research conducted concurrently with this piece of work. Participants from that study also wanted the same kinds of adjustments to be made to NCGI notices to improve their experience and minimise risk of harm.

The following '5 Cs' for allergen communication were co-created with consumers with allergies and hypersensitivities in our PAL research. They have been adjusted to reflect the needs of coeliac consumers in relation to NCGI labelling.

## 5.1 The '5 Cs' for allergen communication:

**1. Clarity:** most important is that NCGI/PAL information clearly communicates cross-contamination risk, in a way that helps consumers make decisions about whether that product is right for them.

In the context of NCGI statements, it is critical that 'headings' on NCGI menus use clear and simple language, avoiding 'non-gluten containing ingredients' phraseology.

Extra care must also be taken to ensure that coeliac consumers do not assume that NCGI statements are meant to communicate the same risk level as 'gluten free' labelling, and that consumers have access to additional detail about the exact measures taken to manage gluten cross-contamination risk in the kitchen.

**2. Consistency:** participants wanted more standardised format and language to be used across NCGI/PAL notices to minimise the risk of confusion and reduce cognitive load.

In the context of NCGI statements, this would mean more standardised 'headings' on menus so that consumers don't have to wonder if a 'non-gluten containing ingredients' menu poses the same cross-contamination risk as a 'non gluten' menu.

**3. Care:** participants were very sensitive to tone and implication of burden around allergen and cross contamination risk management – particularly in the context of feeling that most allergen notices were for business rather than consumer benefit. They wanted language to demonstrate care for communities affected by allergen risk, and not to be made to feel burdensome or difficult for needing business' cooperative support in managing risk. Being given a sense that businesses had genuinely tried to manage risk was also viewed as a signal of care.

Provision of additional detail about how gluten cross contamination risk is managed sends a strong signal to coeliac consumers that their needs are respected by the

business, and enabling informed decision making engenders appreciation and respect.

Ideally, NCGI communications and allergen communications more widely should avoid 'blanket 'risk messaging (e.g., 'we cannot guarantee that any ingredient is fully free of allergen risk'), which is perceived as 'offloading 'risk management responsibility to consumers. Conversely, confirmations that staff are eager to work with coeliac customers to understand and help manage allergen needs are welcomed.

**4. Cognitive load reduction:** participants wanted to be given information in a wording and format that makes it easy for them to understand risk and make decisions, without a lot of extra effort. They didn't want to be left seeking more information to assess personal risk – to have to look hard for the information they wanted – or to have to work hard to interpret information given.

It is important that coeliac consumers don't have to 'hunt 'for information to help them manage risk, and that menu 'headlines 'don't provide a misleading picture of cross-contamination risk. For example, statements that provide additional detail about gluten cross contamination risk (or details about how to get this information) should be easy to read, not in 'fine print. 'Provision of separate menus is appreciated.

**5. Clear on community:** Participants wanted a clear signal about the intended audience for NCGI/PAL notices; that is, to be certain that they are receiving information appropriate for people with severe reactions rather than mild intolerances or lifestyle preferences around allergenic ingredients. They wanted to be able to easily distinguish 'risk information to prevent serious harm of those who are vulnerable to it 'from 'general ingredient or menu information for those interested.'

In the context of NCGI statements, this means that menus and other notices must be careful to flag risk levels for coeliac consumers specifically. Given how likely it is that coeliac consumers (particularly those less experienced) will interpret non-gluten menus as 'safe 'for their consumption without questioning cross-contamination risk,

there may be a need for messaging that mentions coeliac by name to disrupt these potentially harmful assumptions.

For example, if 'non-gluten' menus are provided, they need to clearly specify whether all items included are safe for coeliac customers or provide further information for them to learn more.

## 6. Conclusions

Although coeliac consumers appreciate receiving communication about cross-contamination risks in theory, NCGI does not currently meet their needs in this space in practice. Coeliac consumers' experience of NCGI statements are unhelpful, confusing, and sometimes actively misleading - increasing risk of harm via unintentional gluten exposure.

