

Consumer understanding of new labelling terms for foods marketed for people with gluten intolerance

Qualitative Research
with Consumers and Health Professionals

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Administrative Information

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II About this Report

This report refers to coeliacs in the main body of the text and within quote annotations. It should be noted that for the purposes of this report coeliacs included those who had been clinically diagnosed with coeliac disease and those who were non-clinically diagnosed, that is those that considered themselves gluten intolerant and followed a gluten-free diet, but had not been medically tested for the disease. Where there are differences in the report, these are highlighted. The quotes from coeliacs in the report are from diagnosed coeliacs unless otherwise indicated.

III Executive Summary

Project Approach

- The purpose of this research was to explore reactions towards the new EU labelling legislation with regard to labelling on products marketed to individuals who follow a gluten-free diet, that is 'Gluten-Free' for foods which contain less than 20 parts per million gluten and 'Very Low Gluten' for foods containing cereal ingredients that have been treated to reduce their gluten content and which will contain less than 100 parts per million gluten. This was in order to understand how effective these labelling terms will be, any issues related towards them and how best to communicate these changes when they come into place.
- In order to assess this, the research also sought to understand current strategies used by coeliacs, that is, the labels and information used to make informed food choices.
- A qualitative approach was used and involved group discussions (with 3-7 respondents), paired depth interviews and face to face depth interviews with the target audience. In addition, depth interviews were conducted with various Health Professionals (HP). A further two telephone interviews took place with Coeliac UK telephone advisors. The discussion groups, paired depth interviews and face to face interviews were conducted with adults who had either been clinically diagnosed with coeliac disease (majority of sample) or non-clinically diagnosed, that is those who considered themselves gluten intolerant and were buying gluten-free products or had been advised that they may be gluten intolerant by their GP. The sample also included parents who had children with coeliac disease and who bought food for them. The research was conducted in March and April 2009.

Key Findings

Information Sources

- A wide range of information sources were being used and accessed to understand which foods are suitable for consumption, with Coeliac UK and its various support materials (for example, the Food and Drink Directory) being predominant and a key trusted source for many members. Dietitians were also considered an effective resource especially at the point of diagnosis. Beyond this, the Internet also served to provide access to additional information, for example, manufacturers and supermarkets websites. Word of mouth and relevant literature was also being used by respondents.
- There was little or no evidence of the Food Standards Agency (FSA) being used as a source of information by those in the sample. It was either not readily considered or if it had been it was perceived that it would not offer specific enough information on their condition.

Making appropriate food choices

- Respondents admitted that on initial diagnosis purchasing appropriate foods was confusing, time-consuming and laborious due to the need to continually check food labels and ingredient lists and familiarise themselves with what the terms and what was or was not appropriate. Over time, however, most had become more familiar with labels and the products that were appropriate for them to buy and as such had found strategies to self manage their shopping habits, for example purchasing from 'free-from' aisles, using Coeliac UK Food and Drink Directory, or checking labels. That said, some still remained particularly anxious about what they were buying, despite the labels, and required greater reassurance through a process of cross-checking several indicators relating to product composition (for example, labels, suitability statements, ingredient lists and so on).
- The key area of confusion, and therefore purchases requiring additional care tended to be in identifying suitable foods that are not specifically labelled and marketed as gluten-free, which, if unfamiliar, can require additional checking and interpretation of the ingredients list. It was in purchasing these products that mistakes were occasionally made. It was typically found, however, that if there was any doubt as to suitability then these items would not be consumed.

Current Perception of 'gluten-free' Label

- An important context to understanding reactions to the new labels was that aside from the majority of dietitians (included as part of the health professional sample), there was a general assumption from the majority of the other sample (consumer and Health Professional sample) that existing 'gluten-free' products do not contain any gluten at all. The label had been generally taken at face value and understood by consumers to mean they would not consume any gluten when purchasing these products. Indeed, there was no real understanding of the potential risks associated with foods labelled prior to this legislation and therefore no real understanding of the need to introduce a change. This current understanding is also important to consider when communicating the changes in levels of gluten in relation to the new labels.

Reaction to new labels and descriptions

- Reaction to the new label '*gluten-free*' as a standalone was generally accepted, with the assumption that this would mean (as they assumed previously) that this product would not include any gluten. Further explanation of its gluten content (20ppm) although small did raise concerns with the sample because of their position of understanding that it currently contained no gluten, although they were generally reassured once they heard that it would be suitable for most.
- '*Very Low Gluten*' as a label was less straightforward for nearly all, as it was seen as requiring a judgement as to whether a product displaying this claim was suitable or not for them and their child. This caused anxiety amongst most of the sample who felt that rather than take the risk, they would avoid these products.

Key Recommendations

- Given the lack of awareness about the current levels of gluten included in products labelled as 'gluten-free', it will be important to set the context and provide the rationale for the change. For example:
 - previously gluten-free claims were used on products that could contain up to 200 parts per million of gluten;
 - this level has now been recognised as too high for some individuals and consumption of significant amounts of such foods may have serious long term health implications;
 - changes have been made to help protect consumers and enable them to make safer and more informed choices;
 - what does this mean to the consumer when purchasing gluten-free foods, for example what do they need to look for, what will be included or not?
- For '*Very Low Gluten*' products additional support and guidance may also be required, for example to explain that it still has less gluten than previously on gluten-free products and therefore may well still be suitable. Further an additional symbol to indicate suitability for many coeliacs may also be helpful.
- A number of key channels appeared important to communicate the changes in food labelling amongst people with coeliac disease. A dedicated leaflet or section on the FSA and Coeliac UK websites is likely to be most useful to explain and inform consumers about the changes and reasons behind them, and this could be delivered through the following channels:
 - **Coeliac UK**, is likely to be a very helpful partner in communicating changes in food labelling legislation as many members trust the information that they provide;
 - **Dietitians**, will be helpful to reach newly diagnosed or those that they see at their check-ups;
 - Information at **point of purchase** for example within the 'free-from' aisle is also worth consideration to reach the broad range of those that purchase gluten-free products;
 - **Health settings** for example pharmacists also could be included as a useful point of contact with those receiving prescription foods. However, this is likely to be to a limited audience;
 - The **FSA** currently has low visibility for both parents of those with coeliac disease and coeliacs in this area. However, most parents and coeliacs were open to receiving information from the FSA, therefore the FSA could help support the dissemination of information through the above channels, as well as provide information of its own.

IV Introduction

A. Background

Gluten intolerance, which is usually known as coeliac disease, is a condition whereby individuals suffer from a serious, lifelong autoimmune disease, which is triggered by the consumption of the protein gluten. This protein is found in cereals such as wheat, rye and barley. These people can experience a range of symptoms every time they eat foods containing the protein gluten. Whilst most can tolerate a very low level of gluten in their diet, the sensitivity may vary between individuals. Thus, not everyone experiences exactly the same symptoms or to the same degree. It is recognised that when individuals with coeliac disease eat foods containing gluten, that it damages the lining of the small intestine and stops the body from absorbing essential nutrients. Although most people with coeliac disease can tolerate very small amounts in their diet, continued consumption, over a sustained period of time, can result in detrimental effects on long term health for example osteoporosis, anaemia.

Most people with coeliac disease manage their condition by avoiding foods containing gluten. This generally consists of eliminating products containing wheat from their diet. However, wheat is the basis of a range of commonly consumed foods, such as bread, pastas, pizzas, pastries, cakes, biscuits, etc.; therefore, a diet free of gluten generally results in the elimination of a significant number of staple foods from the diet.

There are many foods that naturally do not contain gluten, such as fruit, vegetables and unprocessed meat and fish. Rice, potatoes and corn are all gluten-free and are good sources of starchy carbohydrate. In some cases products containing naturally gluten-free ingredients signpost the absence of gluten – either directly on the packaging or by listing their product in directories of products suitable for people with coeliac disease. In addition to this, there is currently a range of food products specifically manufactured for people with coeliac disease in which the level of gluten has been reduced or eliminated. The number of foods marketed to people with coeliac disease is increasing rapidly to fulfil the growing demand for these products. This elimination/reduction of gluten is achieved in a number of different ways. Some products have been reformulated to remove the gluten-containing ingredients or to include substitute ingredients i.e. the gluten-containing cereal is replaced by a cereal ingredient which does not contain gluten, such as maize or rice flour. Such products may still have very low levels of gluten, which may be present as a result of cross-contamination at some point in the food chain.

Other products include gluten-containing cereals that have been specially processed to remove the gluten (for example codex wheat starch) and usually contain a slightly higher residual level of gluten than the other range of substitute products made from naturally gluten-free cereals. However, due to technological constraints it is not possible currently to eliminate gluten altogether from all specially formulated foods, and in some cases it is necessary to include a low level of wheat starch in order to maintain the consistency and/or texture of the staple food products for example breads.

In addition, clinically diagnosed coeliacs can obtain a limited number of staple gluten-free products on prescription.

Before January 2009, there was no specific UK legislation to control the level of gluten present in these foods marketed for people with coeliac disease and as a consequence the amount of gluten could vary significantly, creating uncertainty and potential confusion for the consumer. Prior to the publication of EU legislation (see page 12), manufacturers followed the Codex Standard, which suggested that foods marketed for people with coeliac disease, should contain no more than 200ppm of gluten in them. Manufacturers used this level to signpost suitability for coeliacs on the packaging of pre-packed foods. However, more recent evidence has suggested that this level is not sufficiently protective for all coeliacs.

It was therefore agreed that it was important to define labelling terms and set limits for the amount of gluten permissible in these products marketed for people with coeliac disease. It was considered that this would provide consumers with the information they need to differentiate between the different types of products marketed for people trying to control their gluten intake; so that they could make informed choices and manage their condition effectively.

The introduction of the new EU legislation in January 2009, (which applies from 1 January 2012), will ensure that the labelling, advertising and presentation of all foods marketed for individuals with coeliac disease, use the same phrases to indicate their suitability. From this date only two labelling terms will be allowed to indicate the level of gluten on the product. The claim 'gluten-free' may be used for products which have less than 20 parts per million of gluten and the claim 'very low gluten' will be allowed for products which use a cereal ingredient that has been treated to reduce its gluten content (for example codex wheat starch) and contain gluten at levels less than 100 parts per million. This process of standardisation is intended to improve consumer health, enabling people with coeliac disease to identify with confidence foods which are suitable for their condition.

The FSA will need to ensure that these new labelling terms relating to gluten levels in foods are effectively understood by consumers, and wanted to know how to effectively communicate to consumers the meaning of the new terms and how they could be used to make safe food choices to manage their condition.

The purpose of this research was to explore both Health Professionals' and consumers' understanding of the new labelling terms and to identify the most suitable and effective way to inform the target audience about the new legislation.

B. Research Objectives

The main objective of the research was:

To explore how to effectively communicate to consumers the meaning of the new terms relating to gluten levels in foods, and how they should be used by gluten intolerant consumers to help them make safe food choices; also, to determine how this information should be disseminated effectively.

To deliver this overall objective, the research specifically needed to:

- Explore the sources of information used by gluten-intolerant consumers to enable them to choose foods that are suitable for them to eat, and more specifically to:
 - Examine which sources consumers and Health Professionals use for information about suitable foods, and reasons for use:
 - understand how they obtain this information and any formats/channels that are preferred;
 - explore any differences in usage across audience types (for example differences by severity of condition).
 - Explore what are currently deemed the most and least useful methods or models for food labelling in relation to gluten content:
 - understand what are the areas of confusion/lack of comprehension, versus clarity and comprehension;
 - assess what system or method currently works best (in their opinion) and why;
 - explore if there is an 'ideal' system or method of indicating gluten content, and what this might be.
 - Assess the awareness of consumers and Health Professionals of either previous practice or the new legislation in relation to food labelling for gluten content, and what is the source of any information which they have:
 - understand, if relevant, what the views of both audiences on current legislation and practice are, and how this affects food choices for coeliacs/those with gluten intolerance.

- Explore consumer understanding of the meaning of the two new labelling terms and whether these terms alone are sufficient to enable informed and safe food choices:
 - o Ascertain how these terms are interpreted and what they are understood to mean.
 - o Explore how consumers and Health Professionals rate these terms across various factors:
 - ease of understanding - are consumers aware that they can still safely eat products labelled as 'very low gluten'?
 - degree of reassurance provided;
 - advantages/disadvantages;
 - any need for additional information (for example 'suitable for Coeliacs' or the Crossed Grain symbol)?
 - o Understand how the new terms compare with current labelling terms and methods:
 - extent of improvement to aid decision making.
- Investigate the best potential methods, routes and formats for informing consumers about the changes in legislation, and explaining how this will affect the labels on pre-packed foods:
 - o Understand who/which might be the most authoritative, credible, reliable and trusted source(s) for information dissemination and why.
 - o Referring back to current information sources and delivery methods, to understand whether these would still be the preferred routes and formats for this new information.

C. Method and Sample

Method

A qualitative research approach was considered to be most appropriate to meet the objectives of this project. This approach enabled an in-depth exploration of current knowledge levels, attitudes and behaviours in relation to food shopping and label reading. It also allowed the researchers to understand the nuances between the labelling options and to understand how they affected the target audience.

The research consisted of a combination of different methods amongst three types of audience: the target audience (coeliacs/parents of those with coeliac disease), Health Professional audience and those working at Coeliac UK¹. A brief description of the sample and method for each of these audiences are described below. More detail can be found in Appendix 1.

¹ Coeliac UK (www.coeliac.org.uk) is a UK charity for people with coeliac disease. It provides members with information about the disease, a Food and Drink Directory which lists products that are safe to eat, subscription to a magazine and email updates about foods that are safe to eat as well as supporting local members groups around the UK.

Target Audience - Coeliacs (diagnosed and undiagnosed) and parents of those with coeliac disease

Sample and Method:

The method included 9 group discussions (with 3-7 respondents, typically 5 respondents per session), 2 paired depth interviews, 11 face to face depth interviews and one telephone depth interview. Each session lasted for 90 minutes.

The sample included a mix of adults who were either clinically diagnosed with coeliac disease, or non-clinically diagnosed, that is, considered themselves gluten intolerant and avoided gluten in their diet or had been advised by their GP that they may be gluten intolerant but had not been tested. The sample also included parents of children with coeliac disease for whom they bought gluten-free products and who managed their children's diet. All respondents were buying 'gluten-free' products.

A spread of different types of respondent was also included in the sample. These included a mix of those more recently diagnosed and those that were long term diagnosed; a range of ages of adults, a mix of male and female. Within the sample there was also a mix of those who were members of the Coeliac UK charity (a supportive charity for those with coeliac disease) and those who were not. The interviews and research sessions were conducted across the UK in England, Northern Ireland, Scotland and Wales.

Prior to attending the sessions, all respondents were asked to complete a food diary pre-task (see Appendix 4) to allow them to record the types of products they bought and ate over a 3 day period.

The face to face depth interviews were held 'in home' to allow moderators to view the types of foods purchased and how these were determined to be suitable or not, for example via labels, etc. These interviews were also followed by an accompanied shopping trip with the respondent, allowing an insight into how choices were made within a supermarket context.

Health Professionals:

10 depth interviews, each an hour long, were conducted with Health Professionals. These consisted of 5 face to face interviews and 5 telephone interviews. The breakdown of the types of Health Professionals included 6 Dietitians, 1 GP, 1 Pharmacist and 2 Practice Nurses, the emphasis being on the dietitians as they had the most involvement in advising and guiding coeliacs. These interviews were also conducted across the UK.

Coeliac UK helpline staff:

2 telephone interviews were also conducted with Coeliac UK helpline staff in order to understand the types of concerns and confusions that their members had.

Recruitment

Two methods were used to recruit respondents for the consumer sample. Many were free-found by recruiters, that is, recruiters used their contacts and the people they knew to find suitable respondents. In addition, respondents were found with the help of Coeliac UK and their local network of support groups around the country. On these occasions the local group leaders were contacted by Coeliac UK and their members were invited to contact Define if they were interested in taking part in the research.

Respondents were offered and given a monetary incentive to encourage participation, for completing the pre-task prior to being interviewed and for attending the research session.

Fieldwork Locations and Timings

Fieldwork took place in England (Leeds, Birmingham, and London), Wales (Swansea and Bridgend), Northern Ireland (Belfast and Londonderry) and Scotland (Glasgow and Edinburgh).

The Define Research team comprised of Victoria Page, Elodie Le Roux, Jules Kelly, Jill Swindells and Lucy Bush.

Fieldwork was conducted from the 12th of March to the 29th of April 2009.

