

Understanding of Food Labelling Terms

Used to Indicate the Absence or Reduction of Lactose, Milk or Dairy

Research among Consumers, Health Professionals and
Food Businesses

Contents

EXECUTIVE SUMMARY	5
Background and Research Method	5
Key Findings	6
Conclusions	14
1 INTRODUCTION	19
1.1 Background	19
1.2 Aims and Objectives	19
1.3 Research Method	20
2 UNDERSTANDING OF, AND ATTITUDES TO, CONDITIONS INVOLVING A SENSITIVITY TO MILK: THE CONSUMER PERSPECTIVE	26
2.1 Introduction	26
2.2 Symptoms	27
2.3 Diagnostic ‘journey’	28
2.4 Advice and information	31
3 UNDERSTANDING OF, AND ATTITUDES TO, CONDITIONS INVOLVING A SENSITIVITY TO MILK: THE HEALTH PROFESSIONAL PERSPECTIVE	35
3.1 Experience of Milk Sensitive Patients	35
3.2 Diagnostic ‘Journey’	37
3.3 Advice and Information	39
4 FOOD CHOICES: THE INDUSTRY PERSPECTIVE	49
4.1 Introduction	49
4.2 Serving the Milk Sensitive Consumer	49
4.3 Information and advice	52
4.4 Pack Labelling and Use of Claims	54
4.5 Support for claims	59

5	CONSUMERS' BEHAVIOUR AROUND FOOD CHOICES AND SHOPPING	62
5.1	Introduction	62
5.2	Changing their Diet	62
5.3	Food Choices and 'Risk Taking'	65
5.4	Shopping	70
5.5	Use of Pack Labelling	72
5.6	Information sought	75
5.7	Confusions	77
6	UNDERSTANDING OF FOOD LABELLING TERMS	80
6.1	Introduction	80
6.2	Underpinning Framework	80
6.3	'Dairy free'	81
6.4	'Milk free'	84
6.5	'Lactose free'	86
6.6	The Business View	89
6.7	Preferences	93
6.8	Views on a Way Forward	96
7	CONCLUSIONS	104
7.1	Use of the Terms: 'dairy free', 'milk free' and 'lactose free'	104
7.2	Understanding of and Preference for the Terms	105
7.3	Increasing Understanding of the Terms	106
	APPENDICES	108
	Appendix 1: Research Method	108
	Appendix 2: Recruitment Screening Questionnaires	113
	Appendix 3: Letters of introduction	126

TABLES

Table 1: Consumer sample: summary of characteristics21

Table 2: Description of Milk Sensitive Conditions22

Table 3: Summary of main discussion guide points by audience25

Table 4: Respondents’ symptoms by condition28

Table 5: Consumer sample by medical condition 108

Table 6: Consumer sample by location and condition 109

Table 7: Consumer sample by location and gender 109

Table 8: Consumer sample by condition and gender 109

Table 9: Consumer sample by socio-economic group and condition..... 110

Table 10: Consumer sample by socio-economic group and gender..... 110

Table 11: Consumer sample by ethnicity and condition 110

Table 12: Consumer sample by ethnicity and gender..... 110

Table 13: Consumer sample by diagnosis..... 111

Table 14: Health professionals by role and location 111

Table 15: Business Sample 112

FIGURES

Figure 1: The relationship between ‘dairy’, ‘milk’ and ‘lactose’20

Figure 2: Schematic framework underpinning understanding of the terms81

Executive Summary

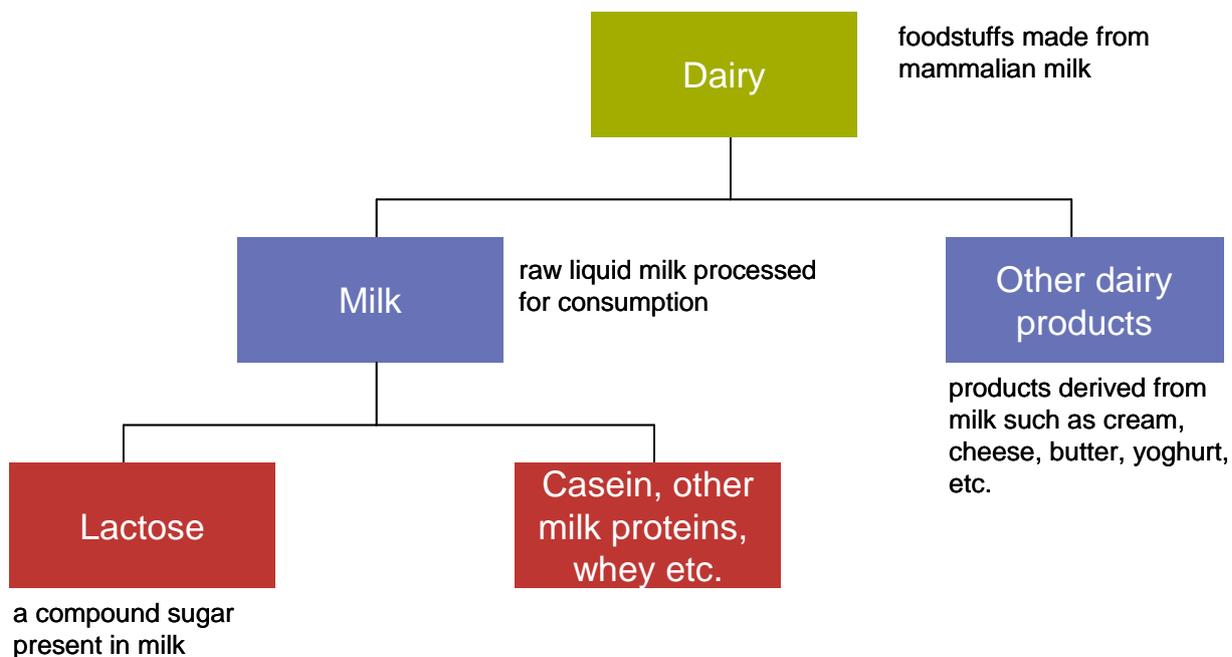
Background and Research Method

This research was commissioned by the Food Standards Agency to help guide UK input into negotiations on legislation that may arise from the development of EU-wide management thresholds for the absence or reduction of lactose in foods and the setting of common rules for the use of labelling terms associated with these thresholds. It should also help to inform the development of guidance to health professionals and the food industry that would accompany any new legislation.

The overall aim of the research is to explore understanding of the terms used on food labelling - 'dairy free', 'milk free', 'lactose free' and others - among three key audiences: consumers with some form of sensitivity to milk, health professionals who may advise such consumers, and food businesses who produce, retail and market products suitable for these consumers.

The relationship between the three components - 'dairy', 'milk' and 'lactose' - is shown schematically in Figure 1.

Figure 1: The relationship between 'dairy', 'milk' and 'lactose'



Sixty-three interviews, a mix of telephone and face to face, were conducted in total, half of these (32) were with consumers with the remainder split between health professionals (15) and food businesses (16).