Currently, NCGI statements are most helpful for highly knowledgeable coeliac consumers who are already highly aware of gluten cross-contamination risks and how to manage these. However, this consumer group already tends to be highly active in managing their exposure risk and are already likely to be engaging with restaurants staff to assess the safe handling of non-gluten containing foods.

For this proactive and educated consumer group, NCGI statements do not provide the additional detail required and thus provide limited additional value beyond offering a reminder for consumers to ask for this detail from staff. This mild benefit is counteracted by a sense that NCGI statements are not for consumer benefit at all - but rather to help food businesses avoid legal repercussions in the case of accidental customer harm.

More concerningly, NCGI statements are often misinterpreted by coeliac consumers - particularly those who are less knowledgeable about cross-contamination risks overall - in ways that may actually increase exposure risk. This research, whilst based on a limited sample size, strongly suggests that less knowledgeable coeliac consumers are more likely to interpret NCGI notices as essentially equivalent as

'gluten free'. NCGI statements may thus be currently leading to increased risk of harm for some coeliac consumers.

For both more and less knowledgeable coeliac consumers, the most useful element of NCGI seems to be business provision of additional information about cross-contamination risk management - rather than the NCGI 'statement' itself.

To minimise risk of harm to coeliac consumers and support informed and safe decision making in future, future adjustments to NCGI regulation and guidance should:

1. Adjust NCGI wording to minimise risk of confusion, ideally via direct testing and/or co-creation with consumers, avoiding the 'non-gluten containing ingredients' phrasing.
2. Encourage businesses to provide information about gluten cross contamination management within the business beyond the NCGI statement itself - both to ensure informed decision making and to support ongoing education of coeliac consumers
3. Ensure that NCGI statements and additional cross-contamination information provided follows the '5 Cs' of allergen communication: providing clarity - consistency - care - cognitive load reduction - and being clear on the intended community for messaging.

## 7. Appendix

### 7.1. Participant Sample Details

#### **Total sample: 15 participants**

- Location: 7 England; 4 Wales; 4 Northern Ireland
- Areas: 5 Urban; 5 Sub-urban; 5 Rural
- Type: 11 Clinical diagnosis; 4 Child with clinical diagnosis
- Ethnicity: 11 White British; 4 Ethnic Minority
- SEG: 7 ABC1; 8 C2DE
- Education: 7 Higher education; 8 No higher education
- Age: 3 ages 18-24; 4 ages 25-44; 5 ages 45-60; 3 ages 60+

### 7.2. Topic Guides and Materials: Pre-Task Introductory Email

#### **Introductory participant instructions by email**

Welcome to the research!

Thank you so much for being willing to spend some time with us exploring gluten allergen labelling in the UK. We are really looking forward to getting to know you and hear your views at the upcoming group discussion.

Before we all meet, we are eager to learn a bit more about you, and to get your early thoughts about a very specific type of gluten labelling you might have seen before (or you might not!). We'd like to hear a bit about your experiences and thoughts with this kind of labelling before the group, which should make it easier to talk about together.

#### **You will be completing two tasks**

You'll be using the FieldNotes app to complete the tasks. Each task should take around 15 minutes to complete.

#### **Task 1: Talking about an example of gluten labelling you find confusing.**

We'd like you to upload a photo of a gluten label you find confusing in some way, and then talk us through it. It would be helpful to know some of the following:

- Where have you found this label? (e.g. supermarket, home cupboard, café menu?)
- How often do you tend to come across labels like this when you are checking products for gluten?
- What does this label mean to you?
- Why did you select this as a label that is confusing?
- How do you feel, reading this label?



- What does this mean for the choices you might make about eating or buying it?

**Task 2: Let us know if you have ever seen ‘no gluten containing ingredients’ or ‘non gluten’ menus, and what you think about those.**

You may have seen menus that say ‘no gluten containing ingredients’ or ‘non gluten’. We’d love to know what you think about them.

First, you’ll tell us if you’ve seen this kind of information before and what you thought about it.

Second, we’ll show you a few examples and get your thoughts.