For further detail on the method, sample and rationale for this research, please see Appendix 1.

D. Analysis

Below outlines our approach to the analysis of the findings.

At the fieldwork stage the research sessions were recorded where it was permitted and/or notes were taken through the session. The executives then listened back to the recording or worked through their notes taken in the sessions to create a set of notes and verbatims. The food diaries were also read through to understand responses.

An internal debriefing session took place with the research team to discuss findings and from this session notes were drawn up which highlight key findings. These were then distilled into a draft presentation, using the interview notes and to verify any detailed points but also to bring to life points via verbatims that have been raised by the respondents. Prior to the final presentation any additional points of clarification were then also discussed with the team.

V Detailed Findings

1. Sources of Information Used

Both coeliacs and parents of coeliacs in the sample tended to use a wide range of information sources to understand their condition. Some of these channels of information were also used in the day-to-day management of their condition, to make informed food choices and purchase suitable food products.

Dietitians and Coeliac UK appeared to be two key sources of information for those clinically diagnosed with coeliac disease. Additional sources of information, for example the Internet, word of mouth, books and magazines, gluten-free food manufacturers, health food shops, and supermarkets were also used by a broader range of individuals.

1.1 Key Sources of Information

1.1.1 Dietitians

For those clinically diagnosed with coeliac disease or with children clinically diagnosed, dietitians were generally the key source of information on how to manage their condition and make suitable food choices. This primarily occurred at the point of diagnosis and for some through their check-ups (annual or once every two years) rather than a more frequent basis.

“I got an awful lot of information from my dietitian...she gave me a list of manufacturers and a list of what I can and can't eat”

[Coeliac, Member, Leeds]

“The hospital dietitian has been wonderful. She gave me a good idea about foods on the market and she'd got packs of food you can buy. She directed me to Coeliac Society and forms to send off and that's how they got into contact”

[Coeliac, Member, Swansea]

At diagnosis, the information provided by dietitians was highly valued as it was felt to be credible, trustworthy and useful, and certainly for those more recently diagnosed there was still a strong reliance on the information provided by the dietitian. However over time, dietitians tend to become less involved with patients and only see them once a year or once every two years, at their review consultations. As a result, over time, the information provided by dietitians was felt by some to be less useful, and many felt they had become more knowledgeable about what foods are suitable for them personally and therefore needed little further guidance. Even for those most anxious, there was not necessarily a reliance on their dietitian, rather they came to rely on other sources, for example, Coeliac UK.

“Us, the sufferers – we are the experts”

[Coeliac, Member, Edinburgh]

Different types of information and support were provided by dietitians. These were consistently mentioned by both the end-users and dietitians themselves. The information provided to both dietitians and those with coeliac disease is outlined below:

Specific information on coeliac disease

This consisted of information about the nature, causes and symptoms of the condition. Some dietitians were relying on specific leaflets provided by the NHS to deliver this information to their patients.

Information on suitable foods to manage coeliac disease

Dietitians were felt to play an important role in informing patients on how to select appropriate food to manage a gluten-free diet. They generally highlighted the range of naturally gluten-free foods that could be safely eaten. They also provided information on grain categorisation (for example helping them to identify gluten containing cereals like wheat, rye, barley etc.) and types of ingredient to avoid when purchasing processed food. In addition, they made both parents and coeliacs aware of the possibility of obtaining ‘gluten-free’ staple foods on prescription, but this was generally only at the time of being clinically diagnosed.

A list of gluten-free product manufacturers and food samples

Dietitians also provided patients with some lists of gluten-free manufacturers to help them purchase suitable food. Some were also receiving free products from the manufacturers and handed them out to their patients. This was felt to be a way of introducing newly diagnosed coeliacs to the range of food brands specifically designed for people with coeliac disease, for example, Glutafin and Juvela.

Signposting to Coeliac UK

Some of the dietitians interviewed encouraged people with coeliac disease to join and use Coeliac UK as a source of information. They directed them to the website and/or provided them with a registration form.

“I always try to promote joining Coeliac UK initially”

[Dietitian, Northern Ireland]

“A lot of people are on the internet so we tend to tell them to go to Coeliac UK because it is evidence based and you’ve got the right information there”

[Dietitian, Wales]

1.1.2 Coeliac UK

It is understood that around 80% of diagnosed coeliacs are members of Coeliac UK (from Coeliac UK). Coeliac UK as an organisation was highly recognised, valued and trusted by its members. It was perceived to have a real understanding of coeliac disease as a condition as well as understanding the impact this can have on an individual's life. Coeliac UK was highly relied upon to help make food choices and purchase suitable foods especially on first diagnosis. However, members often relied on them on a continuing basis. The information provided by Coeliac UK was felt to be extensive, accurate and practical, and it was seen to address the needs of both the newly diagnosed and the long term coeliac.

"I just find that the information I get from the Coeliac Society to be enough for me"
[Coeliac, Member, Glasgow]

Coeliac UK provides information through different channels and formats and the following provides perceptions of these elements:

Website

Coeliac UK website was readily used by younger members and was felt to offer comprehensive information as it covers a wide range of topics in great depth such as:

- coeliac condition
- suitable foods for coeliacs
- campaigns with government, food manufacturers and caterers
- updates on food classified as 'gluten-free'
- recalled foods

Food and Drink Directory

This Directory is published annually by Coeliac UK for members of the organisation. It provides a list of food and drink that are currently available, which are suitable for coeliacs. Monthly updates on additions and deletions of products from the Directory are also available online or through teletext.

"Every year you get a little pocket Directory from Coeliac UK, it's wonderful. You get it free if you're a member"
[Coeliac and Mother of a coeliac, Member, South Wales]

"We got straight onto Coeliac UK. They sent me the Food & Drink Directory"
[Parent, Member, Bridgend]

The Food and Drink Directory was broadly perceived as one of the most valuable sources of information and was often seen as a gold standard reference to purchase suitable food. As such, some members tended to purchase products only if they were referenced within the directory. Some also tended to take it with them each time they went food shopping.

"The other thing I rely heavily on is this food bible from the Coeliac Society"
[Coeliac, Member, Leeds]

"The CUK Directory is like our bible!"
[Coeliac, Member, Birmingham]

"Coeliac UK and the Food & Drink Directory when first diagnosed were crucial, as well as the quarterly magazine"
[Parent, Member, Bridgend]

The Food and Drink Directory was felt to be a key information source that provided great support to individuals, particularly at point of diagnosis. However, it tended to have less perceived value over time, as long-term coeliacs became more experienced and confident towards managing their diet.

"I used the Food & Drink Directory from Coeliac UK but as time has gone on; I tend to look at the labels"
[Parent, Member, Bridgend]

There were also some within the sample, who were less convinced of its usefulness and felt the classification within it was not user friendly and the information dated quickly, however this view was typically in the minority.

"It's too consuming, raking through this book (Food & Drink Directory) unless it's something I specifically want to know...then I'll not use it"
[Coeliac, Member, Edinburgh]

Crossed Grain Magazine

This quarterly magazine was highly valued by most Coeliac UK members. It was felt to provide useful information and advice such as recipes, recommendations on restaurants, airlines and manufacturers as well as articles on labelling legislation.

"What I get from them is information in a practical and professional way"
[Coeliac, Member, Leeds]

eXG-newsletters

These electronic newsletters, which provide information and updates from Coeliac UK, were used particularly amongst the younger respondents who felt more confident with online sources of information. They tended to rely on these emailed newsletters to remain updated about latest product additions and deletions from the Food and Drink Directory as well as other relevant news on their condition.

Local Coeliac UK groups

Coeliac UK has set up voluntary support groups across the country to provide local support to people with coeliac disease. These networks were generally felt to be particularly helpful allowing individuals, to share experiences and knowledge around gluten-free recipe ideas, suitable food choices and management of the condition. Some of these groups were accessed through the research and indicated that they held annual events, and invited manufacturers and supermarket representatives and/or organising cooking demonstrations.

“When I was early diagnosed I was introduced to somebody else who had the disease to help me along my way - she was far more informative than the dietician”

[Coeliac, Member, Leeds]

Coeliac UK Helpline/Email support

Coeliac UK also offers personalised help and support through advice line staff, who aim to address specific queries or concerns raised by members of the public; this can be through a telephone or email helpline. They provide general information on the condition as well as answering questions related to the gluten content of particular products. The view of respondents was that, generally, it was used as an ad-hoc source of information, this helpline/email support was well trusted and was felt to provide reassurance, especially amongst the most anxious coeliacs/ parents.

“We get a lot of calls from people who want to ask us specific questions about products”

[Advice Line Staff, Coeliac UK]

1.2 Additional Sources of Information

Additional sources of information also seemed to play an important role to support coeliacs in the day-to-day management of their condition. These were particularly useful for Coeliac UK non-members and self-diagnosed coeliacs. These two groups were less exposed to the information provided by dietitians and Coeliac UK and therefore relied on various other information sources. That said, members in the sample also often cited these as sources they referred to in addition to information from Coeliac UK.

1.2.1 Word of Mouth

Interactions with others (friends, relatives, colleagues or others), including internet forums, constituted a valuable source of information for many. It was perceived as helpful to share individual experiences, knowledge and advice about a range of issues relating to coeliac disease.

1.2.2 The Internet

For the more 'internet confident' in the sample, the internet was considered to provide an extensive source of information. It was regarded as a valuable resource to obtain general information about coeliac disease as well as practical advice to select and purchase suitable food.

Therefore, the internet was used in a variety of ways. Some refer frequently to blogs and interactive forums related to coeliac disease, some conducted key word searches through search engines (for example, Google) and others tended to visit gluten-free manufacturers' (for example Glutafin, Juvela) and retailers' websites (for example Sainsbury Special Diets).

"I went home and started Googling...I got in touch with Glutafin and Juvela, I got in touch with Coeliac UK and became a member"

[Coeliac, Member, Edinburgh]

By using search engines to research coeliac disease, many in the sample were signposted to Coeliac UK. Hence, some non-members and self-diagnosed coeliacs have also visited the Coeliac UK website to find out more information.

Aside from Coeliac UK, there was little evidence of other websites being heavily relied upon. Those that were mentioned included the BBC and websites from the USA for example glutenfreeliving.com.

1.2.3 Books and Magazines

Some respondents had used, or were using, books as an additional resource for information especially on first diagnosis. The book 'Me and my Tummy' targeted towards children was also mentioned by parents. Information in magazines also provided a useful top-up of information, with one respondent having self-diagnosed her gluten intolerance after reading a magazine article.

"I look in books about wheat, gluten, intolerances"

[Parent, Non-clinically diagnosed, Non-Member, London]

1.2.4 Gluten-Free Food Manufacturers

Some of the sample were directly seeking information from 'gluten-free' manufacturers (for example Juvela, Glutafin) through their websites or their helpline. These were generally felt useful to deliver specific information and updates on their food product composition as well as provide free samples of gluten-free food.

"I phone advice telephone numbers on the packet"

[Parent, Non-Member, South Wales]

"I wrote to all the gluten-free manufacturers and they sent me samples. I Googled the manufacturers and made a list"

[Parent, Member, Bridgend]

1.2.5 Health Food Shops

Health food shops, especially Independents, were valued by a few individuals in the sample, more typically self diagnosed non Coeliac UK members, and in contrast to supermarkets were felt to offer good advice on which items were suitable for those trying to avoid gluten. Staff members were generally felt to have good knowledge and understanding of the following issues/areas:

- the nature and symptoms of coeliac disease;
- the various grains' suitability for all types food intolerances;
- their range of products and their suitability for coeliacs.

1.2.6 Supermarkets

The provision of a list of gluten-free products provided by some supermarkets (for example Sainsburys) was thought useful by some consumers. Supermarkets, however, were generally not considered as a key information source. This stemmed from a perceived lack of knowledge about food intolerances amongst staff on the shop floor.

1.3 FSA as a Source of Information

1.3.1 Current Use of FSA as a Source of Information

The FSA was generally not consciously considered or used as a source of information for this sample. Whilst some may have come across the FSA website via an internet search engine, many claimed they had not specifically used or even considered it. The FSA was rarely signposted by Health Professionals and as such was not top of mind.

"I have never heard of this agency before [FSA] so I have never thought about seeking information there. My dietitian mentioned the Coeliac UK Society but I don't think she talked about the FSA"

[Coeliac, Member, Wales]

At a spontaneous level there was also a general assumption that the FSA was not necessarily appropriate to provide relevant information on this condition. This was underpinned by the overall perception that the FSA remit was on general food issues, for example, eating well or food scares rather than specific information on coeliac disease. When prompted, however, there were no apparent barriers to potentially using the FSA as a source of information.

Given its low consideration, new labelling information clearly needs to be disseminated far more widely than just through the FSA's own channels. The findings suggest a potential opportunity, however, to raise the profile of the FSA as a trusted and valid source via Coeliac UK and Health Professionals.

1.3.2 Reactions to Information Provided by the FSA

Fact sheet on food intolerance and coeliac disease

www.food.gov.uk/multimedia/pdfs/allergyfactsheetcoeliac0308.pdf

The fact sheet was deemed to be well laid-out and user-friendly. The overall language and style were also felt to be clear and straightforward. The information contained was felt to be particularly useful, especially for those newly diagnosed. This was for the following reasons:

- it provides extensive and comprehensive information about the nature, causes, and symptoms of coeliac disease;
- the information was delivered through a step-by-step approach from diagnosis to the daily management of the condition (for example making suitable food choices, buying suitable food).

“The fact sheet does look straightforward and when you read it, it is easy to understand”

[Coeliac, Self diagnosed, Non-Member, London]

Webpages – printouts tested

<http://www.eatwell.gov.uk/healthissues/foodintolerance/foodintolerancetypes/coeliacdisease/?lang=en>

The webpages on coeliac disease (within FSA Eatwell site) were felt to be less user-friendly (compared to the fact sheet) for the following reasons:

- they were generally perceived to be quite wordy and lengthy;
- the lay-out mainly consists of paragraphs of text, rather than broken up into sections;
- the language in parts could be seen as too technical for some which may hinder comprehension (for example the terms ‘part per million’).

However, when focusing on the content, most were engaged with the information provided and it was felt to be factual, relevant and interesting.

“The web pages are good but there is a lot of text to read. It could be better with sections, headlines and a few bullet points”

[Coeliac, Member, Wales]

Text Alert Messages

Respondents were asked if they had received text alerts from the FSA with regard to food recalls. Given the low consideration to the FSA within this sample, it was perhaps not surprising that none had signed up for this service. However, when probed, most engaged with the idea and believed it could be a potentially helpful way to get regular updates.

“This idea of text messages, that’s really interesting”

[Coeliac, Member, Edinburgh]

1.4 Role of Health Professionals

Aside from dietitians, who are a key source of information and advice, other Health Professionals are less used as sources of information, with GPs generally used initially and a few parents with younger children making reference to health visitors who had provided advice.

1.4.1 GPs

Aside from initial guidance, GPs were generally not felt to be a useful source of information for many diagnosed coeliacs in this sample.

“My GP didn’t know much about it”

[Coeliac, Member, Edinburgh]

“The doctor gave no advice. He had no idea”

[Parent, Member, South Wales]

This view was reflected by a GP who took part in the research who claimed he had low involvement in managing patients with coeliac disease. This was due to both a lack of time and resources and also limited knowledge in this area. Whilst the GP may suggest gluten intolerance and therefore coeliac disease as a cause for symptoms, the GP then plays the role of gatekeeper in referring patients to:

- hospital specialists for diagnosis (for example gastroenterologists);
- dietitians for information and symptoms management;
- nurses for ongoing issues and general information.

"I don't personally diagnose coeliac disease. If the patient experiences certain symptoms like abdominal bloating, diarrhoea or weight loss, I would refer him to a gastroenterologist who will make the diagnosis. I am not an expert in this area and I don't really have the time to seek information"
[GP, Scotland]

1.4.2 Practice Nurses

Amongst the coeliacs in the sample, there was little evidence of speaking to practice nurses to gain advice and information. The practice nurses included in the sample, however, were providing information to those with coeliac disease. They provided basic information and monitored symptoms and ongoing issues. These were typically:

- providing advice on diet, suitable food, products available on prescription;
- handing out printed pages from the Coeliac UK website;
- recommending patients to look at the ingredient list;
- encouraging to cook from scratch.

"I suggest to them to read the ingredient list and see if it contains flour, I also print the pages from Coeliac UK website. I also recommend cooking from scratch instead of buying ready-meals, casseroles etc..."
[Practice Nurse, Leeds]

1.4.3 Pharmacists

Pharmacists were not spontaneously suggested as source of information by the respondents. The pharmacist in the sample felt that most coeliacs have a good understanding of their condition and their individual needs. That said the pharmacist did signpost patients to Coeliac UK and advised them on gluten-free vitamins.