Key Findings

Consumers' understanding, use of, and preference for, the labelling terms

Consumers with each of the conditions do not present a homogeneous picture with respect to the severity of their condition, the symptoms and their attitude towards these. A clustering of consumers according to the level of caution with which they approach their diet and shopping for food is suggested. The most cautious (often the most severely affected) follow a strict diet that is carefully planned and accordingly are extremely vigilant with respect to food labels. While they might buy from the 'free from' range of products or look for on-pack positive claims such as 'dairy free', they would nevertheless claim to scrutinise the back of packs for allergens. They felt they could not trust even their staple products not to change their recipe. The reasonably cautious (sometimes those whose tolerance has improved with time), while still cutting out the main problem foods, adopt more of a trial and error mindset and may claim to use common sense to decide what they might try. They would therefore tend to look in detail at the labels on products about which they were unsure or if they were considering buying something that was new. The least cautious (often those who are lactose intolerant and who can tolerate a small amount of milk) might not avoid milk and milk products altogether but ingest them in smaller amounts and be prepared to put up with the repercussions if they overstep the mark. They often had a fairly dismissive attitude to labelling, feeling that making choices was common sense; they were also happy to trust labels making 'dairy free' and similar claims.

Given this context, it can be seen that consumers looked out for the labelling terms 'dairy free', 'milk free' and 'lactose free' to varying degrees. Indeed, some were unaware that products were available with such labels. In discussing their understanding of the terms and preference for them, this was therefore often done on a hypothetical basis rather than based on their experience. Apart from the fact that consumers had not previously considered what they understood by each of these terms,

their understanding was also hindered by a lack of clarity about the meaning of the terms, 'dairy', 'milk' and 'lactose'.

'**Dairy**' was universally seen as including both milk and products derived from milk such as cheese, butter and yoghurt. Question marks were raised however about whether the milk in question was always cows' milk or could include other mammalian milk, and whether eggs could be classed as 'dairy' (about a third of the consumers thought they could).

The common assumption was that a '**dairy free**' claim on a product meant that it was **completely free of both dairy and milk**. When it came to whether lactose would be present in a 'dairy free' product, again, most assumed that it would not be (because it came from milk) although there was some uncertainty. This was based on a lack of understanding of what lactose was. It was questioned whether lactose might be present but from a source other than milk, or whether, as a sugar, it could be added.

All consumers, irrespective of their condition, thought that they should be able to eat/drink 'dairy free' products. Most also thought that people with other conditions could also eat/drink 'dairy free' products although there was a question over those with a lactose intolerance regarding the possibility of 'dairy free' products containing lactose. However, most of those who were lactose intolerant thought they could eat 'dairy free' products.

A claim of '**milk free**' was probably the least known and most confusing of the three with uncertainty surrounding what was included within the term '**milk**' – did it include milk from mammals other than cows, or milk derived from plants (such as soya milk), and most importantly, was it confined to liquid milk or could it include products derived from milk, essentially making it the same as 'dairy free' (except for the possible complication of eggs).

While respondents felt that 'milk free' denoted that the product was **completely free of milk**, they were uncertain as to just what this meant. While some concluded that it meant that it had no milk or milk derived products (and was therefore the same as 'dairy free'), others focused on it being free of just milk (liquid or powdered).

Opinion was therefore divided as to whether 'milk free' products were also **completely free from dairy** or not, with those who saw it as referring just to milk, feeling that the product **could still have other dairy products/derivatives** in it (such as cream, cheese and eggs). There was a similar divide in opinions about the presence of lactose. About two-thirds of consumers (most of whom were lactose intolerant) thought it would be **completely free of lactose** but **many were unsure**. This lack of certainty was mainly based on a lack of understanding of what lactose is but for a few, there was the same uncertainty as with 'dairy free' products about whether lactose could still be present.

'Milk free' was not the claim of choice for consumers (except for galactosaemics who saw it as more focused than 'dairy free') although they assumed that they would be able to eat/drink 'milk free' products. This was largely because they readily made a connection with 'dairy free' products. They also assumed that people with other conditions could also consume products making this claim.

Most consumers understood that '**lactose**' is part of milk but beyond this, there was often a lack of knowledge or confusion about the nature of lactose and how it related to milk and dairy. Many, especially among the lactose intolerant, were aware that it was a sugar but on several occasions it was also referred to as an enzyme. Those who were able to give some explanation of what '**lactose free**' meant suggested that the sugar in the milk had been removed but they did not necessarily have a clear picture.

'Lactofree' milk and other products in the range were the only products mentioned as being 'lactose free' products and while some of those using them understood they were still milk-based but had had the lactose removed, others were confused by the concept and could not envisage how one could have cows' milk without lactose.

It was generally assumed that 'lactose free' products would be **completely free of lactose** but there was **uncertainty over milk and dairy** content. Many thought there could be some milk in a lactose free product – in part because they know that lactose is only part of the milk and also because of their knowledge of 'Lactofree'. Similarly, many thought that low or normal levels of dairy could be present, for similar reasons.

All those who were lactose intolerant recognised that products making a 'lactose free' claim should suit them. All those with a milk allergy were unsure or believed that 'lactose free' would not suit them; one woman was able to articulate that this was

because her allergy is due to a milk protein rather than the lactose in milk. Half of those who were milk intolerant thought that they could eat/drink 'lactose free' products. In part this seemed to be due to a lack of knowledge of what it meant but it could also be in part down to an unclear definition of their condition. While consumers with galactosaemia felt they should be able to eat/drink 'lactose free' products because the assumption would be that the galactose had been removed with the lactose, 'Lactofree' has made them rethink this because it uses an enzyme to break down the lactose into its constituents (glucose and galactase) which means that galactose is still present.

Consumers were asked to place the three claims in order of preference but in reporting on the findings, it should be borne in mind that this did not mean that the other claims would necessarily have no use – rather, they selected the claim that had most resonance for them. Most opted for 'dairy free' because it was seen as more understandable and was often the term that health professionals used in advising them. It was also broader ranging in its coverage of potential allergens (a number had an intolerance to eggs and assumed incorrectly that these were dairy). A few, including those affected by galactosaemia, preferred the greater precision offered by 'milk free'. 'Lactose free' was chosen by about half of those with a lactose intolerance because such products were more tailored to their needs although they were aware that there were few products available making this claim and 'dairy free' was therefore likely to be more useful.

Health professionals' understanding of the labelling terms and the advice given to consumers on making suitable food choices

The majority of the consumers had consulted health professionals and received a diagnosis via this route. However, apart from a few with unresolved symptoms or other conditions, they were not seeing health professionals on a regular basis to review their condition. This demonstrated the importance of the window around the time of diagnosis for information to be given about making food choices.

Information and advice were in three broad areas: the nature of the patient's condition, the foods they can/cannot eat and suggested substitutes, and the use of food labels. The two main groups seen by health professionals were patients who were lactose intolerant and those who were milk allergic (often children who subsequently grew out of the condition). While advice to the former often involved working out by trial and error

whether they were able to tolerate small amounts of lactose in their diet (though some health professionals advised total exclusion), advice to the latter group was very different in tone and focused on the permanent exclusion of all forms of milk and milk products.

Health professionals varied in the detail of the advice they gave about food choices. Those who were most involved with patients with these conditions (often dieticians or practice nurses) often provided very detailed advice extending to, for example, the dangers of milk/lactose as fillers in foods. When it came to food labelling, these health professionals might go into great detail about deciphering on-pack information and might have examples to show patients. They appreciated the difficulties faced by patients in deciding what to buy and felt that providing information that the patient could take away was important. This might be printed from relevant websites or EMIS (Egton Medical Information Systems Limited), or published by their Health Care Trust but there was no standard resource available. Other health professionals were less prescriptive on the basis that failure to comply with milk/lactose avoidance mostly leads to neither serious nor long term effects in individuals with the more common conditions of lactose intolerance and milk intolerance.