It would be helpful to know some of the following:

- Do you remember ever having seen menus with this kind of labelling? When and where?
- What does this language mean to you?
- Does a ‘no gluten containing ingredients’ or ‘no gluten’ menu feel the same as ‘gluten free’?
- If you see a menu like this, would you assume that it was 100% certain the dishes didn’t contain gluten?

**How does Field Notes work?**

Our easy to use platform, Field Notes, will help you easily capture video and photos to complete the task, which are then securely stored for our team to review. To get started, simply click this link. Then just follow the task instructions.

Most people find you stop thinking about the camera pretty quickly! But if using video makes you uncomfortable, just get in touch with the team, who can help you complete the task using audio and photos only.

If you need any help, just get in touch on <email>.

**7.3. Topic Guides and Materials: Pre-Task (Field Notes App)**

**Introduction**

Welcome! Each task should take less than 15 minutes.

Please refer to the task instructions in your email to check the kinds of things we’d like you to talk about in each task.

If you prefer not to answer by video just let us know.

**Task 1: Talking about a gluten label you find confusing**

Please upload a photo of a gluten label you find confusing. <photo upload>

Now, tell us about what you think and do when you see this label: what does it mean to you and why is it confusing? <video or text response>

## **Task 2: Talking about ‘no gluten’ menus**

Have you ever seen a ‘no gluten containing ingredients’ menu or ‘no gluten’ menu?

Where and when was this, and what did it mean to you? Was it clear? <video or text response>

Here is an example of a ‘no gluten containing ingredients’ or ‘no gluten’ menu. Please take a look and tell us what you think. What do these phrases mean to you? Would it mean the same thing as ‘gluten free’?

<Image redacted for food business privacy>

## **7.4. NCGI Consumer Workshops**

### **Moderator Introduction**

This guide is intended to be used flexibly for sessions – serving as an aide memoire rather than detailed agenda or questioning guide.

Each moderator will review participants’ completed tasks before moderating this workshop. Please tailor your questioning to mirror the issues, challenges, interpretations etc that you’ve seen emerging in participants tasks. We are particularly interested in places where labelling is causing confusion or concern, and the impact of this – so please do bring any instances of this that you’ve noticed from the pre-task into the sessions.

As always, we follow the energy, insights and views of participants in our conversations. Use the guide to check that we have roughly covered all areas, but spend time according to what is most useful in the session and conversation in front of you in that moment.

Some sections will thus be covered in more depth in one workshop than others, and may take a different order/approach and that’s ok - we’ll cover everything across the set of workshops for this audience. Please check in with the research team after your session and let everyone know what was covered in most/least depth, what new questions or clarifications we should explore in remaining sessions, and any adjustments you think need to be made to the approach if needed.

Do note the language that participants use as they explore and understand NCGI labelling. Are there places where participant language could be modelled in labelling or consumer education materials?

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### **Introductions and Welcome: 6.30 – 6.35 pm**

*Purpose: to set the stage for discussion, remind participants of their rights, provide reassurance and the opportunity to ask questions and confirm consent*

**Welcome:** Thank you all so much for joining us today and giving us some of your valuable time to be a part of this.

My name is XX, and I work for an independent research agency that is conducting some research on behalf of the Food Standards Agency (FSA).

The Food Standards Agency is the bit of Government that is responsible for making sure that food is safe, and that food is what it says it is.

They are really interested in how the UK public use and understand labels that provide information about allergens, and this project specifically is about understanding something called 'no gluten containing ingredients' notices, which is the kind of notice we had you explore as part of your pre-task.

Today, we're talking to folks with coeliac disease, or people who are shopping on behalf of folks with coeliac disease. So you're in a friendly crowd that probably understands some of the challenges you might face when shopping!

We know that's only one of many kinds of gluten labelling you might come across in your day to day life. We'll talk about others too, but our main job today is to explore your thoughts on that 'no gluten containing ingredients' labelling. So our apologies in advance if we do keep coming back to that today!

**Explain:** After completing the pre-tasks, we're now keen to hear a bit further about some of your own individual experiences. We are keen to hear more about your views, experiences and also what you want from businesses and the Food Standards Agency in this space.

**IF FSA PRESENT:** We actually have a colleague from the FSA here today to listen in, because they know the best way to listen to the public is to actually be in the room to listen! X, can you wave and introduce yourself?