"We don't tend to advise them too much, it's more about deciding on products, on prescription with them and then ordering them in. I always try to promote Coeliac UK"
[Pharmacist, Wales]

2. Strategies and Approaches to Avoid Gluten

2.1 Individual Circumstances and Attitudes

Whilst most people with coeliac disease avoided gluten in their diet in order to manage their condition and their symptoms, different attitudes and strategies towards making food choices emerged. These were determined by 2 key factors:

- The severity of the condition and attitudes towards managing it; and
- Individual levels of confidence

The combination of these two factors impacted on individuals' attitudes and behaviours towards making food choices and food shopping.

2.1.1 Severity of Condition and Attitudes towards Managing it

There were various degrees of severity and sensitivity across the sample, with regard to coeliac disease. These are as follows:

Clinically diagnosed coeliacs (the majority of the sample)

Many of those diagnosed with coeliac disease claimed to experience strong and life affecting symptoms which were often immediate on consumption of any gluten. For this sample there was generally no sense of various degrees of severity of the condition, instead the degree of severity of their/their child's condition and associated symptoms was generally perceived to be high.

Given the high severity of symptoms experienced by this segment, the general attitude was to completely and consistently exclude gluten from their diet.

"You either have it or you don't ..it's not about severity."
[Coeliac, Member, Birmingham]

Clinically Diagnosed - Asymptomatic symptoms

Within those that had been clinically diagnosed, there were a handful of respondents who claimed that whilst they had been diagnosed, they did not experience immediate obvious symptoms by eating gluten, for example abdominal pain, vomiting, diarrhoea, etc. They were conscious that gluten caused the lining of their guts to be damaged and long term damage, for example one had been diagnosed with osteoporosis. For that reason they typically followed a gluten-free diet. Nevertheless, since they did not always experience direct manifestations due to gluten ingestion their approach towards avoiding gluten was sometimes less strict than those who experienced immediate symptoms.

Non Clinically Diagnosed

Within the sample, there was also some who were not clinically diagnosed but who had experienced negative symptoms and so considered themselves gluten intolerant and avoided gluten in their diet. This group included those that had concluded themselves that they were gluten intolerant (for example via the Internet, relatives they knew that had had it, magazine articles, health food shops) and had found that following a gluten-free diet helped them avoid the symptoms they had previously felt. As such they did not necessarily feel the need to seek additional help from medical professionals as they had felt that they managed their condition themselves. There were also a few within this group, who had sought initial advice from their GP, after experiencing negative symptoms, who had suggested they may be gluten intolerant. These respondents had since followed a gluten-free diet which they had found had relieved the symptoms but had not been subsequently clinically tested.

"My brother is a coeliac and I had the same sorts of symptoms so I just assumed that's what I had"

[Coeliac, Non-clinically diagnosed, Non-Member, Northern Ireland]

"I was getting all these terrible symptoms and then I read a magazine article about it and thought that's what my symptoms are, I'm gluten intolerant"

[Coeliac, Non-clinically diagnosed, Non-Member, Glasgow]

The majority of those non-clinically diagnosed and those in the sample who were asymptomatic, tended to avoid gluten all of the time. It appeared, however, that a few were less strict than those diagnosed and there were indications that a few did still consume gluten occasionally. This ranged from once a week to less often. For most it was the consumption of products which may have had 'smaller' elements of gluten in them (which they either had not checked thoroughly or assumed small enough not to have a great impact and were happy to take the risk or had not caused them noticeable problems in the past, for example chocolate, stock cubes) rather than those products with 'obvious' gluten in them, for example, breads and pasta. That said, one self-diagnosed respondent still had a pizza around every 6 months and suffered the consequences.

"When you look at the ingredients list, you see the list of additives and I tend to think what the heck"

[Coeliac, Member, Northern Ireland]

"This is quite new to me so I'm finding it difficult to be vigilant about reading the labels"

[Coeliac, Non-Member, Glasgow]

"You steer clear or take your chances!"

[Coeliac, Non-clinically diagnosed, Non-Member, Glasgow]

2.1.2 Individual Levels of Confidence

Variable levels of confidence in purchasing suitable products were observed across the sample. Whilst many were generally comfortable towards managing their condition and making suitable food choices, some were particularly apprehensive and anxious. These different levels of confidence tended to influence attitudes and behaviours towards making food choices and purchasing suitable products. Two main attitudes emerged: the 'anxious' and 'confident' segments.

Anxious

This group represented a minority of both parents of those with coeliac disease and coeliacs within the sample and these were typically those clinically diagnosed with coeliac disease. They also 'tended' to be, but not exclusively, more recently diagnosed coeliacs, who were often less familiar with being able to identify appropriate foods and were just beginning to understand labelling and what to look out for. In addition, they often had a very high sensitivity which raised their anxiety. This group were particularly anxious about managing their condition and unsure when making food choices. They were constantly concerned about absorbing gluten inadvertently for example, through cross-contamination, or being exposed to low levels of gluten. The existence of this group was reaffirmed by Coeliac UK advice line staff who commented that a proportion of their members were highly anxious.

"We will have people ringing one of us up and then ring back again to double check with someone else – they are so worried"

[Advice Line Staff, Coeliac UK]

Confident

The remaining sample were generally confident about making appropriate food choices. This segment represented both clinically and non-clinically diagnosed as well as members and non-members of Coeliac UK. Although there were degrees of confidence noted, for example, those who had been diagnosed longer tended to be more confident than those more newly diagnosed, most felt relatively confident about their strategies to avoid gluten and had high levels of trust in food manufacturers and the claims they used.

"We have to be confident otherwise we'd spend the whole time suffering"

[Coeliac, Member, Derry, Northern Ireland]

Thus, different approaches and strategies to avoid gluten emerged across the sample. These were generally determined by the degree of severity or perceived severity of the condition as well as personal levels of confidence toward making food choices. There was some correlation between these two factors, with the more anxious typically being

those that suffered severe symptoms and were diagnosed coeliacs. That said, there were those that also suffered severe symptoms, who were by their attitude more confident about choices.

2.2 Food Choices to Manage Coeliac Disease

Different strategies to maintain a gluten-free diet were employed by most coeliacs and parents. In the first instance, many were cooking from scratch and/or eating home-made food (for example home-made bread, pastries, cakes, soups) and obviously eating naturally gluten-free food (for example fruits, vegetables, fish, meat, etc). Clinically diagnosed or parents of children who have coeliac disease were also getting staple food on prescription (for example flour, bread, pizza base etc).

“We cook lots of fresh stuff, we read lots of labels and have bread on prescription. Eat lots of fruit and veg”

[Parent, Member, Bridgend]

“A lot choose more fresh ingredients to cook from scratch”

[Dietitian, Birmingham]

Many also included gluten-free processed food in their diet or the diet of their children. These were either specialist foods marketed as gluten-free (within the ‘free-from’² supermarket aisles) or other processed food outside the ‘free-from’ range, which were judged to be suitable or otherwise through checking through either labels, ingredient lists or Coeliac UK Food and Drink Directory.

Purchasing processed food which were not labelled clearly as ‘gluten-free’, that is they required the consumer to read the labels more carefully, were generally felt to be more difficult (and risky) as it requires a judgement on the claims on the labels which are not always straightforward. The remainder of this chapter will focus on how respondents made those choices.

2.3 Choosing ‘Processed’/Pre-prepared Food

When initially diagnosed, shopping for suitable packaged or pre-prepared food was reported to be time consuming and overwhelming. The lack of familiarity with reading labels made the process of food shopping particularly tedious, long-winded and stressful.

² ‘Free-from’ products is a term used to describe a specific range of food products within supermarkets that are specially produced and marketed to be ‘free-from’ the common allergens and ingredients that people have an intolerance towards, for example gluten, wheat, milk and egg.

Over time, however, most coeliacs or the parents of children with coeliac disease within the sample, adapted and developed various strategies to ease the process. These processes were not mutually exclusive, but included:

- Using the Coeliac UK Food and Drink Directory
- Choosing products from the 'free-from section' (this is a section in the supermarket which sells products specifically designed for people with food intolerances)
- Sticking to familiar, tried and tested products
- Using claims on labels to signify that products are gluten-free or 'suitable for coeliacs'; both outside and inside the free-from aisle
- And learning to interpret ingredient lists to check there are no gluten containing cereals listed

"Somerfield used to do a free-range gluten-free products, so I didn't have to go anywhere other than my local store. It was changing from a supermarket to a convenience store so they are not going to do it"

[Parent, Member, Bridgend]

"Supermarkets keep all the stuff together that makes it easier"

[Coeliac, Member, Derry Northern Ireland]

"I go to the free from section...and I know I can buy stuff"

[Coeliac, Non-clinically diagnosed, Non-Member, Glasgow]

Choosing products from outside of the 'free-from' aisle in the supermarket was typically harder work, especially if buying something new or different. It was in these circumstances that sometimes mistakes were made. In the absence of a clear signpost or claims, for example 'gluten-free' or 'suitable for coeliacs', most felt they had to rely on the ingredient list when selecting products, which was particularly difficult for those who were unfamiliar with the terms or ingredient lists. Different approaches to signposting used by different manufacturers also added to the effort required to identify suitable products. There was also some concern that choosing products not specifically manufactured to be gluten-free, can be more variable in recipes, for example full size Mars Bars are suitable and fun-size ones are not. These differences were generally highlighted by the updates to the Food and Drink Directory, where certain products had been removed because they were no longer considered to be suitable for coeliacs. Some respondents have also had negative experiences when purchasing some of their usual products when they realised they could no longer tolerate them.

"It would be good if all products had to say if they contained gluten ... not just the specialist's products ... you have to look so carefully on some things"

[Coeliac, Member, Birmingham]

2.4 Role of Product Labelling at Point of Purchase

The following findings were based upon comments made within the interview sessions themselves as well as being highlighted within the accompanied shops.

As previously discussed, at the point of purchase product labelling appeared to play a part in helping those in the sample to identify suitable gluten-free products. Most claimed to rely on certain brands as well as various statements on the label which, for them, indicated a product's suitability.

2.4.1 Brands

Many relied on brands of products specifically manufactured and marketed towards consumers with coeliac disease (for example Glutafin, Juvela and so on). Supermarkets also had their own 'free-from' brands which were highly recognised and relied upon by most, especially for staple purchases such as bread and pasta. There was generally a high level of trust and confidence when purchasing these types of products. Moreover, the introduction of gluten-free branded products in supermarkets was greatly appreciated as it was felt to ease the decision-making process when food shopping. Some, however, felt that some of these products were more expensive than their 'ordinary' counterparts and therefore sought alternatives.

"Normally the free from section I don't bother checking, or not as carefully"
[Coeliac, Member, Edinburgh]

Whilst the 'free-from' aisle was deemed to be particularly useful, many felt the range of products was quite limited. Many claimed they could not solely rely on buying food from it when food shopping and therefore also had to buy products outside of the 'free-from' range. When looking for products not explicitly marketed as 'free-from' (for example, soups, beans and sauces) some based their purchases on brands that they had bought and consumed previously without having any symptoms after eating them (often after having previously checked on their label). Whilst this strategy was deemed effective on the whole, there was a sense that it could be more risky, especially when manufacturers changed the recipe and could have included a gluten containing ingredient in a previously safe product.

"I bought a soup that I've always bought from Tesco, same label but they must have changed the recipe because my son was ill straight away"
[Parent, Member, Northern Ireland]

FOOD DIARY: "Sainsbury's Strawberry Jam – I assume it's gluten-free as I have always eaten this product"

2.4.2 The Use of Labels

The use of various claims and descriptors on packaging to identify suitable food was also widespread practice across the sample. Different uses of claims were observed depending on individual levels of confidence towards making food choices. Whilst for many respondents one claim was often enough to reassure, for others who were particularly anxious, a series of cross-checking claims and the ingredients list was put into place before purchase.

Indicators used to purchase gluten-free products were as follows:

“Gluten-free” claim

This was the most commonly used ‘claim’ across the sample. It worked well because it was seen to be a clear and straightforward phrase, implying for most that the product contained no gluten at all and therefore was safe to eat. On certain packs, the statement was also supported by the visual of a ticked box, which helped the claim to have more of an impact. This was helpful of those products that were typically assumed to have gluten, for example gluten-free sausages.

“I think everyone would assume that if it said gluten-free then it would contain none”

[Dietitian, Northern Ireland]

“I don’t read the ingredients if it has the gluten-free symbol”

[Coeliac, Non-clinically diagnosed, Non-Member, London]

“It’s got to be clear and say suitable for coeliacs, gluten-free or free from, one of those things will do so you don’t have to go through reading the ingredients”

[Parent, Non-Member, South Wales]

However the most anxious shopper still required additional reassurance, seeking back-up information (for example the ingredient list).

“If it says gluten-free then I’ll still check the ingredients”

[Coeliac, Member, Edinburgh]

“Some of our members simply don’t trust labels, so will call for reassurance”

[Advice Line Staff, Coeliac UK]

“Suitable for coeliacs” statement

This statement was generally felt to be reassuring by most, as it was obviously directly targeted towards consumers with coeliac disease and was broadly well-known and trusted. Nevertheless, some felt that it was often difficult to spot on packs (for instance, it was often hidden at the back of the pack).

“Suitable for coeliacs is very helpful and reassuring”

[Dietitian, Northern Ireland]

“As long as it is clearly labelled suitable for coeliacs it tends to be a lot easier for them”

[Dietitian, South Wales]

“The symbols are quite easy now- there’s a coeliac symbol on food I can eat”

[Coeliac, Member, Leeds]

Some within a group of Coeliac UK members, who were particularly knowledgeable, believed these products should still be eaten in moderation despite the ‘Suitable for coeliacs’ statement.

“Meanings can be unclear, like ‘suitable for coeliacs’ the Coeliac Society advises that you should eat that in moderation”

[Coeliac, Member, Birmingham]

Crossed grain symbol

The crossed grain symbol originates from Coeliac UK and is used to indicate foods that are suitable for coeliacs. Different versions of this symbol have also been developed by supermarkets and other food manufacturers. Unsurprisingly Coeliac UK members tended to be more aware of this symbol, as they were familiar with the Crossed Grain Magazine, as well as the work of Coeliac UK. For this particular group, the crossed grain symbol was highly reassuring and trustworthy, as it tended to suggest such products have been endorsed by Coeliac UK.

“If I see the crossed grain I don’t need to check the ingredients for peace of mind”

[Parent, Member, Bridgend]

There was lower awareness of this symbol amongst non-members of Coeliac UK, since they were less exposed to the various information channels delivered by this organisation. There was also some confusion around the meaning of the crossed grain symbol which some assumed meant wheat free.

In the absence of 'gluten-free', there is a heavy reliance on the information provided on the label and packaging (for example, the allergy box, ingredient lists) as well as the Coeliac UK Food and Drink Directory to provide reassurance.

2.4.3 Allergy Box

The presence of an allergy box on pack (with a list of allergenic foods) was useful to most as it was felt to ease and speed up the decision making process when purchasing suitable food. For many, the allergy box was seen as an effective and instant way of indicating presence or absence of gluten in foods, rather than reading through the ingredient list.

"The allergy box is good"
[Coeliac, Member, Birmingham]

The positioning of the allergy advice box did frustrate some, however, who felt it was 'hidden' at the back of the pack.

"Nothing is ever printed on the front it's always on the packet at the back"
[Parent, Non-Member, South Wales]

Although not highlighted by the end-user sample themselves, there were indications from the Coeliac UK advice line staff that sometimes the allergy box was not always accurate, sometimes failing to highlight a potential allergen within the ingredients.

"Sometimes the product might have wheat flour in it and they don't put it in the allergy box"
[Advice Line Staff, Coeliac UK]

2.4.4 Ingredients List

Reading the ingredients list was also common practice, especially amongst those more confident about their abilities to choose appropriate products without more explicit labelling, such as 'gluten-free' or 'suitable for coeliacs'. Dietitians, as well as Coeliac UK advice line staff, claimed to encourage their patients or callers to check the ingredients list to ensure products did not contain any gluten. This was also actively encouraged to allow coeliacs to be able to access a broader repertoire of foods, rather than relying on those labelled as gluten-free.