Advice about labelling tended to focus on what patients should look out for and avoid in the ingredients list and allergen information rather than more positive claims such as found in the own brand 'free from' ranges of products or products labelled 'dairy free', 'milk free' or 'lactose free'. Patients might be made aware of the 'free from' section in supermarkets and these 'green light' terms (as they were sometimes called), but while they might make shopping easier, health professionals felt it was important that patients understood the specific constituents that they should avoid. There was some welcome for 'lactose free' milk as an option for those with lactose intolerance but not all health professionals were aware of it.

Responses from health professionals showed marked similarities to the consumers, both in terms of how they interpreted the three labelling terms, 'dairy free', 'milk free' and 'lactose free', and the fact that they found the task confusing.

Definitions of '**dairy**' were in line with those of consumers (e.g. milk plus other products derived from milk such as cream and butter) with some health professionals feeling that

dairy products might include types of mammalian milk other than cows' milk, and possibly eggs. They expected that **'dairy free'** products would be **completely free of both dairy and milk** but like the occasional consumer, they were sometimes uncertain about lactose, feeling that a product labelled 'dairy free' would not necessarily be 'lactose free' because it might be present in a form such as flavouring. While 'dairy free' products would be suitable for people with most forms of sensitivity to milk, a few health professionals therefore raised questions about whether 'dairy free' products would be appropriate for lactose intolerant patients.

'Milk free' claims caused some puzzlement among health professionals as they did among consumers with some questioning why a manufacturer would use this claim rather than the more familiar 'dairy free' and 'lactose free'. Health professionals were also divided on whether 'milk free' products were **completely free from dairy** or not, with those who saw the claim as referring just to milk itself, feeling that the product **could still have other dairy products/derivatives** in it (such as cream, cheese and eggs). Similarly with respect to the presence of lactose in 'milk free' products, some health professionals thought they would be **completely free of lactose** but **many were unsure** because again, lactose might be present in other forms. For this reason, health professionals agreed that 'milk free' products would certainly be suitable for milk intolerant and milk allergic patients but some were unsure about their suitability for those who were lactose intolerant.

While health professionals thought that 'lactose free' products would be **completely free of lactose**, they were **unsure about the milk and dairy** content. Many thought there could be milk in a 'lactose free' product – in part because they know that lactose is only part of the milk (other components such as casein might be present) and also because, in some cases, of their knowledge of 'Lactofree'. Many also thought that low or normal levels of dairy could be present.

'Lactose free' products were understood by health professionals to be suitable for lactose intolerant patients but not for those with a milk intolerance or allergy. However, in line with the confusion over what 'lactose free' meant, a proportion of health professionals felt that such products would also be suitable for those with a milk intolerance or allergy.

In comparing the usefulness of the three terms, **'dairy free'** seemed to be suitable for most conditions and to cover the broadest range of possible allergens, but some health professionals queried whether it would be clear for all patients (for example, would they expect it also to be 'lactose free' and 'egg free'). Given the similar potential variation in understanding of the claim **'milk free'**, it was felt to be an unclear term for both patients and themselves.

Health professionals felt that the phrase **'lactose free'** was both clear and extremely useful for patients who had been diagnosed as lactose intolerant and received advice on what to avoid, but that it would mean nothing to patients who had self diagnosed or not received advice about their condition, what lactose is, or what this means in terms of the foods they can and cannot eat. It was therefore felt that it may be confusing for those patients who do not realise that the product could still contain some milk protein/milk product. It was also felt that the term would be too complex and technical for some patients, particularly those with low literacy.

Food manufacturers' and large food retailers' understanding of the labelling terms, their use and the marketing techniques used to target these consumers

The food industry sample included businesses that were catering for the milk sensitive consumer to varying degrees. It encompassed large businesses whose focus was on a mainstream market and who were not catering for those with a milk intolerance /allergy or lactose intolerance in the absence of clear market demand, a legal standard to which they could confidently conform, and the ability to produce products at the right price for the supermarkets. It also included niche manufacturers for whom, some or all of their products were 'dairy free' or 'milk free'. In addition to their own branded products, some of these companies were also producing 'free from' ranges for supermarkets. The retailers in the sample all carried own brand 'free from' products; some confined these to 'gluten free' products while others felt that catering for those wishing to avoid lactose/milk/dairy was an important part of their health and nutrition offer and did make 'dairy free' and 'milk free' claims on their own brand products.

Developing and marketing products that make a 'dairy free' or similar claim was not seen as a straightforward matter, both from the standpoint of defining the market place and then deciding what claims are appropriate, while at the same time working within the boundaries of what is legally and technically possible. Some of the large

manufacturers, two of the retailers and some of the niche manufacturers preferred to make claims such as 'suitable for those avoiding milk' or 'suitable for vegans' because of the difficulties of making a 'dairy free' claim that could be substantiated.

The measures that underpinned the 'dairy free' and 'milk free' claims being made were a combination of strictly enforced manufacturing processes, allergen management policy and procedures, and testing. Several of the niche manufacturers had dairy free factories in which milk or dairy ingredients were not permitted, reinforced by practices such as back checking of suppliers and testing to ensure 'dairy'/'milk free' status 'at the door'. Manufacturers who were producing own label 'free from' products might face additional procedures instigated by the retailers such as audits, risk assessments and surveillance testing.

Setting in-house management thresholds was seen as fraught with difficulty in the absence of legal limits. The ever lower thresholds demanded by the supermarkets which were possible because of increasingly sophisticated equipment and more sensitive detection levels were not always welcomed or viewed as essential but the two niche players who were producing own label products for the supermarkets were working to the retailers' exacting standards. The lowest thresholds cited were for casein at 2.5 parts per million (ppm) and beta lactoglobulin at 5ppm as measured by ELISA (Enzyme Linked Immunosorbent Assay).

In a situation where levels are dictated by technical advances rather than set at an agreed level, certain manufacturers have withdrawn, or are considering withdrawing, 'dairy free' claims because they do not meet the new lower requirements of the supermarkets, sometimes due to the difficulty of sourcing compliant 'dairy free' ingredients. The establishment of a legal threshold for 'dairy free' would be broadly welcomed by manufacturers in our sample.

Food businesses are using a variety of channels to market and sell their products to consumers and sometimes, to health professionals. Retailers and niche manufacturers in particular, are actively considering the needs of the milk sensitive consumer with online access to product lists, information about ingredients, the facility to contribute to customer forums and to find information about allergies and intolerances. Email and telephone contact are also offered.

Across the business sample, 'dairy free' and to some extent, 'milk free' were the preferred claims although several admitted that the terms might be used fairly interchangeably in different forms of communication. In opting for one or other, the reasoning reflected some of the thinking of consumers and health professionals; 'dairy free' has broadest applicability to all types of milk sensitivity and is most readily understood; 'milk free' is useful because it focuses on the allergen, milk, and would not be seen as including eggs (which 'dairy free' might).

Within our sample, 'lactose free' was not a claim that was generally used because these businesses were not, by and large, producing products that were only 'lactose free' as they wished to sell to as wide a market as possible. 'Lactofree' was generally seen as being responsible for bringing the 'lactose free' claim into the marketplace and given that the products in its range are clearly labelled, it was felt that consumers who have been diagnosed with a lactose intolerance were likely to know what they were looking for. However, questions were raised about whether other consumers are confused by the new term, 'lactose free'.