**Reassure them:** We are just seeking their experiences and views – there are no right or wrong answers! Don't worry if this is something you've never thought about, or something you have really strong views about. Don't worry if you feel really confident about allergen labelling, or if it's something that frustrates and confuses you.

It's also really important that you can feel free to be honest, and that you know that nothing you say will offend us. We've seen in the pre-tasks that everyone has different experiences around this, and that's totally ok – the whole point is that if any of you have frustrations or concerns, others will too, and we want to hear about those so that we can make it better.

**(Re)explain their rights.** There are strict regulations regarding data protection, and we take these very seriously. We hold your details securely, anonymise what you share with us, and delete all identifying information once the report from this work is public.

The session will be recorded and used for our notes only, but we don't share full transcripts with FSA and can take comments 'off record' at any time.

We will be writing a report, but your name will never be included, and no one will know that they have taken part. All data, including the recordings, are destroyed after a period of time. Your videos will only be used in the report if you told us in the consent form that this was ok with you.

Only answer questions you are comfortable with, and only share what you are happy to share. We know that food can be an emotional subject for some people, so we'll go at whatever pace feels comfortable today and follow your lead.

Your comfort is so important to us, so just do what feels right for you. If you need a break, take a break, if you need the bathroom just go, if you want to stop you just let us know.

### **Check if they have any questions for us? Confirm permission to record**

*Note to moderators: adjust your questioning throughout based on the level of comfort you're getting from participants. Feel free to use projectives and less direct methods wherever it feels necessary to go softer. Do watch for emotional moments and ensure that participants are cared for.*

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### **Group introductions and hand signals introductions: 6.35 – 6.45 pm**

*Purpose: to help warm up participants, get an early check on participant dynamics, and introduce hand signals for use in the remainder of the session*

**Group introductions:** Great. To get us started, let's get to know each other a little bit. I'd love you all to introduce yourselves using:

- Your name and your pronouns if you'd like to share them
- Who lives in your household
- Who in the household is coeliac and when they found out

Moderator to model an introduction, including pronouns, then invite participants to introduce themselves one by one

Lovely, great to get to know you. Before we get started, I also want to introduce a tool we'll be using today which helps us all sense how people are feeling and what they are thinking, which is a little bit harder when we're all working remotely like we are today.

We're going to use some hand signals to help us do that. So if you hear something you agree with that really resonates with you, use a thumbs up. If you hear something and you have a really different view, or it doesn't quite resonate with you, use a waggle hand. If you want to share your view on something, put your hand up.

Hands up is pretty obvious, but let's try out our thumbs up and waggle hands. So what would you say if I said....

I love the weather where I live today  
Food isn't that interesting or important to me  
It's really easy to figure out if foods might contain gluten...

Great you've got the hand of it. Let's go.

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### **Living with coeliac: blob tree discussion: 6.45 – 7.05 pm**

*Purpose: to explore the real life context of living with coeliac for our participants, using a projective technique that elicits more honest feedback with minimal vulnerability.*

So one thing we tend to hear when we talk to people about allergies is that living with allergies means lots of different things to different people. I'd love to hear a little bit about what that means for you all as people who are coeliac and have to be careful about gluten.

To help us talk about it, we're going to use this lovely **blob tree**. I'd like you to find one or two images on this blob tree that resonates with you about what it's like for you and the people you share your home with.

Put your **hand up** when you've found one or two that speak to you and we'll talk about them.

*Moderator to share screen with [blob tree image](#).*

**Moderator to let participants talk through their picks, exploring what they feel and why, and encouraging other participants to use hand signals to indicate when something resonates.**

#### **Probe to understand:**

- How confident do people feel currently about avoiding gluten?
- When/in what situations are people likely to feel more or less comfortable around gluten information provided?
- What is making it harder for people to live with and navigate coeliac

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### **Using NCGI and other gluten labelling: overview responses - 7:05 – 7:30**

*Purpose: to explore experiences of using NCGI labelling, what is working more and less well for them, and immediate understandings and interpretations of NCGI. We'll get gut reactions here.*

So before this session all of you did a pre-task to help us understand what it was like to use gluten notices in real life. I'm going to show you a little bit of what that was like for everyone in a moment, but first I'm going to ask you a few questions I'm most curious about. Please do use those hand signals if you hear something that resonates!