"The only way you really know is by the labels"
[Coeliac, Member, Edinburgh]

"You just learn to read everything"
[Coeliac, Non-Member, Birmingham]

"If in doubt, I always look at the ingredient list"
[Coeliac, Non-Member, Derry, Northern Ireland]

Whilst many have learnt to understand ingredient lists, it was not always felt to be a straightforward approach. The use of 'scientific' terms for the ingredient's names can be misleading and ambiguous and some were unsure about the suitability of certain ingredients (for example barley malt extract). Also, some ingredients were easy to miss or the consumer did not realise that it contained gluten (for example, oven chips dusted with flour, certain crisp flavours, Rice Cheerios, and so on).

"You have to check the ingredients list but you don't always know what all the items are"

[Parent, Non-Member, Birmingham]

"We get a lot of calls about cereals, we have them in our Directory but the ingredients say barley malt extract and so we have members ring and check"

[Advice Line Staff, Coeliac UK]

There were also some in the sample who did not feel confident enough to simply rely on reading the products' composition and preferred to have a claim to endorse suitability.

"It is confusing because the packaging is all different so you have to put the time and effort in to take care to read everything"

[Coeliac, Non-clinically diagnosed, Non-Member, Birmingham]

On the occasions where the labelling was not clear for these respondents, or they were uncertain, they may refer to the Coeliac UK Food and Drink Directory, or contact Coeliac UK to check its suitability. This was also reinforced by Coeliac UK advice line staff, who discussed that many of their callers could be anxious about 'getting it right' just by reading ingredient lists.

If further information about a product was unable to be ascertained then, without this additional reassurance, a product would be avoided and not bought.

"When in doubt, leave it out"

[Coeliac, Member, Birmingham]

"I wouldn't say 100% but usually pretty confident, and I don't buy products I'm not sure about"

[Sufferer, Member, Leeds]

3. Awareness of Current Practice and New Legislation

3.1 Awareness of Current Practice

Gluten-free claims are currently made on products which might contain as much as 200 parts per million of gluten.

Most dietitians in the sample generally had a good knowledge and understanding of the current practice and levels of gluten that may be present in foods. A couple of dietitians also spontaneously mentioned the potential risks associated with these higher levels of gluten in food.

“We say there are different levels at which it might affect you... and equate it to some people can get away with eating more fat. We encourage people to experiment with different levels of gluten to see what they can tolerate”
[Dietitian, Glasgow]

“There are some coeliacs who are highly sensitive to any levels of gluten in their diet and at the moment they can’t eat any processed food”
[Dietitian, Birmingham]

Generally the rest of the sample, including consumers and other Health Professionals, were not familiar with current practice or the current level of 200ppm of gluten. It was a common misconception that products labelled ‘gluten-free’ did not contain any gluten and this general assumption was also noticed and confirmed by Coeliac UK advice line staff and dietitians. Given this lack of awareness of the current practice of the level of 200ppm of gluten, there was also no sense of the potential risks that this may cause.

3.2 Awareness of New Legislation

Unsurprisingly, many of the dietitians and the Coeliac UK staff appeared to be the only respondents aware of the new legislation. They generally had heard of it through the Coeliac UK website or through professional meeting updates in hospitals.

Within the consumer group, a few were aware of the new legislation and these tended to be members of Coeliac UK. They claimed this had been raised through their local Coeliac UK groups, articles within the Crossed Grain magazine/newsletter or the Codex Standard section of the Food and Drink Directory.

“All I know is labels are supposed to be changing to be clearer, either I heard it on the news or in the newsletter”
[Parent, Member, Bridgend]

Given that it was Coeliac UK members that were aware of the changes in legislation, it highlights the importance of Coeliac UK as a channel to inform and provide guidance to its members.

4. Reactions to the New Labelling Terms

In terms of exploring the new labelling terms, respondents were shown the relevant pieces of information in the following order:

- The new stand-alone phrases, i.e. 'gluten-free' or 'Very Low Gluten'
- The definition of the phrases, i.e. Parts per million of gluten allowed in the product
- Suitability of the product, i.e. who could eat this product

The following chapter discusses reactions to each piece of information in turn, for both 'gluten-free' and then 'Very Low Gluten'.

4.1 'Gluten-Free'

4.1.1 Spontaneous Reactions to the Claim

The term 'gluten-free' was instantly interpreted to mean the product would contain no gluten by most of the sample (with the exception of dietitians). As discussed most were readily using the 'gluten-free' claim (albeit to a different standard) to guide purchases and therefore the new phrase was generally taken at face value and would be trusted.

Given the high awareness and familiarity with the existing claim, there was no real impact on current attitudes and behaviours towards purchasing products marketed as 'gluten-free'. Most claimed they would still buy products with the same level of confidence although the most anxious stated they would still require further reassurance. Amongst Health Professionals, most believed products labelled with these terms would still be suitable for all their patients.

"I'd have faith in that and wouldn't check it for gluten. I'd trust 'gluten-free' to be gluten-free"

[Parent, Non-Member, Bridgend]

"I would be happy to go with that straight away"

[Coeliac, Member, Leeds]

"That means I can buy it"

[Parent, Member, Derry, Northern Ireland]

"Calling it 'gluten-free' to me means that there is no gluten in this product...it equals naturally gluten-free"

[Coeliac, Member, Edinburgh]

4.1.2 Understanding and Reactions to Definition

Respondents were then introduced to the new definition of the 'gluten-free' claims, this was as follows:

[Gluten-free] = 'Allowed on foods that contain less than 20 parts per million gluten'

Presenting this definition generated different reactions from those observed at sight of the claim alone. Given the general assumption around previous 'gluten-free' claims, information that 'gluten-free' actually contained some gluten raised concerns across many respondents, with the exception of the dietitians and the most informed Coeliac UK members. Firstly, the fact that it contained some gluten jarred with their expectations and challenged beliefs that the previous gluten-free claims meant that products were completely free from gluten. Secondly, it also raised questions and doubts about the products they had been buying, to the extent that some of the respondents felt that they had been previously cheated by this claim. Thirdly, the 'parts per million' unit of measure was not immediately clear, as although it was assumed to be very low, it was not instinctively easy to grasp. Some respondents did mention that if it was written as a percentage it would be easier to understand.

"That would put me off completely because it contains gluten. It's either gluten-free or suitable for coeliacs"

[Parent, Member, Bridgend]

"If it's gluten-free it shouldn't have any gluten in it at all. It should be a product that doesn't have gluten in it, like rice. What would be the harm in that?"

[Parent, Non-Member, Bridgend]

"Gluten-free should be gluten-free, nothing in it at all, because that's contradictory"

[Coeliac, Member, Edinburgh]

"I'd be a bit miffed, it's a bit cheating - you're buying a product as gluten-free and that's what you're expecting"

[Coeliac, Non-Member, Glasgow]

"I would probably still want to look at the ingredients the first time I tried it"

[Parent, Member, Derry, Northern Ireland]

"That's got me very wary now...it's definitely false advertising...that's shocking"

[Coeliac, Non-Member, Glasgow]

A few respondents were less concerned about the definition and conceded that 20 parts per million was a very low amount of gluten and they felt relatively confident to keep purchasing these products. Although not readily noted by end users themselves, some Coeliac UK advice line staff were concerned that these new levels that manufacturers will have to adhere to, may reduce the range of 'gluten-free' products available for coeliacs (where they had been eating them without concerns previously).

"I don't know if it's 20ppm currently when it says 'gluten-free', but if it says gluten-free then I would eat it"

[Coeliac, Member, Leeds]

"Gluten-free' is something we are used to seeing. It'll be fine"

[Coeliac, Member, Belfast, Northern Ireland]

"That's it, I'm happy with that. I hone-in if I see that. I'd give it a try. If I see it's 'gluten-free' it's good enough"

[Coeliac, Member, South Wales]

It was clear therefore that coeliacs will need strong reassurance that although 'gluten-free' contains some gluten, these gluten levels are negligible and still suitable for people with coeliac disease. Moreover, these findings highlighted the importance of communicating that products that are labelled as gluten-free will now contain less gluten than those previously labelled as such and will hence be safer to consume.

4.1.3 Understanding and Reactions to Suitability

Finally, respondents were shown a statement on products' suitability within the context of the current legislation. This is as follows:

Most people with coeliac disease will be able to eat all of these foods

This statement worked well at providing reassurance and re-establishing confidence amongst most coeliacs and parents. Some respondents were unsettled that it was not 'all people...' with a concern that they may not be the ones for whom it was suitable. Many, however, felt comforted that gluten levels contained in products marketed as 'gluten-free' would be safe and suitable for people with coeliac disease. Hence, this suitability statement appeared to be vital in the communication process to overcome any immediate concerns. This could also act as additional information on packs to help provide further reassurance, that is, 'Suitable for Coeliacs'

4.2 'Very Low Gluten'

4.2.1 Spontaneous Reactions to the Claim

For many of the sample, the 'very low gluten' claim raised concerns and confusion, as although it states 'very low' it still suggested that there was some gluten present in the product. For most respondents with coeliac disease, gluten avoidance was seen as an indispensable requirement to manage their condition. In their approach to making food choices, most aimed to exclude gluten absolutely from their diet rather than consuming a minimal amount of gluten. Consequently, many questioned and rejected the suitability of products labelled 'very low gluten' for people with coeliac disease.

"Who is that for? Most coeliacs tend to just steer totally clear from gluten"
[Dietitian, Leeds]

"All we want to know is if it contains gluten or not. Simple as that!"
[Coeliac, Member, Belfast, Northern Ireland]

"It's a bit deceiving that wording 'very low gluten'..."
[Parent, Member, Derry, Northern Ireland]

"Well 'gluten-free' is already there, but 'very low gluten', I'm not sure who that's for. Not me!"
[Coeliac, Member, Belfast, Northern Ireland]

Further, it raised the question as to the suitability of products with 'very low gluten' claims, as without further information it was difficult for them to decipher the exact levels meant by 'low'.

"Well then I need to know what my sensitivity levels is....that's my immediate reaction"
[Coeliac, Member, Edinburgh]

"I'd like to know how much would they be meaning by 'very low'..."
[Coeliac, Non-Member, Glasgow]

In addition, parents of children with coeliac disease expressed their anxiety toward these new claims. They were concerned that these could generate confusion for their children when they are making their own food choices.

"My daughter doesn't know what effect it is going to have on her. I'm not always going to be there, I'd rather she just was guided by 'gluten-free' "
[Parent, Member, Leeds]

In terms of impact on behaviour and purchase, most end-users claimed they would not buy a new product with this claim. Respondents said that if it appeared on a product they currently purchased as gluten-free, some may continue to purchase the product and others may assume the ingredients have changed and therefore the product was no longer suitable. Only some non-clinically diagnosed respondents mentioned they might try such products (albeit cautiously) to assess if it had any impact. The non-dietitian Health Professionals in the sample (the GP, the pharmacist and nurses) were unsure about recommending these products to their patients. The dietitians claimed that they may still recommend these products to their patients to try and see if they experience adverse symptoms, as they believed reactions between patients may vary, depending on degrees of sensitivities. Coeliac UK Helpline staff had some concerns that coeliacs might start following a 'very low gluten' diet, as they may not understand the long term damage to their health from this level of gluten absorption. It was also mentioned that if this phrase was to appear on current prescription products, it may raise questions from the recipients, for example, 'Can I still eat this?'

"I'd just totally avoid it...I couldn't be bothered"

[Parent, Non-Member, Glasgow]

"I might start thinking should I, shan't I, with this?... I don't know how tolerant I am to these things"

[Sufferer, Member, Leeds]

"I think people do notice changes, so if it changed from 'gluten-free' to 'very low gluten', they might think they've put more gluten in it"

[Advice Line Staff, Coeliac UK]

"One concern is if a dietician says that you can include these products they might start following a very low gluten diet, it needs to be explained that you are following a gluten-free diet but you can have these occasionally"

[Advice Line Staff, Coeliac UK]

4.2.2 Understanding and Reactions to Definition

Respondents were then presented with the following definition of the 'very low gluten' term.

[Very Low Gluten] = These will include those products which are manufactured using a special type of starch that has been treated to take out almost all of the gluten and will generally have a higher level of gluten in them (up to 100 parts per million)

The definition generally failed to address the issues and concerns raised by respondents when introduced to the phrase. The '100 parts per million' of gluten compared to 20 parts per million was felt to be relatively high and generated some anxiety. Given that 'parts per million' was an unfamiliar measurement for nearly all, it was difficult for respondents to understand how this measure related to what was safe for them to consume. Thus, most still questioned the suitability of products containing such levels of gluten and for some there were requests to show how much of it was safe to consume.

"With 100 parts per million it's still low but how will I know whether I can take the risk?"

[Parent, Member, Derry, Northern Ireland]

"The only way I would buy that, would be if the Coeliac Society said to me 'you could tolerate a certain amount of gluten so you would probably be ok with this product'"

[Coeliac, Member, Leeds]

"The 'gluten-free' one is easier, it's black and white... you think 'I'm fine, I'm being strict'. The very low gluten...is it my choice to have it?"

[Coeliac, Member, Glasgow]

"If I understood what it meant. I would buy it"

[Coeliac, Non-clinically diagnosed, Non-Member, London]

"It does put doubt in your mind"

[Coeliac, Member, Glasgow]

Furthermore, some were concerned that these claims would apply to products using modified starch and would therefore contain hidden gluten because they understood starches to contain gluten.

"From the start I've always been told if it's a modified starch...stay away!"

[Coeliac, Non-Member, Derry, Northern Ireland]

In addition, some of the respondents who were not members of Coeliac UK, were unsure about the phrase 'special type of starch' which sounded a little too 'processed and off-putting'.

"I'm not sure about the special type of starch, that sounds a bit dodgy, like GM foods"

[Coeliac, Non-clinically diagnosed, Non-Member, London]

4.2.3 Understanding and Reactions to Suitability

Finally respondents were introduced to the following suitability statement:

Not everyone will be able to eat these foods, so it will be important for those with a gluten intolerance to speak to a doctor or dietician before introducing them into their diet.

This suitability statement had a different impact on the various audience groups. Most respondents who were diagnosed with coeliac disease felt these foods were not suitable for them and believed they would be too risky for their condition. Parents were particularly more anxious and cautious and were not prepared to take any risk of purchasing these products for their children. Both coeliacs and parents believed they would be unlikely to specifically contact a Health Professional (particularly their GP) to assess whether products are suitable for them/their child or not. They felt this would be too time-consuming or believed they had greater knowledge and experience of what triggers their/their child's symptoms than their GP.

"If I saw 'Very Low Gluten' I wouldn't buy it unless it said 'Suitable for coeliacs'"
[Parent, Member, Bridgend]

"What's suitable for someone with an intolerance and someone with coeliacs is different"
[Coeliac, Non-Member, Derry, Northern Ireland]

"It will cause a great deal of problems...you're the coeliac who knows more about your diet and to have to go back to your doctor...we know more than the doctor's do"
[Coeliac, Member, Leeds]

Across some non-clinically diagnosed individuals, some claimed they may consider purchasing products labelled 'very low gluten' but would require further information to judge the product's suitability.

"I would go with that if it had the crossed-grain symbol or if it said 'suitable for coeliacs'..."
[Coeliac, Member, Leeds]

Dietitians agreed and engaged with the overall statement. They agreed that 'very low gluten' foods may not be suitable for all coeliacs and should be tried under medical supervision.

4.2.4 Considerations for Communication of the Phrase 'Very Low Gluten'

Greater detailed communication seems to be required to overcome questions and concerns raised by the introduction of the new phrase 'Very Low Gluten' in terms of providing a context. It seemed important to raise awareness that before now levels of gluten in 'gluten-free' products, may have contained up to 200 parts per million of gluten, and to stress that eating large amounts of such products may have put some people at risk of long term health complications. It was felt critical to create understanding amongst both end-users and Health Professionals that products labelled 'very low gluten' may be safer than some products currently labelled 'gluten-free'. For some, a way of demonstrating how the level of gluten contained in a 'very low gluten' product might relate to recommended daily amounts was thought to be potentially helpful, for example, a percentage or a pie chart representing the ratio between the amount of gluten contained in the product and the maximum tolerable daily intake of gluten recommended for a coeliac could help them assess the risk and make more informed food choices. Furthermore, if possible, supporting the claim 'very low gluten' with the statement 'suitable for (many) coeliacs' may help provide more reassurance.