Conclusions

Use of the Terms: 'dairy free', 'milk free' and 'lactose free'

The research found a general recognition that labelling and other forms of information aimed at consumers with a sensitivity to milk have improved greatly in recent years. The availability of milk substitutes (e.g. soya milk), the bringing together of 'free from' products in particular ranges or sections of the supermarket, improved allergen and ingredients labels, and the use of claims such as 'dairy free', 'milk free' and 'lactose free' have all made life easier for those who are diagnosed with lactose or milk intolerance, milk allergy or galactosaemia.

A high proportion of milk sensitive consumers are scrutinising labels on-pack to help guide their food buying, at least on an occasional basis, and they are looking for a variety of information. However, while positive claims such as 'dairy free' are helpful to many, allergen and ingredient information are often more important. This seems to be in part because many people are unaware of products making such claims or because they may not buy them for reasons of cost. It was also the case that while some welcomed the 'green light' given by such claims, they might still wish to check out the

back of the pack for allergens and ingredients. The claims have therefore not yet established themselves as a device that everyone feels they can rely on.

This picture is reflected in the practice of the health professionals who tend to focus on educating patients about excluding specific ingredients rather than seeking out the positive claims made on 'free from' products.

Among the food industry, a mixed picture was also evident with respect to the adoption of 'free from' claims, in particular the 'dairy free' claim. While some manufacturers and retailers are actively developing the market, others are holding back from entry and some established niche suppliers are reconsidering their position. One of the reasons for this difference in perspective is the uncertainty over the threshold levels that manufacturers should work to in order to support a 'dairy free' claim. At present, the supermarkets seem to be setting the standards by insisting on a threshold that is as close to zero as can be detected by the latest test methods that are available. There is a strong desire for an agreed threshold for 'dairy free' so that everyone is aware of the target that they need to reach. The fact that the European Food Safety Authority (EFSA) is considering a threshold for lactose, rather than dairy, was not seen as a priority for most of the businesses.

Understanding of and Preference for the Terms

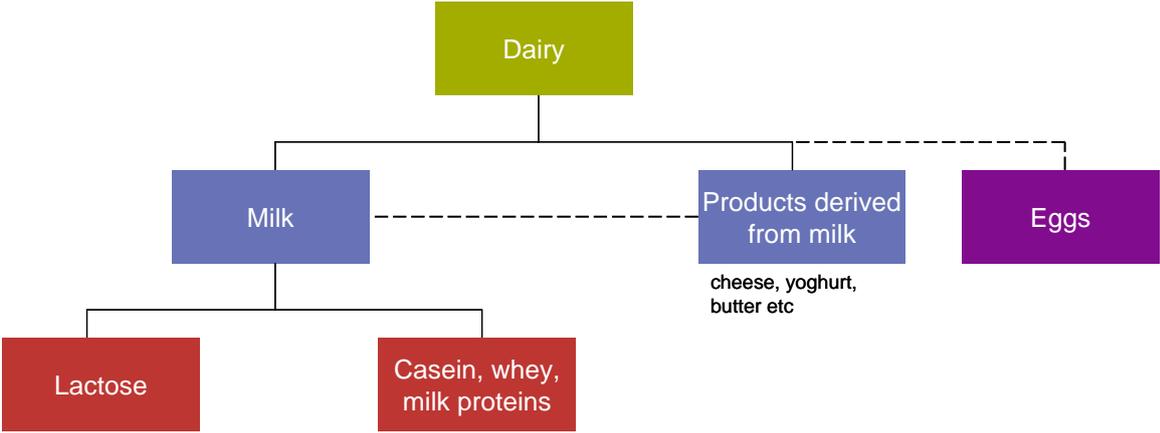
Understanding of what constitutes 'dairy', 'milk' and 'lactose' is far from clear and in the context of the terms, 'dairy free', 'milk free' and 'lactose free', these meanings become more ambiguous and confused. This applies not only to consumers, but also to health professionals and food businesses. Moreover, there is a high degree of overlap across the different audiences in the confusion over the meaning of the various terms, with health professionals and businesses anticipating, and to a degree, empathising with, the difficulties faced by consumers.

The terms 'milk free' and 'dairy free' are often used interchangeably (by all audiences) and until the entry of 'Lactofree' to the market, it was also suspected that 'lactose free' would not have had a specific meaning for consumers.

Figure 2 attempts to sum up in schematic form the framework that the various audiences were using in understanding the terms 'dairy', 'milk' and 'lactose' and

therefore 'dairy free', milk free' and 'lactose free'. The dashed lines indicate the areas of particular uncertainty – principally, whether 'dairy' includes eggs, and whether 'milk' refers to just liquid milk or includes products derived from milk too. A full explanation of how the terms were interpreted is given in section 6.

Figure 2: Schematic framework underpinning understanding of the terms



For the most part, 'dairy free' is the term that seems to have broadest appeal across the audiences and is most readily understood (certainly in terms of being free of milk and milk-derived products) although this understanding can at times be inaccurate when 'dairy' is seen as including eggs. The term 'dairy free' is liked for its familiarity and the fact that 'dairy free' products should be suitable for everyone with some form of sensitivity to milk. It is generally seen as meaning that a product making this claim is also 'milk free' although there is some uncertainty over whether it might contain lactose from a non-milk source.

Apart from terms such as 'non-dairy' and 'suitable for vegans', consumers are not actively seeking other claims although a number of them, backed up by some of the health professionals, would like to see more positive statements such as 'suitable for people with a lactose intolerance'. The provision of such statements is not how manufacturers and retailers would like to see the market developing, in part because of the difficulty of making such very specific claims, but also due to the lack of space on-pack to accommodate them. Ironically, such statements (e.g. 'suitable for those avoiding milk') are sometimes now used by manufacturers and retailers as a more

precautionary claim rather than the positive assertion that consumers and health professionals would like to see.

In the UK market, 'lactose free' products are not present in great numbers but there is some sign that, in the form of the 'Lactofree' range, they are beginning to establish themselves with lactose intolerant consumers and that in part, based on the information provided on-pack, there is some understanding of the product in terms of what it is and who it is suitable for. However, this does not extend across the milk sensitive market and many are confused about the nature of 'lactose free' products and who they are suitable for. The products seem to represent a particular difficulty for consumers who are galactosaemic because they retain galactose when the assumption would be that galactose would be removed with the lactose and therefore would be suitable for them.

Greater guidance was felt to be needed to help consumers understand what the terms mean if they are to make appropriate use of them.

Increasing Understanding of the Terms

Some consumers feel that the supermarkets and some manufacturers are performing an important role in educating affected consumers and helping them make informed food choices. This is done principally through online product and health information. Some retailers and manufacturers also see themselves as supplementing the advice given to the public by the health profession and even having a role in informing health professionals about what may be poorly understood conditions.

Health professionals acknowledge that they see only a small proportion of those affected by these conditions, particularly the intolerances, and that many may suffer adverse effects because they either do not present or do not receive a diagnosis that helps them. Alternative information sources or sources that prompt those affected to seek professional help may therefore be of value. Even where a diagnosis of an intolerance is achieved, it is often difficult for the practitioner to provide clear guidance because of the individual nature of the condition, and the need for the patient to work out for themselves where the limits of their tolerance lie.