- In the first task, which kinds of gluten notices or labels really stood out to you as confusing?
- In the second task, how many of you recognised the 'no gluten containing ingredients' notices we talked about?
- For folks that put their hand up:
  - What did those notices mean to you? Either from the task, or from past experiences?
  - How useful you have found those notices in the past?
  - What if anything has been confusing about those notices for you?

Great. We'll talk more about all of that in a minute. First, I just want to play a very short video that shows a bit of how you found it when you were trying to use the labelling in real life.

I'm going to ask you to use those hand signals again please. If someone shares an experience that really resonates with you give me a big thumbs up.

### **Moderator to show short video.**

What resonated for you all there? Did anyone have experiences that you've had too? Does anyone actually have new questions now that they've seen how other participants use or interpret those labels?

### **To explore a few examples from the group, briefly probing to understand:**

- What's working well/less well about NCGI labelling for most participants
- Any points of confusion/misinterpretation/worry/challenge
- Impact of this on behaviour (e.g. not purchasing, double-checking, asking for more information, etc) and emotion (confidence, worry, confusion, etc.)
- Moderators to listen out for and note any points of misinterpretation at this point but not directly challenge.
- Moderator to then select an example of NCGI labelling that felt clear to participants and had a fairly agreed definition.

One thing that I'd like to understand is how these labels compare to other labels that talk about gluten in foods. We're going to do a side by side comparisons to see which label feels clearest to you, which label feels 'stricter' in terms of gluten

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### **Regulator and business perspectives: 7:30-7:55**

*Purpose: to explore consumers assumptions about NCGI business and regulatory intent. We want to identify any disconnect between assumptions around regulation and business action and what is happening in practice.*

So far, we've mostly been talking about these labels as if you just saw them in everyday life – because it matters a lot to the FSA whether everyday consumers can actually use this information and find it helpful and clear.

But I want to flip this around for a minute and ask you to think about this not as a consumer, but in terms of why regulators might use this, and what you think businesses are doing to use these notices.

What do you think the **regulator** is trying to do with these NCGI notices?

- What is the purpose of their use?
- What are they hoping these notices communicate to customers?
- What do you think they expect of businesses when using these notices?
- Do you think that what the regulator intends is working? Does it help protect consumers? Does it help them feel confident making food choices?

And what about **businesses**?

- What do you think businesses see as the 'point' of NCGI notices?
- What do you think businesses' motivation is for using these notices?
- What do you think they have to do in practice before they can use notices like this?
- What would you HOPE businesses do in practice before they can use labels like this?

**Moderator to then provide clarification about how NCGI currently works in practice. EG that they are used to indicate foods whose ingredients aren't in themselves gluten containing ingredients – but they do not make any claims that the product in itself is 100% gluten free.**

- Are there any surprises here?
- What are your feelings about this?
- Knowing this, does it change anything about how you feel about NCGI notices?
- Knowing this, does it change anything about how you would use them?

So, the FSA is really interested in your ideas about how to make things better. In fact, we're going to do a whole set of research sessions just on that, based on what you all have shared with us today. But we'd love to hear your ideas too:

- What if anything would they like to see happen to make NCGI clearer, more useful, or increase their confidence in use?
- Changes to notice wording?
- Changes to when they are used?
- Changes to what businesses need to do before using NCGI notices?
- Other consumer education that they would want provided?
- What else?

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**Close: 7.55 – 8:00**

Thank you all for your time again this evening and over the course of this session. It's been a pleasure to meet you and have the opportunity to hear your thoughts on this important subject.

Is there anything else that people haven't had a chance to say that they'd like to share, or any final questions for me?

Before we go I just wanted to invite our colleague from the Food Standards Agency to say a few words.

**FSA representative to thank and highlight next steps.**

**Moderator to reiterate confidentiality points, thank and close.**

Thanks again everyone and have a great evening.