5. Communicating the New Legislation

A dedicated piece of communication about the labelling changes, for example a leaflet or section on a website, was considered to be helpful to stand out and reach audiences and support the labelling changes. These could be distributed through a number of key channels and are as follows:

5.1 Coeliac UK

Amongst Coeliac UK members and Health Professionals, Coeliac UK was seen as a key channel to disseminate information on the new legislation. The organisation is trusted and valued. Most believed they would also be particularly well placed to tackle any issues and concerns around the phrase ‘very low gluten’, as they were heavily relied upon for support and reassurance. Most believed Coeliac UK could effectively deliver information through various channels and supports, such as their website (which they have begun to do), the Crossed Grain magazine, leaflets sent to members, newsletters, eXG and local groups. There is also potential to highlight suitable foods in the Food and Drink Directory, which is offered through the organisation.

Communication through Coeliac UK would most likely reach most of their members, dietitians and potentially some non-members – who have knowledge of the organisation and visit their website.

“Coeliac UK are the ones who know what’s what”

[Coeliac, Member, Leeds]

“The most direct way would probably be Crossed Grain (magazine). Everybody who is a coeliac is generally a member of Coeliac UK. I can’t see the benefit in normal media unless they were generally advertising a new product”

[Parent, Member, Bridgend]

“I think that sometimes things get missed in our other mailings, a dedicated leaflet to start with is probably helpful”

[Advice Line Staff, Coeliac UK]

“Through the magazine or the newsletter”

[Coeliac, Member, Leeds]

5.2 Retailers

Supermarkets and health food shops were also mentioned as a relevant channel by many parents and coeliacs. This is likely to target a broad range of coeliacs including self/clinically diagnosed and Coeliac UK members/non-members.

It was most commonly suggested that they could display information on posters and leaflets in the 'free-from' aisle within supermarkets – that is, at the point of purchase. Retailers or 'gluten-free' product manufacturers were also thought to be potential sources to endorse this information. Some respondents suggested that retailers could organise events targeted towards consumers with coeliac disease in local supermarkets. Some believed supermarkets could also provide consumers with this new information on their website or in their own magazines. Although not currently readily considered, the FSA was also regarded as a credible source of information.

"When you go to the shelf with the free-from range they could put a little stand up with a leaflet and new information on it"

[Coeliac, Member, South Wales]

"I think that they should have leaflets in the supermarket, just where you are buying this sort of food, you would be bound to notice it"

[Coeliac, Non-clinically diagnosed, Non-Member, London]

5.3 Dietitians

Dietitians were also generally perceived as an important channel to inform end-users about the new food labelling legislation and those interviewed claimed they would be willing to play this informative role. Most coeliacs believed dietitians could deliver the information at first point of diagnosis to newly diagnosed patients or at annual follow-up consultations, to longer-term coeliacs. Many dietitians felt that they would be most likely to get their information either through Coeliac UK, British Dietetic Association or through their Primary Care Trust. Both end-users and some dietitians considered a leaflet to be a useful way to support any information provided during the consultation.

"Making the information available to us. They (FSA) could produce some literature we could hand out to patients"

[Dietitian, South Wales]

"Some posters or leaflets to have to distribute would be useful"

[Dietitian, Glasgow]

5.4 Health Settings (for example Pharmacists)

To a lesser extent, pharmacists, as well as other contacts with the health service, were seen as a potential source of information amongst clinically diagnosed coeliacs. Pharmacies are points of regular contact for some respondents, as they regularly collect certain staple foods on prescription. Hence, it was suggested that pharmacists could potentially hand out leaflets when filling prescriptions, although of course, this is likely to be to a limited audience.

5.5 FSA: A Credible Source of Information

The FSA were not spontaneously mentioned as a potential channel to disseminate information on the new legislation. Nevertheless, when prompted there were no barriers or issues raised about the FSA providing this sort of information. All respondents perceived the Agency to be credible and legitimate, and believed it could play a role in the overall communication of information: through their website, in providing retailers with leaflets and through their factsheet on food intolerance and coeliac disease. A higher profile and better visibility may be required for the FSA to become a top of mind information source and this potentially could be achieved through promotion by Health Professionals, particularly by dietitians.

VI Conclusions and Recommendations

6.1 Sources of Information

Those interviewed used a wide range of information sources to make suitable food choices for a gluten-free diet. For those clinically diagnosed, the key channel of information was through their dietitian, especially when first diagnosed. Coeliac UK also played a prominent part for their members in providing information about the day to day management of their condition.

Aside from these two main sources of information, other resources, such as the Internet, product manufacturers, retailers, word of mouth (from relatives and friends), relevant literature and staff at health food shops were also being used by respondents.

The FSA was generally not used as a source of information by those in the sample. Most respondents had simply not considered the Agency in this way, as they often had the perception that the FSA would not offer specific enough information on their condition. In general, there was a lack of awareness of what the FSA could have to offer, with a common assumption that the Agency was linked to food scares or general 'healthy eating' messages, rather than specific health related conditions.

6.2 Current Issues in Purchasing Processed Food

When respondents were first diagnosed with coeliac disease, they admitted that food shopping was initially confusing, time-consuming and laborious due to the need to continually check food labels. Over time, however, most had become more familiar with labels and the products that were appropriate for them to buy and as such had found strategies to self manage their shopping habits. Furthermore, the introduction of the EU labelling legislation for food allergens (which specifies that all 14 named allergens should be declared on the labels of pre-packed foods), as well as the expansion of the 'free-from' ranges (that is, those products which have been specially manufactured and marketed to be free from gluten or other potential allergens) in supermarkets, had significantly contributed to alleviate some of this confusion and to ease the process of food-shopping. That said, some still remained particularly anxious about what they were buying, despite the labels, and required greater reassurance through a process of cross-checking several indicators relating to product composition (for example, labels, suitability statements, ingredient lists etc).

The main area of confusion, and therefore requiring additional care, tended to be in identifying suitable foods that are not specifically labelled and marketed as 'gluten-free' and therefore located away from the free-from aisle in the supermarket. Different strategies were observed amongst both the parents of those with coeliac disease and the coeliacs themselves to purchase suitable food from the non-specialist aisles. Some strongly relied on the Coeliac UK Food and Drink Directory, and only purchased products listed within it. Some tended to scrutinise the ingredients list and check the allergy boxes on food packs, as well as any other additional signposts that would indicate suitability. However, this latter process was generally felt to be tedious, complicated and confusing, especially when seeking information on new products and particularly for those who had previously bought the same products on a regular basis because they regarded it as 'safe' for them to eat.

When making these decisions, it appeared clear that if a respondent was not fully confident about whether a product was suitable or not they would simply avoid purchasing or consuming it. This indicates that coeliacs place high importance in understanding the 'make-up' of the products they consume.

6.3 Current Assumptions Around Gluten-Free Labelling

A critical finding in the research was that, aside from most dietitians, there was a general assumption amongst both the consumer and Health Professional sample that '**gluten-free**' products do not contain any gluten. The label had been generally taken at face value and understood by consumers to mean they would not consume any gluten when eating these products. Indeed, there was no understanding of the potential risks associated with foods labelled prior to this legislation and therefore no understanding of the need to introduce a change. Clearly this disparity between reality and perception is important to understand as it reflects how consumers perceived the new labelling definitions and further should be of strong consideration through communication of the new labelling and their definitions.

6.4 Reactions to the New Labelling Terms

In terms of the new claims, their definition and suggested suitability, 'gluten-free' and 'very low gluten' elicited different reactions. As a stand alone label, 'gluten-free' was generally well received and taken at face value, as it was for the old labels – that is, it would be used on products that do not contain any gluten. However, informing respondents that the new definition of this label means that the product can contain up to 20 parts per million of gluten was as surprising as the reality that the current system allows for up to 200 parts per million of gluten. Given their lack of understanding of the current system, the perceived 'new' information about how this phrase was defined tended to undermine the level of trust and confidence in the label, raising concerns over suitability.

The provision of additional information on the packaging about the suitability of the food, for example, it is suitable for most people with coeliac disease, helped to reassure and overcome these concerns. Further, backing up the new label with the supportive claim 'suitable for coeliacs' or the 'Crossed Grain' symbol may also help to allay any doubts that people may have about a products' suitability after learning that the product does contain some gluten.

The '**very low gluten**' phrase was even less straightforward for the sufferers and parents of sufferers within this sample.

It was seen as requiring a personal judgement on behalf of the purchaser to assess whether a product displaying this claim was suitable or not for them or their child. The '**very low gluten**' claim created anxiety amongst many of the coeliacs and parents who therefore felt that, rather than take the risk, they would avoid such products. Consequently, extra reassurance would be required to assure consumers about this claim. This could be communicated by stating through the different communication channels mentioned in section 11, for instance, that products which are now labelled 'very low gluten' may actually include foods they had previously eaten. Moreover, there was some indication that an estimated maximum daily allowance of gluten (for example via a percentage or chart) or amount considered suitable over a week would be particularly valuable to help consumers make informed judgements and choices on these 'very low gluten' foods. Finally, if possible, a suitability statement, for example, 'suitable for some coeliacs', on packaging may help reassure the most anxious.

6.5 Communicating the Changes in Labelling

Given the lack of awareness about the current levels of gluten included in products labelled as 'gluten-free', it will be important to set the context and provide the rationale for the change. For example:

- previously, gluten-free claims were used on products that could contain up to 200 parts per million of gluten;
- this level has now been recognised as too high for some individuals and consumption of significant amounts of such foods may have serious long term health implications;
- changes have been made to help protect consumers and enable them to make *safer and more informed* choices;
- what does this mean to the consumer when purchasing 'gluten-free' foods in the future, for example what do they need to look for, what will be included or not?

A number of key channels appeared important to communicate the changes in food labelling amongst people with coeliac disease. A dedicated leaflet or particular section on the FSA and Coeliac UK websites would probably be most useful to explain and inform consumers about the changes, and reasons behind them, and this could be delivered through the following channels:

- a) **Coeliac UK** is likely to be a very helpful partner in communicating changes in food labelling legislation, given its high penetration of membership amongst coeliacs (estimated at 80%). More specifically, they seem to be well placed to raise understanding of previous levels of gluten that may be present in foods labelled to indicate their suitability for people with coeliac disease. As such, Coeliac UK may be well placed to address current misconceptions, as well as to raise awareness of the rationale and benefits of the new legislation. The inherent trust which many of their members place with them means that they can also provide reassurance and information on suitability of products labelled 'very low gluten' – perhaps through their Food and Drink Directory, which is already a very important source of information for many people with coeliac disease. It was discussed at the presentation of findings to the FSA that a separate piece of communication could be helpful to 'stand-out' to members – either an email or leaflet. In addition, a separate section in the Food and Drink Directory was also considered a suitable approach.
- b) **Dietitians**, and to a lesser extent, other Health Professionals also constitute a useful channel to communicate information on changes. Dietitians will obviously reach those newly diagnosed as well as potentially being able to inform those that they see for their yearly/biannual check ups.
- c) The provision of information at the **point of purchase of 'gluten-free'** products, for example, within supermarkets and health food shops, is also worth strong consideration. This would ensure that information about labelling changes would be readily accessible to the broadest number of coeliacs.
- d) **Health settings**, for example Pharmacists also could be included as a useful point of contact with those receiving prescription foods. However, this is likely to be to a limited audience.
- e) The **FSA** has low visibility for both parents of those with coeliac disease and coeliacs themselves. However, most parents and coeliacs were open to receiving information from the FSA, therefore the FSA could help support the dissemination of information through the above channels, as well as provide information of its own.

Appendices

Appendix 1 Sample, Method and Rationale

Appendix 2 Discussion Guide (End-Users)

Appendix 3 Discussion Guide (Health Professionals)

Appendix 4 Food Diary

Appendix 5 Food Diaries Examples

Appendix 6 Photos (Depth In-home Interviews)

Appendix 7 Approach Letter to Health Professionals

Appendix 8 Health Professionals: Recruitment Questionnaire

Appendix 9 Parents/Coeliacs: Recruitment Questionnaire

Appendix 10 Invite Letter for Coeliac UK

Appendix 11 Letter to Respondents Who Have Been Recruited

Appendix 12 Permission for Further Research Letter

Appendix 1

Sample, Method and Rationale

a) Parents and coeliacs sample in detail

Country	Group/ depth	Respondent Total	Membership of Coeliac UK	Gender	Parent/ coeliacs
ENGLAND	4 Depths 4 Groups	23	12 members 11 Non-members	6 Males 17 Females	7 Parents 16 coeliacs
N. IRELAND	2 Depths 2 Groups	12	10 Members 2 Non-members	5 Males 7 Females	1 Parent 11 coeliacs
WALES	2 Depths 2 Groups 1 Paired Depth	12	9 Members 3 Non-members	3 Males 9 Females	4 Parents 8 coeliacs
SCOTLAND	3 Depths 1 telephone depth 1 Paired Depth 1 Group	11	4 Members 7 Non-members	1 Male 10 Females	3 Parents 8 coeliacs
TOTAL	12 Depths 9 Groups 2 Paired Depths	58	35 Members 23 Non-members	15 Males† 43 Females	15 Parents 43 coeliacs

- o Each session was for 1.5 hours
- o Face to face interviews were held in respondent's home

The sample also met the following criteria (see appendix 9 for the screening questions used with this sample for recruitment).

Research criteria

- participants had either had been clinically diagnosed with coeliac disease, were non-clinically diagnosed but considered themselves gluten intolerant, or were parents of children with coeliac disease, (who were managing their children's diet);
- all were purchasing 'gluten-free' products;

Additional information on sample

- parents had children for whom they bought 'gluten-free' products for;
- spread of ages of adult;
- spread of those who were newly diagnosed with coeliac disease vs. longer term coeliacs;
- it is understood that the proportion of males: females coeliacs is 1:2 hence the numbers in the samples;
- mix of those who were and were not Coeliac UK members. It should be noted that a high number of members were encountered in the recruitment. It is also understood that approximately 80% of diagnosed coeliacs are members of Coeliac UK.

Research Approach

The approach within the depth interviews and group discussions was as follows:

- Ten of the depth interviews were face to face for 1.5 hours in the respondent's home. The depth interview included:
 - o A pre-task given to the respondent. This comprised of keeping a food diary (see appendix 4), which asked the respondent to note a) what they had eaten for three days and b) how they knew it was suitable for them to eat.
 - o Looking at the contents of the respondents cupboards, to understand the types of foods they were buying.
 - o A shopping visit. This comprised of both the moderator and respondent visiting a local supermarket and the respondent talking through the products that they normally bought and discussing the difference the new claims might make.
- The original aim of the sample was to include a mix of group discussions and face to face interviews, in order to get both the benefits of a useful debate in a group setting and also the benefit of one to one discussions. However, due to a lower than required response from Coeliac UK members, there was one session with only 2 members and therefore there was a need to do additional face to face interviews to top up the sample as described below.
- One depth interview was face to face, but this was not accompanied by a shopping trip as it was a last minute replacement for a short fall of respondents in the group discussion.
- One depth interview was conducted by telephone to top up the number of respondents in Scotland of which there was a small shortfall due to the limited response to the invite from Coeliac UK. This was with a non-member of Coeliac UK.
- Group discussions comprised of between 3-7 respondents (most typically 5) for 1.5 hours. The respondents attending these were also pre-tasked to keep a food diary (as above) and also were asked to bring with them any packaging from products that they used at home.

Rationale for the Approach

- *Mini-group discussions:* this research method provided the opportunity to understand the range of views, behaviours and experiences in following a 'gluten-free' diet. Mini groups were chosen (as opposed to more standard groups of 8 people) as they allowed for a greater number of sessions to be conducted across more variables and regions. Mini-groups were also ideal for generating a richer response to the proposed labels in a more creative environment.

- *Individual in-home depth interviews with an accompanied shopping element:* These interviews were included in the research method to provide the opportunity to explore individual differences in more detail. In addition, these depth interviews provided the opportunity for the team of moderators to go to the respondents' home allowing an 'in-situ' observation. This ethnographic element enabled the moderator to explore the type of food purchased by the respondent, for example, by looking through their cupboards, allowing for further understanding of the decision making process made by the respondent.
- Each of these interviews also included a 30 minute accompanied shopping trip with the respondent to their usual supermarket. The purpose of this shopping trip was to understand the shopping process, the use of 'labelling' and the extent to which they were reliant upon labelling. This also provided insight into how labelling impacted upon their ability to make safe and confident choices. In addition, the in store experience was used to assess how the new labelling terms may work in context i.e. explore how respondents feel the new terms would impact on identification of appropriate foods.
- *Food Diary:* All respondents were asked to keep a food diary, prior to the mini-group and the depth interview, and to note what they had eaten for three days and how they knew these foods were suitable to them (see appendix 4). This pre-task was an effective way of gathering information about labels/signposts currently available as well as respondents' knowledge levels and what they currently used (and the information they relied upon) to make their food choices. In addition it helped them to consider how they made their decisions in food choices prior to being interviewed, thus 'warming them up' to the topic prior to being interviewed.

b) Health Professionals sample in detail

Type			Total
Profession	GP	1	10
	Practice Nurse	2	
	Pharmacist	1	
	Dietitian	6	
Location	N. Ireland	2	10
	Wales	2	
	Scotland	2	
	England	4	

- 5 interviews were conducted face to face and 5 were conducted over the telephone;
- each interview lasted 1 hour.