Looking ahead at the potential need to harness existing communication channels to inform consumers about the meaning of claims, both health professionals and

businesses offer useful routes. With respect to health professionals, any such information would need to be given around the time of diagnosis, along with guidance about food choices and what to avoid. This is because, apart from those with other ongoing health problems or for whom symptoms remain unresolved, there seems to be little ongoing management of their condition.

The consumers who spoke of an effective relationship with their health professional, as well as the most knowledgeable health professionals, often described clear, printed guidance that could be taken away and referred to, although currently there is not a standard piece of information that performs this task. Consideration might be given to the development of such material.

Finally, the establishment of an expert information resource/charity comparable with Coeliac UK could be helpful for all parties.

Introduction

1.1 Background

Since 2005 people with a sensitivity to milk (lactose intolerance, milk allergy, milk intolerance and galactosaemia, further explanation is provided in Table 2) have been able to consult the ingredients list on all pre-packed foods to identify any milk ingredients. In addition, they may have taken note of on-pack claims that a product is 'lactose free', 'milk free', 'dairy free' (most commonly) or similar. The use of such claims to indicate the absence or reduction of lactose, milk or dairy is not regulated and practice regarding the labelling terms and associated threshold levels varies across the EU with manufacturers setting their own unofficial thresholds for making such claims.

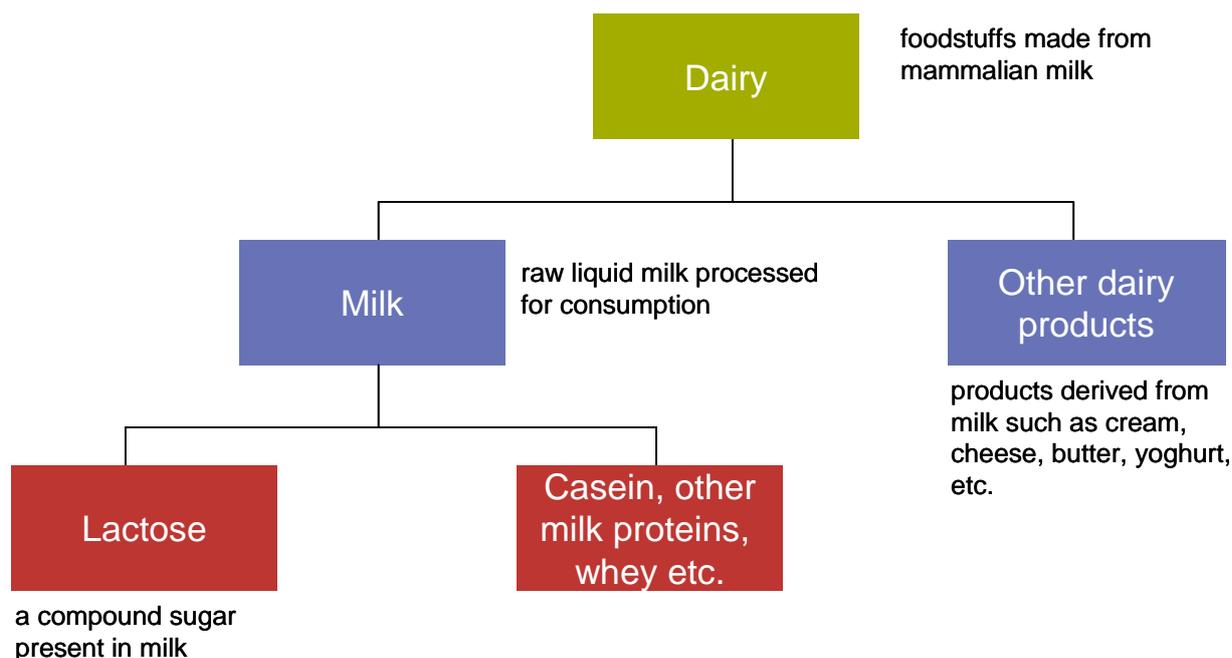
Following a proposal from Finland in 2007, the development of EU-wide management thresholds for the absence or reduction of lactose in foods and the setting of common rules for the use of labelling terms associated with these thresholds is currently under consideration by the European Food Safety Authority (EFSA), who is due to publish a scientific opinion on the subject in summer 2010. The Food Standards Agency represents the UK in discussions on food labelling legislation to ensure that any developments are appropriate for UK consumers who could be affected, as well as the UK food industry. In order to inform such discussions, the Agency commissioned this research to determine current understanding of the food labelling terms used to indicate the absence or reduction of lactose, milk or dairy by UK consumers with some form of sensitivity to milk, health professionals (secondary care specialists, general practitioners, nurses and dieticians) who advise such people, and food businesses.

1.2 Aims and Objectives

The overall aim of the research is to explore understanding of the terms used on food labelling - 'dairy free', 'milk free', 'lactose free' and others - among three key audiences; consumers with some form of sensitivity to milk, health professionals who may advise such consumers, and food businesses who produce, retail and market products aimed at these consumers.

The relationship between the three components, 'dairy', 'milk' and 'lactose' is shown schematically in Figure 1.

Figure 1: The relationship between 'dairy', 'milk' and 'lactose'



The research should not only help guide UK input into negotiations on any legislation, but should also help to inform the development of any guidance for health professionals and the food industry that would accompany any new legislation (if it were developed).

More specifically, the objectives for each audience are to explore:

- among lactose intolerant, milk allergic, milk intolerant and galactosaemic consumers, understanding, use of, and preference for, the labelling terms.
- among health professionals, understanding of these terms and the advice given to consumers on making suitable food choices.
- among food manufacturers (large and small niche producers focused on the intolerant/allergic market) and large food retailers, understanding of these terms, their use on products (along with any other terms) and the marketing techniques used to target these consumers.

1.3 Research Method

The research was conducted using a mix of telephone and face to face interviews. Sixty-three interviews were conducted in total, approximately half of these with consumers (32) and the other half split between health professionals (15) and businesses (16).

In this section, we have provided an overview of the research method; the different research samples, recruitment and discussion content. Further detail about these is provided in appendix 1. Recruitment screeners, letters of introduction and discussion guides are also included in appendices 2- 4.

1.3.1 Research Sample

Consumers

Sixteen face to face and the same number of telephone interviews were carried out with consumers across the four nations, who were affected by one of the ‘milk sensitive’ conditions. The characteristics of the sample are summarised in Table 1. A more detailed breakdown of the sample is provided in appendix 1.

Table 1: Consumer sample: summary of characteristics

Base: 32 respondents

Characteristic	No. of respondents
Condition	<ul style="list-style-type: none"> • Lactose intolerance (15) • Milk allergy (7) • Milk intolerance (8) • Galactosaemia (2)
Who is affected	<ul style="list-style-type: none"> • 26 respondents had one of the conditions themselves • 6 respondents were parents of children with one of the conditions
Source of diagnosis	<ul style="list-style-type: none"> • Medically diagnosed (23) • ‘Self’ diagnosed or diagnosed by an alternative or complementary practitioner (9)
Gender	<ul style="list-style-type: none"> • Female (26) • Male (6)
Socio-economic group	<ul style="list-style-type: none"> • AB (3) • C1C2 (22) • DE (7)
Location	<ul style="list-style-type: none"> • England (11) • Scotland (8) • Wales (6) • Northern Ireland (7)
Ethnicity	<ul style="list-style-type: none"> • A quarter of the consumers were of BME heritage

A description of each of the four conditions is provided in Table 2.