Rationale for the Approach

- *Depth interviews:* There were a number of reasons for conducting depth interviews with stakeholders. Depth interviews allow for more flexibility around the potential participant's diary and therefore allow for the researcher to schedule an appointment to suit the individual respondent, thus maximising participation. Depth interviews also enabled the inclusion of a spread of areas across the UK within a relatively small sample size. In addition,

each stakeholder had a different job role and focus (dietitians versus GPs) and thus conducting individual depth interviews maximised the project learnings from each interview, and allowed the different job roles to be taken into account at the analysis stage.

- *A mix of telephone and face to face interviews:* Whilst face to face is generally the ideal, given the range of locations required in the research the inclusion of telephone interviews enabled more effective recruitment and reduced travel costs. In addition there were no issues, given the subject matter, in conducting these interviews over the telephone.

Further criteria included:

- all were involved in consulting with coeliacs;
- all of the dietitians interviewed had British Dietetic Association accreditation.

Sample broken down by country

England

Group/depth	Respondent No.	Member or not member	Male/Female	Parent/Sufferer
Depth	1	Non-Member	Male	Sufferer
Group	2	Non-Member	Female	Parent
	3	Non-Member	Female	Sufferer
	4	Non-Member	Male	Sufferer
	5	Non-Member	Male	Sufferer
	6	Non-Member	Male	Parent
Depth	7	Non-Member	Female	Sufferer
Group	8	Non-Member	Female	Sufferer
	9	Member	Female	Sufferer
	10	Non-Member	Male	Sufferer
	11	Non-Member	Female	Parent
	12	Non-Member	Female	Parent
Group	13	Member	Female	Sufferer
	14	Member	Female	Sufferer
	15	Member	Female	Sufferer
	16	Member	Female	Parent
	17	Member	Female	Parent and Sufferer
Depth	18	Member	Male	Sufferer
Depth	19	Member	Female	Sufferer
Group	20	Member	Female	Sufferer
	21	Member	Female	Sufferer
	22	Member	Female	Sufferer
	23	Member	Female	Parent

Northern Ireland

Group/depth	Respondent No.	Member or not member	Male/Female	Parent/Sufferer
Depth	1	Member	Female	Parent
Group	2	Non-Member	Male	Sufferer
	3	Member	Male	Sufferer
	4	Member	Male	Sufferer
	5	Member	Male	Sufferer
	6	Member	Female	Sufferer
	7	Member	Female	Sufferer
	8	Non-Member	Male	Sufferer
Depth	9	Member	Female	Sufferer
Group	10	Member	Female	Sufferer
	11	Member	Female	Sufferer
	12	Member	Female	Sufferer

Scotland

Group/depth	Respondent No.	Member or not member	Male/Female	Parent/Sufferer
Paired Depth	1	Member	Female	Sufferer
	2	Member	Female	Sufferer
Group	3	Non-Member	Female	Sufferer
	4	Non-Member	Female	Sufferer
	5	Non-Member	Female	Parents
	6	Non-Member	Female	Parents
	7	Non-Member	Female	Parents
Depth	8	Member	Female	Sufferer
Depth	9	Non-Member	Female	Sufferer
Top Up depth (no accompanied shop)	10	Member	Female	Sufferer
	11	Non-Member	Male	Sufferer

Wales

Group/depth	Respondent No.	Member or not member	Male/Female	Parent/Sufferer
Depth	1	Member	Male	Sufferer
Group	2	Member	Male	Sufferer
	3	Member	Female	Sufferer
	4	Non-Member	Female	Parent of respondent no. 3 still involved in buying gluten-free food for her daughter on occasions
Trio (but one person mis-recruited so focused on pair)	5	Member	Male	Sufferer
	6	Member	Female	Sufferer
Depth	7	Member	Female	Parent
Group	8	Non-Member	Female	Sufferer
	9	Member	Female	Sufferer
	10	Member	Female	Sufferer
	11	Member	Female	Parent
	12	Non-Member	Female	Parent

Appendix 2

Discussion Guide (End-Users)

1711 FSA – Food labelling for people with Gluten Intolerance/Coeliacs

1.5 hour Depth/Group Interviews with people with Gluten intolerance/Coeliacs and Parents

N.B This Guide indicates the areas to be explored in the discussion, the likely order in which topics will be covered and the kinds of questions and techniques which may be used. There will be some flexibility of discussion, however, to account for each individual being interviewed, and to focus on areas most relevant to them.

Not all respondents will respond to the same level of language or explanation. While the questions below details how we intend to cover topics in our own 'language', efforts will be made to meet the communication needs of the individuals interviewed.

Timings on the guide are approximate and give an indication of where the emphasis in the conversation will be.

Stimulus Materials required:

- *Information – advice from Coeliac UK and FSA:*
 - o *Printed pages from FSA website:*
<http://www.eatwell.gov.uk/healthissues/foodintolerance/foodintolerancetypes/coeliacdisease/?lang=en>
 - o *Intolerance fact sheet*
www.food.gov.uk/multimedia/pdfs/allergyfactsheetcoeliac0308.pdf
- *New labelling stimulus*
- *Selection of food packaging*
- *Respondents to bring along their pre-task (food diary)*

Introduction – 5 mins

- **Moderator**

Moderator to introduce self, explain the process of market research to respondents and the format of the interview/discussion, saying that the interview will involve a trip to the local supermarket where appropriate.

- **Inform**

Explain topic of discussion is on gluten intolerance/Coeliac disease and in particular labelling on foods that are marketed to those people who are gluten intolerant. Reiterate independence of Define in development process and the need for honesty to help with research. Ask if they are happy for the interview to be recorded and reassure on confidentiality and that any comments will not be attributed to them (unless they are happy for us to do so).

Brief Background – 5 mins

For those who have gluten intolerance / Coeliac disease:

- Moderator to obtain brief background details from each respondent: What is their name, working status, Family background, how long they have had Coeliac disease/gluten intolerance, severity of intolerance, diagnosed by a medical professional or not, how they currently manage their intolerance, where do they go shopping for food and why?
 - o Do they get any of their foods on prescription?
 - o Do they eat foods currently labelled as gluten-free?
 - o Do they cook everything from scratch, or do they use pre-prepared ingredients
 - o Do they receive text messages about recalls of products from the FSA?

For those with children with gluten intolerance / Coeliac disease

- Moderator to obtain brief background details from each respondent – Who they are, family background, how long their children had Coeliac disease/gluten intolerance, age of the child with Coeliac disease, severity of intolerance, how they currently manage the disease for their children, particular difficulties for those with children and where do they do their food shopping and why?

Information used to make Food choices – 10 mins

To explore the information that respondents currently use to make informed food choices

NB *Through the course of the discussion listens out for any confusion or frustration concerning information or any gaps that may exist*

At point of realisation/diagnosis

- When you/ your child realised that they had gluten intolerance what information was available to you about your food choices and gluten intolerance and how to manage it? [*Moderator to obtain spontaneous suggested resources*]
- Was information given to you about your potential food choices? By whom?
 - What sort of information was this?
 - Who did you speak to? What were you told?
 - What did you read?
- What information on your food choices did you look for independently? Why that?
- *If not raised spontaneously.* What sources of information did you find to help you make choices about food? [*Moderator to note*]

Current Information sources

- What sources of information do you currently use / refer to when trying to make food choices? Why do you use these now?
- Is there information about food choices that you no longer refer to? Why?
- Are some sources of information about food choices more/less valuable to you? Which ones? Why?
- Are some more/less trustworthy in your opinion? Which ones? Why?
- Which sources of information on food choices would you say you refer to most/least?
- What makes these more/less important/useful?
- If not mentioned prompt the following: have you ever used any of the following when making decisions and what do you think of:
 - Information from the supermarkets
 - Information on food packaging
 - FSA (website) (for example the **FSA intolerance fact sheet**) or other Government department for example Department of Health website
 - Health professionals
 - Coeliac UK website and Directory
 - Word of mouth

For Coeliac UK members:

- What do you gain as a member? What extra information is available to you about food choices as a member? How useful is this? If not mentioned prompt 'gluten-free food directory' from Coeliac UK – how useful is this? Anything else?

For those with children with Coeliac disease, also ask:

- Was there any advice that was specific to their child's food choices needs? How easy/difficult was this to follow?
- Was there specific information about food choices that made things easier to manage? How did it help?

If not covered, for all groups:

- How do you keep updated/ find out about any new information with regard to food choices and gluten intolerance/ coeliacs disease?
- What sources of information have you seen/used most recently? Why that?
- How useful were these sources of information?

Moderator to conduct a ranking exercise

- Can you put those preferred sources of information in order according to which are best/worse?
- Why do these rank better/worse? What are your reasons for this?

For groups: respondents are asked to do the ranking exercise individually. They will then report back to the group and discuss the reasons behind their ranking

Labelling and sign posting – 10 mins

To explore the current use of labels and signposting to identify appropriate foods

*Although there may be an element of crossover with the previous section, it will be important to understand specifically perceptions and understanding of current **labelling** on foods*

Thinking about when you go shopping for food...

- What do you look out for specifically when buying food to ensure that it is suitable for you/your child to buy and eat? Why these things?
- How are foods identified to signify that they are appropriate individuals with gluten intolerance [Moderator to obtain spontaneous comments on labels / symbols / guidance used]
- Are there labels / symbols which identify food you/your child can eat? Which labels do you look out for? Why those? How is this information displayed?

- What about signs, words or images on packaging which identifies food that is suitable? Which do you look out for? Are some more/less useful for identifying appropriate foods? How is this information displayed?

Moderator to then prompt with if not raised spontaneously with examples to hand:

- What about allergy advice boxes, or 'cross grain symbol' or 'gluten-free' or 'suitable for coeliacs'
 - o Are you aware of these?
 - o Do you use any of these symbols/labels when making food choices?
 - o How useful are these?
- Any other strategies you use when you go shopping? [spontaneous then prompt reading ingredients list on food packaging, sticking to certain brands, using certain supermarkets, etc]
- Any other strategies when buying for children?

For Depths:

At this stage ask if you can look in respondent's cupboards/fridge/freezer and ask them to point out the labels / symbols on their packs of food that they look for when making a purchase (photographs of labelling and sign posting would be taken to use in analysis)

NB: If necessary clarify with respondent we are not interested in state of cupboards/fridges but simply the products they contain.

- Talk me through what you have in your cupboard and why you have chosen these as suitable for people with gluten intolerance
- Which signing/labels do you feel are working best/worse in helping you decide whether that product is suitable for you / your child? What makes them better/worse? Anything else?

For Groups:

Ask if you can look through their pre-task to note which products they have eaten (and the current tools (signs, labels, brands, etc) used to identify those that were safe to eat). Also look through the packaging they had brought along to see how these labels / symbols work in the context of the new packaging/labelling changes.

Moderator: To ask respondents views to a list of current labelling and sign posting examples. (Moderator will show a range of products)

- What do you think of these types of labelling and sign posting?
- Are any familiar? Are there any which you currently use? Why these and not others?
- Which provide you with the best/worst information?
- How more/less likely are you to look at any of these types of labelling? What are the reasons for this?

Levels of confidence in current system – 10 mins

To explore the confidence in the current system.

Although some of this may have been covered through the previous discussion, it will be important to check any areas of confusion that users may have.

- Do you find it easy/hard to make the appropriate food choices? For what reasons?
- How confident do you feel in food choices that you are making?
- What labels/codes/signs make your choices easier? Why these ones?
- Are there any times you haven't felt confident to make the correct choices? When was this? [Moderator probe for examples or stories]
- What made your choices more difficult? Are there any areas of confusion in relation to the food choices you are making?
- Have you ever made mistakes? If so, do you have examples? What caused these mistakes? How could these have prevented?
- In your eyes, how do you think existing labelling / signposting could be improved? Any other way?

Reaction to proposed labelling – 15-20 mins

Aim to understand any awareness of new labelling, then spontaneous reaction to the new labels.

- Are you aware of any new laws for labels on products for people with gluten intolerance/Coeliacs?
- If yes, what have you seen about it? When and where did you see it? What have you heard about? Where did you hear about this?
- If No, Where would you first expect to hear about any changes to labelling guidance / rules for gluten-free produce?
- What would be the best channel to inform people about changes? Why?

Moderator to explain that a new EU legislation means that in future the use of the label claims 'gluten-free' and 'Very Low Gluten' will be strictly controlled and that new lower levels of gluten will have to be met to be able to use these terms. From 2012 only foods which conform to specified criteria will be allowed to use these phrases and the claim will have to be put on the front of pack.

Stimulus:

Label: 'gluten-free'

Gluten Content: "Allowed on foods that contain less than 20 parts per million gluten"

Suitability: Most people with coeliac disease will be able to tolerate all of these foods

Label: 'Very low gluten'

Gluten Content: 'These will include those products which are manufactured using a special type of starch that has been treated to take out almost all of the gluten and will generally have a higher level of gluten in them (up to 100 parts per million)

Suitability: Not everyone will be able to eat these foods, so it will be important for those with a gluten intolerance to speak to a doctor or dietician before introducing them into their diet for the first time

Moderator to show each new label in turn and get spontaneous reactions as to understanding i.e. 'gluten-free' and 'Very Low Gluten' and then go on to explain the maximum level of gluten allowed (order in which these are shown are rotated across interviews). And then go on to explain suitability, as follows:

Show/discuss label as stand alone

- What do you think of this?
 - o Initial Reactions – what do you think it means?
 - o How useful or otherwise is this labelling?
 - o How well does this sit with current labelling? Is it likely to cause any confusion? Why?
 - o Is this the only information that you/your child would need? If not what else might you need as well as [note any spontaneous thoughts]
 - o What other comments do you have about the new phrase?
 - o What else did you expect from new labels? Anything else?

Show parts per food allowed linked to label

- How easy is it to understand? Why?
 - o Benefits/issues?
 - o How useful would this be for you/your child? For what reasons?
 - o Does it help to clarify any issues/concerns? How?
 - o What does that term mean to you/your child?
 - o Would you still buy products with this label?
 - o [*gluten-free label*]: Do you understand that it still will contain some gluten i.e. does not have 0% gluten. If not explain and assess reaction

Describe suitability

- Does this surprise you?
 - o Do you think this is suitable for you/your child?
 - o Is there any risk of confusion?
 - o Now that you know this, what do you think of the labels?
 - o Do you think that this needs further clarification?
 - o [Very low Gluten label]: How aware are you that you/your child may be able to still safely eat products with this label? How do you feel about this? Would you be happy to eat products labelled as 'Very Low Gluten'?

Moderator to then ask for any difference if used with/alongside existing logos/labels for example 'suitable for coeliacs' and/or the 'cross grained symbol'.

- What difference does this make? What does the additional information add, if anything?
- Do you think that this makes it more/less helpful for you?

Overall:

- How useful will these changes be for you in making food choices? For what reasons?

Labelling in context – 20-30 mins
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- To understand how this new labelling will work in real life on the range of products that they buy, at POS and advertising

For group discussions:

Moderator to display a range of products as well as the respondent's pre task stimulus. Then ask:

- How would you feel if these new labels were on all of these packs?
 - o Instead of the current labelling / symbols?
 - o In addition to the current labelling / symbols?
- What extra reassurance does this give? Why?
- Does the addition of the new labelling solve any confusion around you/your child's food choices? Why/why not? Does it add any confusion?
- Is more information required? What information is that?
- How could they make the new labels more effective? (without changing the words on labels for example "gluten-free" and "Very Low Gluten")
- How about if they had these labels as a sign/on leaflets to talk about appropriate foods in the supermarket? How useful/helpful would they be?
- How about if products were advertised using these labels? How would you feel about that? Benefits/concerns?