Table 2: Description of Milk Sensitive Conditions

Lactose intolerance is caused by the absence or reduced production of the enzyme lactase, which is needed to break down lactose (a sugar found naturally in milk) into glucose and galactose for absorption into the bloodstream via the intestine. If degradation of lactose does not occur or occurs only partially, bacteria in the large intestine will ferment the undigested lactose, producing fatty acids and gases, which may cause symptoms such as abdominal pain, bloating, flatulence and diarrhoea. The symptoms of lactose intolerance tend to develop within one to two hours of lactose consumption and the threshold of reaction to lactose can vary widely between lactose intolerant individuals. The main treatment for lactose intolerance is the avoidance of dietary lactose, although small quantities may be tolerated. In the UK, lactose intolerance is more prevalent in adults than in children. Approximately 5% of the UK adult population are lactose intolerant, and the prevalence amongst some ethnic groups is higher than this.

Galactosaemia is a rare, inherited, metabolic disease which is caused by the absence or reduced production of one of the three enzymes needed to metabolise the sugar galactose into glucose. Without the enzyme, levels of galactose in the blood become toxic and cause life-threatening symptoms including poor feeding and poor weight gain, vomiting and diarrhoea, cataracts, hepatomegaly (enlarged liver) and encephalopathy (brain damage). In the UK, approximately 1 in 45,000 babies are born with galactosaemia. The main source of galactose is lactose (which is present in milk), thus the main treatment of galactosaemia is a strict milk lactose/galactose free diet. Early diagnosis is essential and milk/galactose must be excluded from the diet throughout life.

Milk allergy is often confused with lactose intolerance, however it is driven by a completely different aetiological mechanism and the symptoms may be more severe. Milk allergy is caused by an abnormal immune response to milk proteins and it is mediated by the antibody Immunoglobulin E (IgE) which is specific for the milk antigen in question. Many milk proteins from many different animals have allergenic potential. The symptoms of milk allergy may include urticaria (hives), angio-oedema (swelling of the skin), atopic dermatitis (a type of eczema), vomiting and diarrhoea, and difficulty breathing. In severe cases, even small amounts of milk proteins may lead to the rapid onset of anaphylaxis and possibly death. Currently, the only treatment for milk allergy is to avoid the consumption of all foods containing milk proteins. Milk allergy in the UK is more prevalent in children than in adults. Milk allergy is estimated to affect 2-7% of the UK infant population.

Milk intolerance is not as well understood as lactose intolerance, galactosaemia or milk allergy. Milk intolerance is a non-IgE-mediated reaction to milk proteins. The most common symptoms of milk intolerance are gastrointestinal in nature including nausea, abdominal pain, bloating, and vomiting and diarrhoea. Non-IgE-mediated reactions tend to be delayed, with the onset of symptoms occurring from one hour to several days after ingestion of milk proteins. The main treatment for milk intolerance is the avoidance of milk proteins in the diet, although as with lactose intolerance, small quantities may be tolerated. The prevalence of milk intolerance in the UK is unknown.

Health Professionals

Four face to face and eleven telephone interviews were conducted with a range of health professionals across the four nations who treated patients with one or more of these conditions. The conditions which they saw most regularly were lactose intolerance and milk allergy. The sample included practice nurses (6), GPs (5), dieticians (3) and one secondary care specialist. Further details of the health professional sample are provided at appendix 1.

Businesses

A total of 16 interviews were conducted with food businesses and related organisations, five of these face to face. This part of the sample was made up of a mix of trade associations (2), retailers (4) with a presence in most, if not all, of the four nations. This also included large food manufacturers (4) with a range of products and/or product brands, and niche manufacturers (6) with products aimed at consumers with a sensitivity to milk. Those who were interviewed had responsibility for some aspect of the labelling of products. While most were based in England, half of the niche manufacturers were in Wales and Scotland. Further details of the business sample are provided at appendix 1.

1.3.2 Recruitment

Respondents were recruited to take part in the research using a mix of methods. Recruiters in the field identified consumers through networking and the Galactosaemia Support Group helped identify respondents with this condition (one of the respondents was active in the group). Health professionals were found using a mix of databases and recruiters on the ground. Intermediaries and our own internet and retail searches helped identify businesses and sometimes the most relevant individuals within them. Recruitment screening questionnaires were used to select consumers and health professionals for interview (see appendix 2.)

The consumer questionnaire was directed to finding people who made use of on-pack labels to some degree in deciding which foods to buy and who either had one of the milk sensitive conditions themselves or who had a child who was affected. It also looked in some detail at how a diagnosis had been arrived at. The principal quotas set were in relation to condition and the nation in which the respondent resided.

Demographic data were also collected and the aim was to try and achieve a mix in terms of age, gender and ethnicity.

The recruitment questionnaire for health professionals focused on the type of health professional and the nation in which they worked. In order to ensure that respondents were at least reasonably knowledgeable about one or more of the milk sensitive conditions, and in the position of giving advice to affected patients, it stipulated that respondents should see such patients on at least an occasional basis and at least within the last three months.

Letters from the Food Standards Agency were given or sent to respondents introducing the research and giving reassurances about anonymity and how the information would be used (appendix 3).

1.3.3 Discussion content

Copies of the discussion guides for each of the audiences are included in appendix 4. The principal areas of discussion are summarised in Table 3.

Face to face interviews (25) lasted up to an hour while the telephone interviews (38) varied in length by audience but were typically 30-45 minutes. Interviews were conducted between 4 February and 25 March 2010.

Table 3: Summary of main discussion guide points by audience

Audience	Discussion points
Consumers	Nature of condition; symptoms and how a diagnosis was achieved
	Advice given about diet and how the condition affects their approach to food, in the home and outside it
	Patterns of behaviour with respect to food buying; where they shop and what they buy
	Sources of information used in food buying; online, in-store, on-pack
	Use of different types of information, hierarchy of importance; specific use of 'free from' type of claims
	Understanding of each of the claims; 'dairy free', 'milk free' and 'lactose free' (and any others used) and what they mean in terms of content of each of these constituents and who they are suitable for
	Preferred claim; any suggestions for developments in labelling that would help in food buying.
Health professionals	Role, specialism, profile of patient population including those affected by one of the milk sensitive conditions
	Presentation, diagnosis and management of the conditions
	Information and advice given to patients with respect to diet, shopping, use of food labels
	Issues with patient understanding
	Understanding of each of the claims; 'dairy free', 'milk free' and 'lactose free' (and any others used) and what they mean in terms of content of each of these constituents and who they are suitable for
	Concerns about and benefits of 'free from' labelling and thoughts on the most appropriate form of labelling to help patients.
Businesses	Role with respect to labelling of products and interest of company in meeting the needs of consumers with specific dietary requirements, including milk sensitive conditions
	If relevant, setting of in-house thresholds for dairy/milk/lactose and how these are arrived at. How are they maintained?
	Support provided to consumers e.g. online, customer care line etc
	Approach to labelling and terms used to denote 'free from' status (if relevant)
	Understanding of labelling terms, 'dairy free', 'milk free' and 'lactose free' and views on consumer understanding of these.

2 Understanding of, and Attitudes to, Conditions involving a Sensitivity to Milk: The Consumer Perspective

2.1 Introduction

Before we describe the use made by consumers of food labelling and the terms associated with this, we have provided some context about how they came to be diagnosed with their condition, how they viewed it and the influence this may have had on their food choices. In this section, we look at the consumer experience of the different conditions and then, in the next section, move on to that of the health professionals. In many ways, they present a complementary picture.

Respondents who shared a condition were not a homogeneous group. They may have had a diagnosis many years previously or might be in the process of working out how to deal with their condition; their symptoms might range from unpleasant feelings of nausea to bouts of diarrhoea that prevented them working or leaving the house; they may have become adjusted to living with the condition and the constraints it imposed, or might be taking anti-depressants because of its effect on their life.

Against this backdrop, it is perhaps not surprising that respondents' attitudes towards their condition were very variable. The factors that seemed to come into play were:

- Whether they had arrived at a diagnosis (by whatever means) that seemed to make sense and which allowed them to plan their diet and thereby alleviate their symptoms. They may, as part of this, have been advised or have worked out for themselves that they can tolerate milk/dairy/lactose to a certain level.
- How long they had lived with the condition and whether others in their family also lived with the condition – if they had had it for some years or had lived with somebody with the condition for some time, then they had generally settled into a way of coping with it.
- How serious in medical terms their condition was – hence someone with galactosaemia with its potentially serious longer term consequences would be far more vigilant than someone who would suffer temporary discomfort because of their intolerance to milk/lactose.

- The actual and perceived severity of their symptoms - the frequency of bouts of diarrhoea or the severity of headaches could prevent some consumers getting on with their lives and some dreaded the return of symptoms such as skin flare-ups or mucus formation. Others however, were still experiencing symptoms from time to time if they ate something they shouldn't, but they did not find them so difficult to cope with.
- Whether it is an adult or a child who is affected – for the most part, parents said they were more vigilant with their children's diet compared with their own.

Certainly those who had been living with their condition for some years and had developed patterns of behaviour (sometimes very strict) that they thought suited them, might appear quite relaxed while others who were still working out how to cope might seem very anxious. We suggest that all these factors feed into how individuals approach their condition and influence their behaviour with respect to:

- their desire/need for ongoing advice and support
- their approach to their diet and how strictly they follow a regime
- their approach to shopping and their use of on-pack labelling.

2.2 Symptoms

In the table on the next page we have summarised the symptoms that respondents commonly described for each of the three main conditions; lactose intolerance, milk intolerance and milk allergy. There is clearly much overlap in these and in particular between lactose and milk intolerance although the presence of mucous was particularly associated with the former. While some form of eczema-like skin condition was reported by a number of respondents regardless of condition, the swelling of the face and mouth, and more serious skin eruptions were characteristic of those with a milk allergy.

While most were clear about their diagnosis, a small number used terms interchangeably, in particular milk and lactose intolerance or dairy and lactose intolerance. In one case, an original diagnosis of lactose intolerance had become changed to milk allergy with the appearance of new symptoms. None of the milk

allergic respondents had suffered anaphylactic shock although one of the children had been identified as having stage 3 anaphylaxis. Only one carried an epipen.

Table 4: Respondents’ symptoms by condition

Lactose intolerance	Milk intolerance	Milk allergy
constantly nauseous, vomiting mucous, catarrh eczema, hives, itchy skin constipation, bloating, wind stomach cramps & diarrhoea migraine	nausea & vomiting eczema, rash bloating, stomach cramps & diarrhoea sinus pain, migraine joint pain	acne-like skin condition itchy red rash, eczema swollen face and mouth nausea & diarrhoea

Galactosaemia is not included in the above chart because it is identified in infancy and due to the seriousness of the condition (liver disease, cataracts and other more variable symptoms), those affected adhere to a lifelong milk free diet.

2.3 Diagnostic ‘journey’

Several respondents could trace their symptoms back to childhood. In the case of galactosaemia, the condition was identified shortly after birth with a diagnosis within weeks. A number of those with other conditions recalled symptoms beginning in childhood (typically feeling sick after drinking milk) even if their condition was not diagnosed at that time. In one case, a woman with a milk allergy had been advised not to eat dairy foods since her childhood in Canada due to her asthma; when she had eaten soft cheese as an adult, this led to a red itchy rash all over her body that a nurse at the local pharmacy suggested was an allergic reaction. Another woman had not had dairy products since infancy because she immediately brought up any milk; her mother had tried to introduce dairy into her diet throughout childhood without success and it was only recently that she had found she could tolerate a small amount of pizza with cheese on it. She has not sought a further formal diagnosis.

"They haven't done all the, you know you do the dietary test and you have all the different blood tests or whatever you have, I haven't had that... I've just never taken milk once I knew that I couldn't stomach it, so I've just stepped away from it". (Milk intolerance. Self diag. N.Ireland)

Most had begun their journey with a visit to their General Practitioner (GP) and some had received a diagnosis there. Respondents were often hazy about any tests that were carried out to help arrive at this but these included, blood, skin prick and patch tests, stool analysis and keeping a food diary. They had often then been advised to eliminate the potentially problem foods and to reintroduce them gradually. A small number of consumers had at some point seen a dietician who may have confirmed the diagnosis through a process of elimination and reintroduction of foods or who may have given them advice about diet. On a couple of occasions, respondents referred to clinics where they were sent some years previously for further tests, but they were unclear about the type or the nature of the tests.

GPs also referred those with the most severe symptoms to secondary care specialists; dermatology, gastroenterology and paediatrics, all figured in our sample. As these specialists tried to discover the cause of the symptoms, these consumers may have undergone investigations for, or been treated as suffering from, acid reflux, appendicitis, irritable bowel syndrome, gall bladder problems, rheumatoid arthritis and acne.

Across the sample, many expressed frustration at the apparent difficulty of arriving at a definite diagnosis and how it seemed almost by chance that the possibility of some dietary intolerance was mooted as a possible cause of their symptoms. Two respondents were so dissatisfied by the response from their GP, that they had made a complaint. One had gone on to consult a doctor privately who told her to keep a food diary in order to identify the offending foodstuffs.

“He says, ‘I need you to keep a diary of everything you’re eating, drinking, when it’s occurring.’ I had to put down what time I ate and what time the rash came and I tell you, that was the best thing I did, to go and see this guy. ... but with my own self-confidence, I knew what the problem was...”

How long did it take for you to work it out?

... I’d say probably into my third week ... the trigger points were these regular foods I was eating. ...It was all the wrong stuff and there was a pattern.” (Self and parent of child with Milk allergy. Med. diag. England)

Some respondents had firstly visited their GP who had not definitively diagnosed a specific condition but instead ‘suggested’ it could be something to do with an intolerance to some foodstuff, possibly dairy-related. In a few cases, this led them to seek further

guidance from an alternative practitioner or to try and work it out for themselves by trying to eliminate dairy from their diet.

“Basically, I got fed up of going back to the doctors and I took it on my own back and I started eating some things and seeing how I felt and I basically worked it out that it was the dairy, it was milk. And it was later on down the line that I realised, well, actually, it’s lactose maybe more than dairy, so I just stay away from dairy completely... ..”

How did you discover or how did you decide it was milk that was the problem?...