For Depth interviews:

Moderator to take respondent to their local supermarket so that we can understand how the new labels might be viewed in context. Allow the respondent to spend 10 minutes shopping for products where they have to read the packs (for example sauces) and then 10 minutes specifically within the gluten-free aisle. Ensure that you cover a range of products including stores own branded gluten-free and more general products

- How would you feel if these new labels were on all of these packs?
 - o Instead of the current labelling?
 - o In addition to the current labelling?
- What difference would it make?
- What does it add when combined with the additional information?
- How do you imagine these labels will help you?
- Would it give you any extra reassurance?
- Is this the only information you/your child would need? If not what else might you need?
- If one product had the new labelling compared to a product just with the old labelling would it make your choices clearer? Why?
- Does the addition of the new labelling solve any confusion around you/your child's food choices? Why/why not?

Informing consumers about change – 10 mins

To explore the best way to inform people about the changes to labelling and how best explain how this will affect the labels on pre packed foods.

NB: in this discussion moderator to reference previously mentioned information sources.

- What would you consider to be the best way to inform those with Gluten intolerance/coeliac disease or affected by it (i.e. parents of child sufferers) about these changes in labelling? Give examples of preferred routes.
- Where would you expect to see information about these changes? Anywhere else?
- Who would you most/least trust to tell you about these changes? Why those?
- Would you expect to receive the information from the sources you currently use?
- Why from these sources?
- Is more information required? What information is that?
- In the ideal world how would you find out about new information?

Last comment – 5 mins

To summarise user thoughts and ideas, focusing on key needs and issues

- What difference do you think the new labelling system will make?
- What additional support/information do you think would be helpful to those people with gluten intolerance when these new labels are brought in
- If it was your responsibility, how would you best communicate the new changes and the meanings of the new labelling?
- Is there anything else you would like to say in light of today's discussion?
- Would you be willing to take part in any future FSA research and for your contact details to be kept for this purpose only?
- If any further information is required please go to www.eatwell.gov.uk

Thanks and close

Appendix 3

Discussion Guide (Health Professionals)

1711 FSA – Food labelling on foods marketed for people with gluten intolerance / coeliac disease

1 hour Depth Interviews with Health professionals

N.B. This Guide indicates the areas to be explored in the discussion, the likely order in which topics will be covered and the kinds of questions and techniques which may be used. There will be some flexibility of discussion, however, to account for each individual being interviewed, and to focus on areas most relevant to them.

Not all respondents will respond to the same level of language or explanation. While the questions below details how we intend to cover topics in our own 'language', efforts will be made to meet the communication needs of the individuals interviewed.

Timings on the guide are approximate and give an indication of where the emphasis in the conversation will be.

Stimulus Materials required:

- New labelling stimulus
- Selection of food packaging

Introduction and Background – 5-10 mins

- Moderator

Moderator to introduce self, explain the process of market research to respondents and the format of the interview/discussion

- Inform

Explain topic of discussion is on Gluten Intolerance and in particular labelling on foods that are marketed specifically for those people with gluten intolerance / coeliac disease. We do not need to seek information on the suitability or otherwise of oats, but instead, concentrate on the labelling of processed foods. Reiterate independence of Define in development process and the need for honesty to help with research. Ask if they are happy for the interview to be recorded and reassure on confidentiality and that any comments will not be attributed to them (unless they are happy for us to do so).

To establish respondent context and warm up – briefly

- How long have you been working in your current job?
 - o When did you first start working in the area of (specify their general area of expertise here)?
 - o What other roles have you had over the years?
- What level of interaction do you have with those with gluten intolerance/ coeliac disease in the context of your overall role and responsibilities?

Advice given and sources used – 10 mins
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To understand what sources of information are typically used by Health Professionals.

General

- What tends to be the typical queries/concerns that your clients/patients have in regard to gluten intolerance/coeliac disease and making their food choices?
- What other key concerns do they have? Any others?

Food choices

- Can you tell me what sort of advice you tend to give to your clients/patients about what they can buy and eat?
- What is the process you go through when advising on the choices that people have about what they can eat and drink?

(Moderator to allow respondent to describe this process spontaneously, and then to prompt as appropriate and necessary):

- o Can you describe a typical conversation you might have when advising on what foods a client/patient with gluten intolerance/coeliac disease can eat. Do you talk about how to find the information they need on a food label?
- o How might this vary? For what reason(s), and what respect(s)? E.g. Does this vary at all depending on the severity of their condition/length of time affected by their condition? Does this differ by age of sufferer/if a parent is making food choices for a child? How do you consider foods available on prescription?
- Which pieces of information/advice on appropriate food choices do you feel is most useful/valuable to clients/patients? Why?
- Which are less useful/valuable? And why?
- When advising clients/patients what might you give them/direct them towards to get more information? Why these places?

(Moderator to allow respondent to describe signposting spontaneously, and then to prompt as appropriate: print, on-line, verbal, etc giving full details of each)

- How confident do you feel using/referring to these sources of information? Why?
- Do you feel you have/there is enough / too much information to advise your patients/clients? Is there anything that would help you/your clients in terms of information needs?

Specifically for Dietitians working at Coeliac UK (discuss where appropriate)

- *When people call you are you their first point of contact? If no, who else have they tended to have spoken to? If yes, why do they think that is?*
- *Who else do people tend to speak to most often for information/advice on their gluten intolerance and the food choices they make?*
- *When they call you what are their typical queries about food choices?*
- *What tends to be the main (most heard) query about food choices? For what reasons? How do you address this query?*
- *What are their key concerns? What about when considering shopping and food choices?*
- *What do you feel it is like for coeliacs when trying to make food choices?*

Labelling and sign posting – 10 mins

Aim to evaluate Health Professionals' attitudes towards current labelling including the perceptions of their clients and patients, helping to identify potential issues that those with coeliac disease may have.

Some of the following may have been discussed in the previous section, moderator to ask as appropriate:

- Can you tell me all of the current methods of labelling on foods to allow those with gluten intolerance /coeliac disease to avoid gluten? (respondent to give a list)
- Which of these methods are you more/less familiar with? Why?
- What are the typical questions you get asked by clients/patients with regard to labelling?
- How confident are people about the information provided by the manufacturers? Why? Are there typical areas of confusion? Are there areas of concern? [gain examples where possible]
- What is the most common concern around labelling? Why?
- Are there areas of labelling clients/patients feel more/less confident with?
- What advice around shopping for appropriate foods and the labels to look for would you offer to clients/patients? For what reasons?

Moderator to then prompt with if not raised spontaneously:

- Previously products marked as 'gluten-free' or 'Suitable for Coeliacs' may have contained anything up to 200 parts of gluten per million. Where you aware of this?
- What about allergy advice boxes, or 'cross grain symbol' or 'gluten-free' or 'suitable for coeliacs' symbols / icons?
 - Are any of these something that you tell people to look out for?
 - Do you have any sense about how people feel about using these to make choices?
- Any other strategies you advise? [spontaneous then prompt reading ingredients list on food packaging, sticking to certain brands, using certain supermarkets]
- Any other strategies specifically for children?
- Overall, in your experience, what works best for clients/patients in terms of labelling?

Reaction to new labelling – 15 mins

To understand any awareness of new labelling, then spontaneous reaction to the new labels.

- Are you aware of the new labelling that is coming into effect on products for those with a gluten intolerance/coeliacs?
- If yes, what have you seen? When and where did you see it? What have you heard about? Where did you hear about this?
- If No, Where would you first expect to hear about any changes to labelling?
- What would be the best place to inform people like you about changes? – explore channels to inform HPs and also their thoughts on channels to inform consumers.

Moderator to explain that a new EU legislation means that in future the use of the label claims 'gluten-free' and 'Very Low Gluten' will be strictly controlled and that new lower levels of gluten will have to be met to be able to use these terms. From 2012 only foods which conform to a specified criteria will be allowed to use these phrases and the claim will have to be put on the front of pack.

Stimulus:

Label: 'gluten-free'

Gluten Content: "Allowed on foods that contain less than 20 parts per million gluten"

Suitability: Most people with coeliac disease will be able to eat all of these foods

Label: 'Very low gluten'

Gluten Content: 'These will include those products which are manufactured using a special type of starch that has been treated to take out almost all of the gluten and will generally have a higher level of gluten in them (up to 100 parts per million)'

Suitability: Not everyone will be able to eat these foods, so it will be important for those with a gluten intolerance to speak to a doctor or dietician before introducing them into their diet

Moderator to show each new label in turn and get spontaneous reactions as to understanding i.e. 'gluten-free' and 'Very Low Gluten' and then go on to explain the maximum level of gluten allowed (order in which these are shown are rotated across interviews). And then go on to explain suitability, as follows:

Show/discuss label as stand alone

- What do you think of this?
 - Initial Reactions – what do you think it means? What do you think your clients/patients will think it means?
 - How useful or otherwise is this labelling?
 - How well does this sit with current labelling? Is it likely to cause any confusion? Why?

- o Is this the only information that clients/patients would need? If not what else might they need as well as [note any spontaneous thoughts]
- o What other comments do you have about the new phrase?
- o What else did you expect from new labels? Anything else?

Show parts per food allowed linked to label

- How easy is it to understand? Why?
 - o Benefits/issues?
 - o How useful would this be for your clients/patients? For what reasons? Will it feel more or less useful for them compared with current practices?
 - o Does it help to clarify any issues/concerns for clients/patients? How?
 - o What does that term mean in the context of those with gluten intolerance/coeliac disease?
 - o Do you think you would still suggest this as suitable for all those clients/patients that you see? Why/why not?
 - o How aware do you think your clients/patients are of the meaning of this term and that they may be able to still safely eat products with this label?

Describe suitability

- Does this surprise you?
 - o What do you think that your patients/clients would think in terms of suitability for them?
 - o Is there any risk of confusion?
 - o Now that you know this, what do you think of the labels?
 - o Do you think that this needs further clarification?

Moderator: We would like you to imagine this is on a pack (show a couple of food packs to demonstrate in face to face interviews)

Moderator to then ask for any difference if used with/alongside existing logos/labels for example 'suitable for Coeliacs' and/or the 'cross grained symbol'.

- What difference does this make? What does the additional information add, if anything?
- Do you think that this makes it more/less helpful for your patients/clients?

Overall:

- How useful will these changes be for your clients/patients in making food choices? For what reasons?
- How useful will they be for you in advising patients/clients? For what reasons?
- Do you think they will understand the difference between the two phrases?

Informing consumers about change – 5-10 mins

To explore the best way to inform people about the changes to labelling and how open they are to convey these changes. (Some of this may have come out in the discussion on Reaction to new labelling.)

- What would be the best way to inform you as a health professional about these changes to labelling? Give examples of best routes
- What would you consider to be the best way to inform those with gluten intolerance/coeliac disease about these changes to labelling? Give examples of ideal routes.
- How willing would you be to inform your clients/patients about these changes?
- What support would you need to help to convey these changes? How might you go about doing so?
- What do you think the role of FSA could be in informing you/your clients of these changes

Last comment – 5 mins

To summarise stakeholder thoughts and ideas, focusing on key needs and issues

- In your opinion, what would be the ideal way to best communicate the new changes and the meanings of the new labelling?
- Are there any other things that the FSA should consider when thinking about information and communication to those with Gluten intolerance/Coeliac disease?
- Any other comments?
- Would you be willing to take part in any future FSA research and for your contact details to be kept for this purpose only?
- If any further information is required please go to www.eatwell.gov.uk – FSA website

Appendix 4

Food Diary

Food Diary

- Thank you for agreeing to take part in this research.
- In asking you to complete the food diaries we are aiming to gain 3 main pieces of information:
 - What type of food you / your child eats
 - What brand of food you / your child eat
 - Why you have chosen to eat a particular type of food for example indicates it was suitable for coeliacs, I have always eaten it, it was recommended by my doctor.
- Please complete this food diary (using the instructions for completion) and bring it along to the research session where it will be used to discuss what labels and information people find useful on a day-to-day basis.
- Please could you also bring 2-3 packs of food to illustrate what information you use. These could be empty packs of food that you've used or packs that you are still using – whichever is most convenient to you.

Thank you in advance for your help

Name: _____

please tick as appropriate:

- ☐ I am gluten intolerant
- ☐ My child is gluten intolerant

Food Diary

Instructions for completion

- Please pick 3 days in the coming week (they can be consecutive or not either weekdays or weekends).
- On the days chosen, simply write down anything you / your child eats and drinks (whoever is the gluten intolerant individual).
- Please give details of what is eaten and record the names and /or brand of any commercial food you eat for example Tesco wholegrain rice, Sainsbury's chicken curry.
- We do not need you to record quantities of food eaten.
- As well as knowing what you eat, we are also interested in knowing why you chose to eat a particular product, i.e. what was the information on the pack that you used to determine that it was suitable for you / your child. for example the label, the brand, ingredient list, allergy box, etc.
- If you ate out, please record the information used to make your decision, for example it was on the menu, told restaurant staff specific dietary requirements, etc.
- Try to write down when they are eaten, so foods are not forgotten. It should only take a minute or two to complete.
- Feel free to contact if you have any questions

Once again thank you for completing these diaries

EXAMPLE: Day one (Date: Friday 20th March 2009)

	What did you/your child eat? Please write down the foods you ate and the brand of food (i.e. Tesco's wholegrain rice). You do not have to state quantities.	Brand	Why you chose to eat/your child to eat this particular kind of food? (please note reason for example brand, label, symbol, ingredient list etc. Where this is not appropriate, please mark N/A)
6am - 9am	Fruit salad Toast Strawberry jam	N/A Dietary specials Sainsbury's	N/A The label said gluten-free I assumed this is gluten-free as I have always eaten this product
9am - 12pm	Apple and a pear	N/A	N/A
12pm - 3pm	Pre packed chicken and potato salad with fresh tomatoes and rocket Yogurt	Boots Boots	Said "Suitable for Ceolians" on the label The allergy box said it did not contain gluten

EXAMPLE: Day one (Date: Friday 20th March 2009)

	What did you/your child eat? Please write down the foods you ate and the brand of food (i.e. Tesco's wholegrain rice). You do not have to state quantities.	Brand	Why you chose to eat/your child to eat this particular kind of food? (please note reason for example brand, label, symbol, ingredient list etc. Where this is not appropriate, please mark N/A)
3pm - 6pm	Bar of chocolate	Cadbury's	I checked ingredients list
6pm - 10pm	Apple and a pear Broccoli, carrots, peas Whole grain rice Gravy	Tesco N/A Sainsbury's Sainsbury's	N/A N/A I eat rice regularly-I know it is gluten-free Had the gluten-free symbol on the product
10pm - 6am			

DAY ONE (Date:)

	What did you/your child eat? Please write down the foods you ate and the brand of food (i.e. Tesco's wholegrain rice). You do not have to state quantities.	Brand	Why you chose to eat/your child to eat this particular kind of food? (please note reason for example brand, label, symbol, ingredient list etc. Where this is not appropriate, please mark N/A)

DAY ONE (Date:)

	What did you/your child eat? Please write down the foods you ate and the brand of food (i.e. Tesco's wholegrain rice). You do not have to state quantities.	Brand	Why you chose to eat/your child to eat this particular kind of food? (please note reason for example brand, label, symbol, ingredient list etc. Where this is not appropriate, please mark N/A)

DAY ONE (Date:)

	What did you/your child eat? Please write down the foods you ate and the brand of food (i.e. Tesco's wholegrain rice). You do not have to state quantities.	Brand	Why you chose to eat/your child to eat this particular kind of food? (please note reason for example brand, label, symbol, ingredient list etc. Where this is not appropriate, please mark N/A)

DAY ONE (Date:)

	What did you/your child eat? Please write down the foods you ate and the brand of food (i.e. Tesco's wholegrain rice). You do not have to state quantities.	Brand	Why you chose to eat/your child to eat this particular kind of food? (please note reason for example brand, label, symbol, ingredient list etc. Where this is not appropriate, please mark N/A)

DAY ONE (Date:)

	What did you/your child eat? Please write down the foods you ate and the brand of food (i.e. Tesco's wholegrain rice). You do not have to state quantities.	Brand	Why you chose to eat/your child to eat this particular kind of food? (please note reason for example brand, label, symbol, ingredient list etc. Where this is not appropriate, please mark N/A)

DAY ONE (Date:)

	What did you/your child eat? Please write down the foods you ate and the brand of food (i.e. Tesco's wholegrain rice). You do not have to state quantities.	Brand	Why you chose to eat/your child to eat this particular kind of food? (please note reason for example brand, label, symbol, ingredient list etc. Where this is not appropriate, please mark N/A)

Appendix 5

Food Diaries Examples

- Cornflakes and Muesli – Mesa Sunrise and Alara
 - *“Both are branded as gluten-free”*
- Biscotti di Riso- La Finestra sul Cielo
 - *“Bought in Italy by my daughter as branded as gluten-free”*
- Bread: home-made with Juvela flour
 - *“Juvela flour obtained on prescription”*
- Blueberry muffin - Glutafin
 - *“Given as a food sample”*
- Chocolate – Quality Street
 - *Classified within the ‘Food and Drink’ Directory*
- Chocolate Biscuit – Tesco
 - *“Gluten-free label”*
- Thai Stir-fry sauce - Uncle’s Ben
 - *“Nothing specified on the packaging but the ingredients did not state that it contained any wheat or gluten neither did it say in the allergy section”*
- Fruit Yoghurt- Sainsbury
 - *“Did not state ‘gluten-free’ but the ingredients were ‘gluten-free’. The packaging only stated it contained cow’s milk as allergy warning”*
- Crisps- Walkers
 - *“States ‘suitable for Coeliac”*
- Spread – Heinz
 - *“States it is gluten-free”*
- Pesto sauce- Sacla
 - *“No wheat and no gluten in the ingredients”*
- Rice pops – Sainsbury’s
 - *“Label said “suitable for Coeliacs”*

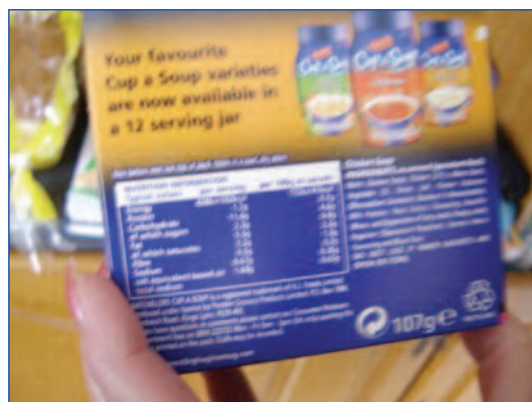
- Chocolate Easter eggs – Sainsbury's
 - *"Said it had no gluten"*
- Oat biscuits - Sainsbury
 - *Said it only contained "oat gluten"*
- Cottage cheese and pineapple – Sainsbury's
 - *"Gluten-free on label"*
- Salmon fillet with vegetables – Sainsbury's
 - *"Naturally gluten-free"*
- Rice noodles – Blue Dragon
 - *"States gluten-free"*
- Bar of chocolate – Cadburys
 - *"I checked the ingredient list"*
- Whole-grain rice – Sainsbury's
 - *"I eat rice regularly, I know it is gluten-free"*
- Gravy – Sainsbury's
 - *"Had the gluten-free symbol on the product"*
- Toast – Dietary Specials
 - *"The label said gluten-free"*
- Strawberry Jam – Sainsbury's
 - *"I assume it's gluten-free as I have always eaten this product"*
- Pre-packed chicken and potato salad – Boots
 - *"Said 'Suitable for Coeliacs' on the label"*
- Yoghurt
 - *"The allergy box said it did not contain gluten"*

Appendix 6

Photos (Depth In-home Interviews)







Appendix 7

Approach Letter to Health Professionals

Health Professionals: Comfort Letter

www.food.gov.uk



xxxxxxxxxxxxxxxx 2009

Dear xxxxxxxxxxx

LABELLING OF GLUTEN LEVELS IN FOOD

We are currently conducting research on gluten intolerance and food labels.

As part of our study we wish to conduct face-to-face interviews with a range of Health Professionals who work with people with gluten intolerance, to understand the current issues, concerns and questions that people with gluten intolerance have in terms of making appropriate food choices, as well as understanding the Health Professionals' own perspective on this subject.

We would very much appreciate your participation in this research. The interview can be conducted at a time and venue of your choice, and will last approximately one hour. Ideally the research would be conducted within working hours, however if this is not possible then in accordance with standard market research practice, a compensation payment of £xx will be provided by Define to you as a token of appreciation.

The research is being carried out by Define Research and Insight Ltd, an independent market research company. Define is a member of the Market Research Society and are bound by their code of conduct (for further details please visit www.mrs.org.uk). Define have been commissioned by the Central Office of Information (COI) who monitor for quality control and manage research on our behalf.

Your comments will form part of the feedback but will not be attributed personally to you, and will be kept anonymous (unless specifically instructed otherwise by you).

Any personal details (for example, names, address) will be kept confidential, held securely and will not be used for any purpose beyond this specific project unless you give permission to do so. All these details will be removed from our records on completion of the project.

..... from Define will contact you over the next few days to ask if you are able to help with this project. If you have any questions in the meantime please contact Victoria Page, Project Manager, Define on 020 8346 7171. I do hope you can help us with this project.

Yours sincerely

Danielle De Feo
Social Science Research Officer
Analysis & Research Division

020 7276 8499

Appendix 8

Health Professionals: Recruitment Questionnaire

Job number

1711

COI/FSA RECRUITMENT QUESTIONNAIRE: Food labelling

Interviewer:.....

Respondent:.....

Address:.....

.....Post Code:.....

Tel:.....(Hm).....(Mob)

INTRODUCTION

Good morning/afternoon/evening. My name is (...) from **Define** an independent market research company. We are conducting research on behalf of the Food Standards Agency and we are looking to speak to different Health Professionals who advise people with gluten intolerance. All the answers that you give in this questionnaire will be completely confidential.

If you have any questions about the research please call Define Research and Insight on 0208 346 7171. Please ask to speak Victoria Page, Research Director, who will be happy to answer questions you may have.

At no time during the interview/discussion will any attempt be made to sell anything to you, this is purely a research exercise.

First, could you spare me a few minutes of your time to answer a few simple questions?

QA. Do you or any of your close friends or relatives work in the following occupations?

Market Research	1 – CLOSE	Journalism	2 – CLOSE
Advertising/Marketing	3 – CLOSE	Government	4 – CLOSE
Television	5 – CLOSE	Public Relations	6 – CLOSE
Food manufacturing	7 – CLOSE		

QB. Have you ever taken part in a market research depth interview or group discussion on any subject?

YES 1 When was this? _____
What subject? _____

NO 2 **CLOSE** -> IF TOOK PART IN ANY MARKET RESEARCH IN LAST 6 MONTHS
CLOSE -> IF ATTENDED ANY MARKET RESEARCH AT ANY TIME ON SIMILAR SUBJECT

QC. Male/FemaleAIM FOR SPREAD

QD. What is your age?

Under 40 1

Over 40 2

AIM FOR SPREAD

MAIN QUESTIONNAIRE

Q1. Which of the following describes your occupation?

GP	1	
Practice Nurse	2	
Pharmacist	3	
Dietician	4	Go to 1b
Nutritionist	5	CLOSE

Q1b. As a dietician are you currently registered with the British Dietetic Association?

Yes	1	<i>Continue</i>
No	2	CLOSE

Q2. In your current role have you in the last 12 months given advice to or diagnosed people who are gluten intolerant or who have Coeliac disease?

Yes	1	
No	2	CLOSE

Q3. How long have you been a health professional?

Up to 5 years	1	
5-10 years	2	
10 years plus	3	

AIM FOR A SPREAD

Thanks, recruit and hand respondent invite and letter

Appendix 9

Parents/Coeliacs: Recruitment Questionnaire

Parents/Sufferers: Recruitment Questionnaire

Job number

1711

COI/FSA RECRUITMENT QUESTIONNAIRE: Food labelling

Interviewer:.....

Respondent:.....

Address:.....

.....Post Code:.....

Tel:.....(Hm).....(Mob)

INTRODUCTION

Good morning/afternoon/evening. My name is (...) from **Define** an independent market research company. We are conducting research on behalf of the Food Standards Agency and we are looking to speak to different people gluten intolerance and food labeling. All the answers that you give in this questionnaire will be completely confidential.

If you have any questions about the research please call Define Research and Insight on 0208 346 7171. Please ask to speak Victoria Page, Research Director, who will be happy to answer questions you may have.

At no time during the interview/discussion will any attempt be made to sell anything to you, this is purely a research exercise.

First, could you spare me a few minutes of your time to answer a few simple questions?

QA. Do you or any of your close friends or relatives work in the following occupations?

Market Research	1 – CLOSE	Journalism	2 – CLOSE
Advertising/Marketing	3 – CLOSE	Government	4 – CLOSE
Television	5 – CLOSE	Public Relations	6 – CLOSE
Healthcare industry	7 – CLOSE	Food manufacturing	8 – CLOSE
Healthcare professional	9 – CLOSE		

for example GP, Nurse, Dietician

QB. Have you ever taken part in a market research depth interview or group discussion on any subject?

YES 1 When was this? _____
What subject? _____

NO 2 CLOSE -> IF TOOK PART IN ANY MARKET RESEARCH IN LAST 6 MONTHS

CLOSE -> IF ATTENDED ANY MARKET RESEARCH AT ANY TIME ON SIMILAR SUBJECT

QC. What is the occupation of the head of your household?

.....

A B C1 C2 D E CHECK QUOTA

QD. Male/FemaleCHECK QUOTA

QE. What is your age?

Under 40 1

Over 40 2

CHECK QUOTA

QF. What is your current living situation?

Single, no children 1

Married/co-habiting, no children 2

Single/Married/Co-habiting children living at home 3

Single/married/co-habiting children now not living at home 4

AIM FOR SPREAD

QG. Which of these best describes you?

White British

White Irish

Any other white background

Mixed - White and Black Caribbean

Mixed - White and Black African

Mixed - White and Asian

Any other mixed background

Indian

Pakistani

Bangladeshi

Any other Asian Background

Caribbean

African

Any other Black background

Chinese

Any other (please write in below)

--

MAIN QUESTIONNAIRE

Q1. Are you or is your child following a gluten-free diet?

YES, I am	1	
YES, my child is	2	
NO	3	<i>CLOSE</i>

Q2. How do you or your child follow this gluten-free diet?

I read the labels and avoid products containing gluten	1	
I buy/receive and eat products labelled as suitable for Coeliacs	2	
I buy and eat products labelled as 'gluten-free'	3	
Other _____.	4	CHECK WITH OFFICE

Q3. Are you responsible/jointly responsible for purchase of these types of products for you / your child?

Yes	1	
No	2	<i>CLOSE</i>

Q4. What are the reasons for you or your child to follow a gluten-free diet?

I want to manage my weight or my child's weight	1	<i>CLOSE</i>
I want to eat healthy/I want my child to eat healthy	2	<i>CLOSE</i>
Gluten makes me feel bloated and uncomfortable	3	<i>CLOSE</i>
I/my child has Coeliac disease	4	
I/my child am/is gluten intolerant and if I/my child do not follow a gluten-free diet, my health/my child's health can be affected	5	
Other – check with office	6	

NOTES TO THE RECRUITER: we are looking at recruiting respondents following a gluten-free diet for **genuine gluten intolerance only – these may or may not be those with Coeliac disease**. We would like to exclude from the research any respondents following a gluten-free diet for any other reasons: personal choice, lifestyle, weight management etc.

Q5. Which of the following best describes the severity of your/your child intolerance to gluten?

I am extremely intolerant to gluten, and I have very severe symptoms if I do consume any gluten	1	
I am very intolerant to gluten and would have a bad reaction even if only consuming a minute amount	2	
I am fairly intolerant to gluten, however if I have trace amounts of gluten I do not normally have a bad reaction	3	
I think I am a little intolerant to gluten - if I have some it can make me a little bloated	4	CLOSE

Q6. Have you ever sought medical help or advice with regards to gluten intolerance?

YES and I/my child have been diagnosed by a medical professionals as having Coeliac disease/being intolerant to gluten	1	Medically diagnosed
I am in the process of speaking to my GP/medical professional about my/my child's symptoms	2	
No I have not sought any medical help/advice	3	

CHECK QUOTA FOR SELF DIAGNOSED/MEDICALLY DIAGNOSED

Q7. How long ago did you find out that you/your child were intolerant to gluten?

Last 12 months	1	Recent sufferers
Last 1-2 years	2	
2-5 years ago	3	3
Between 5-10 years ago	4	4
Over 10 years ago	5	5

SPREAD OF RECENT VS LONGER TERM SUFFERERS

Q8. Which symptoms have you/your child ever experienced as a result of gluten intolerance?

Please ask respondents to spontaneously mention any symptoms they have experienced. Then prompt with list below and see if they match with some of the list below. This is to ensure we identify the right respondents who genuinely suffer from gluten intolerance i.e. should code more than just bloating or tiredness

Symptom	Spontaneous	Prompted
Bloating		
Abdominal pain		
Nausea		
Diarrhoea		
Excessive wind		
heartburn		
Indigestion		
Constipation		
Any combination of iron, vitamin B12 or folic acid deficiency		
Tiredness, headaches		
Weight loss (but not in all cases)		
Recurrent mouth ulcers		
Hair loss (alopecia)		
Skin rash (dermatitis herpetiformis- 'DH')		
Defective tooth enamel		
Osteoporosis		
Depression		
Infertility Recurrent miscarriages		
Joint or bone pain		
Neurological (nerve) problems such as ataxia (poor muscle co-ordination) and neuropathy (numbness and tingling in the hands and feet).		

Q9. Are you a member of Coeliac UK?

Yes	1
No	2

Thanks, recruit and hand respondent invite and letter

Appendix 10

Invite Letter for Coeliac UK

Date

Addressee

Dear

Market Research Invite; Labelling of Gluten Levels in food

We are currently conducting some market research on understanding views on labeling of gluten levels in food.

As part of our study we would like to speak to members of Coeliac UK to understand how they feel about the current labels being used to identify suitable foods for people with a gluten intolerance.

The research is being carried out by Define Research and Insight Ltd, an independent market research company. Define is a member of the Market Research Society and bound by their code of conduct (for further details please visit www.mrs.org.uk). Define have been commissioned by COI who monitor for quality control and manage research on our behalf.

Define are looking to invite members of Coeliac UK (either those with gluten intolerance or those with children who have gluten intolerance) to take part in either a one to one interview or a group discussion (with other members) over the next few weeks.

The interviews would take place in your home and then to your local supermarket to understand how you use labels whilst shopping. The group discussions would take place in a local location. The content of the discussion would be around your current shopping habits, which labels/logos/phrases/brands you use/ don't use to identify appropriate foods as well as the places where you look for information and advice. The sessions would last 1½ hours and as an appreciation of your time you would receive £40 from Define as a thank you for taking part.

During the research, any comments given will form part of the feedback but will not be attributed personally to you, and will be kept anonymous. Personal details will also be kept confidential to Define, not used for any purpose beyond this specific project and removed from their records on completion of the project.

If you are interested in taking part, please contact either Define direct by calling Alison Samuel, Field Director on 020 8346 7171, or emailing field@defineinsight.co.uk or contact xxx at Coeliac UK who if you are happy will forward your details to Define.

It would be greatly appreciated if you could respond by the 10th March if you are interested in taking part.

I do hope you can help us with this important project.

Yours sincerely

Appendix 11

Letter to Respondents Who Have Been Recruited

Dear Sir/Madam,

Food Labelling Research

Thank you for agreeing to take part in this piece of market research on gluten intolerance and food labelling

The research is being carried out by Define Research and Insight Ltd, an independent market research company, on behalf of the Food Standards Agency. We are a member of the Market Research Society and bound by their code of conduct (for further details please visit www.mrs.org.uk).

Your comments will form part of the feedback but these will not be attributed personally to you and will be kept anonymous. Any personal details (for example, names, address) will be kept confidential, held securely and will not be used for any purpose beyond this specific project unless you have given permission to do so. All these details will be removed from our records on completion of the project.

If you have any further questions please feel free to call me on the following number 020 8346 7171.

Yours faithfully,

Victoria Page

Research Director

Appendix 12

Permission for Further Research Letter

Dear Sir/Madam,

Permission for contact details

Thank you very much for taking part in this research. Your views are very valuable and you have played an important part in helping us and the Foods Standards Agency (FSA) understand the issues around labelling for those with gluten intolerance.

The FSA may wish to contact you in the future to take part in further research and therefore seek your permission for your name, address and telephone number to be passed on to them for this purpose only. We must stress that your personal details will not be attributed to what you have said today – we are merely asking your permission to pass your contact details only onto the FSA for the purposes of further research only.

Your details will be stored securely by the FSA and you will only be re-contacted for the purposes of further research. Giving permission now does not mean you have to participate at a later date. As with all research, you will have the option to opt-out throughout the research, should you not wish to take part.

If you do give your permission for your details to be forwarded, then Define will transfer the data (name, address and telephone number only) via encrypted CD and secure courier to the FSA, where it will be stored in a locked drawer. Define will not retain your details after this point.

If you have any further questions please feel free to call me on the following number 020 8346 7171.

Yours faithfully,

Victoria Page

Research Director