...’Cause every time I drunk milk or I ate yoghurt or I had a milkshake or I love rice pudding but I if have a bowl of rice pudding, by the end of the day I’m doubled over, so it was just basically working it out myself and just common sense.” (Self and parent of child with lactose intolerance. Self diag. Wales)

In one case, the GP had referred a patient to a homeopathy clinic and in another, a patient had self-referred to an acupuncturist who was diagnosed as dairy intolerant on the basis of the York Test. Other alternative practitioners who were consulted included a kinesiologist (by three respondents), a reflexologist and a traditional healer in India. One woman had also been to a private testing clinic that had used the York test to identify that she was intolerant of not just lactose but other foodstuffs such as tomatoes. In these cases, the respondents were often given similar advice to that received from the medical practitioners, essentially to try cutting out certain foods for a period of time. The man who had consulted the traditional healer about his skin flare-ups, expressed his scepticism but had felt he had nothing to lose and through a process of trial and error had arrived at a diet that alleviated his symptoms.

"I had found something that was working, an improvement in the skin condition and a way of dealing with that. I didn't believe that a doctor would give me anything else, the problem was being dealt with." (Milk allergy. Self diag. England)

A small number had drawn on their own resources to self diagnose. This might have started with a suggestion that led to research or through matching up symptoms with others in the family and drawing on their experience to learn to cope with the condition. One lactose intolerant mother who was diagnosed herself by a kinesiologist had noted the same symptoms in her 14 year old son and had ‘diagnosed’ him by changing his diet and watching him improve.

"So cut milk out of the diet, chocolate and sweets and switched to lactose free milk with cereal and it started to clear up, the diarrhoea stopped and the skin got better." (Parent of child with lactose intolerance. Self diag. Scotland)

Other mothers of children with a condition painted a similar mixed picture; there was some frustration with the difficulty of obtaining a diagnosis, some feeling of a lack of support by medical practitioners, and a need to find their own information and way forward. Half of those with affected children had relied on self-diagnosis.

2.4 Advice and information

Much of the advice given by health professionals was tied up with arriving at a diagnosis so that as soon as a dietary intolerance was suspected, the elimination and reintroduction of foods came to the fore. Once the foodstuffs responsible for the symptoms had been identified, guidance might turn to possible substitutes for the foods that had to be avoided or suggestions for ways in which those foods might be better tolerated. For some respondents, these suggestions seemed to have been very detailed; for others, of a more general kind.

"I was told to go onto 'Lactofree' milk, which is a brand of milk without the sugars, and if I was going to have semi-skimmed cows milk to have a small amount, like in my coffee or my tea, not to actually have it, like with cereal or something like that." (Lactose intolerance. Med. diag. England)

"Well, my daughter's diet [daughter is milk allergic], it was really awkward, because you know, they said 'dairy products' which I just naturally thought would be, you know, eggs, milk, butter, cheese, that type of thing, and at the time, I didn't know biscuits had skimmed milk in it. I just used to think it would be like creamed rice and things like that that would have milk in it. I'd never really thought about it... So it wasn't just the milk itself, but anything ... Yes it was really hard then..."

...So how did you go about trying to work it out?...

...I think it was my GP that said, 'you know, it's not only dairy products as such. You have to look in other foods as well because you'd be surprised that skimmed milk and milk or dried milk could be in other foods', which it really did surprise me then. I'd go shopping and it would take so long because you'd be looking constantly through the different things to see if there was dried milk or skimmed milk." (Milk intolerance. Med. diag. Wales)

In a few cases, respondents had been advised that they might need to supplement their diet in order to make up for nutrients that might be lost such as calcium, either by taking supplements in tablet form or eating other foods rich in that nutrient.

A small number of consumers mentioned that they had been given information in printed form by a medical practitioner and it tended to be these respondents who were most satisfied with the depth of the advice they had been given and talked of returning to their doctor if they had a recurrence of symptoms.

Many expressed dissatisfaction that guidance from health professionals tended to be very general rather than giving them specific information that would help them live their lives – it might, for example, tell them what they should avoid eating without telling them what they could eat.

“But I wouldn’t say that they said, ‘you should get this, or you should get that, or you can get this here’. It was only, like I said, we were in toddler group and I was talking about it ... we were having biscuits at the time and then, ‘can xxx have one?’ and I was like, ‘no, she can’t’ and they were like, ‘why?’. I explained and they said that you can get a ‘lactose free’ lot of stuff, and I said, ‘well you know, I didn’t know anything about it’, and they told me where to get it from.” (Child with lactose intolerance. Med diag. Wales)

“Not a lot to tell you the truth which has annoyed me slightly. Nobody is really willing to, I’ve just done it myself. I bought books, looked on the internet for dairy free cooking and ‘lactose free’ and stuff like that, which has helped me to get a bit of an idea of what’s in the supermarket.” (Lactose intolerance. Med diag. Scotland)

Others however, seemed to accept that there was a limit to what medical practitioners could do. They felt that they had to learn to manage their condition themselves and should not keep ‘running to their GP’.

The sort of advice provided by alternative practitioners does not seem to have been very different although they were often more specific about the food components that were to be avoided and were able, in some cases, to give the patient greater apparent certainty. Hence, this respondent was willing to spend several hundred pounds gaining similar but more precise information about foods to avoid from a private clinic on the basis of the York Test.

“I have been to an NHS doctor, but with all due respect they just tell you the basics – you shouldn’t have this, and you shouldn’t have that – and send you on your merry way, so it’s down to me to actually think there’s a bit more to it than ... you know, it brings my asthma up as well, and that’s another symptom. And my eczema, so there’s a bit more to it than, you know, you shouldn’t really ... you really should stay off it. I needed to understand. I’m quite like that. I want to drill down and find the reasons behind it.” (Lactose intolerance. Med. diag. England)

Those who self-diagnosed on the basis of the experience of family members would seek guidance from them as to the most effective behaviour to alleviate symptoms. For many, whether depending on their own research to arrive at a diagnosis or supplementing a diagnosis or the suggestion of a diagnosis from other sources, turning to books or the internet was common practice.

The internet was often used by respondents, initially to seek further information about their condition but then to help with decisions about what to eat and cook on an ongoing basis or to check out products they used that might have changed their recipe to include milk as an ingredient. A frequent practice was to simply Google the condition or a recipe request and follow up the search results. The woman with the galactosaemic child had turned to the Galactosaemia Support Group's (GSG) website and the equivalent of this in the United States, while others had used food allergy websites generally and the Anaphylaxis Campaign specifically. One woman had signed up for alerts about new products and contaminants from the Food Standards Agency website. The GSG collect information about foods, send it out to members and post it on the website.

"When we find something out, we try to e-mail everybody in the Group as well, like the FSA do. So we send an alert-type e-mail out. It's quite difficult. Like xxx Crisps, for instance, they introduced milk in their 'salt and vinegar' just before Christmas, so when one person goes and checks a packet – obviously you check every time, and, 'Oh, now contains milk'. So it's a case of texting, putting it on the website, let's let people know." (Parent of child with galactosaemia. Med diag. England)

The GSG also funds a dietician to go round all the food companies every six months and put together a complete listing of milk free foods suitable for galactosaemics.

Supermarket websites were used for information and product listings, especially by those shopping online, and a couple of product websites were mentioned, those of Alpro and Lactofree. One woman described herself as a 'member of the Lactofree website'. The Vegan Society website was also used.

A few recalled books they had read or dipped into. This was especially the case when they were first diagnosed to gain more information about their condition; a dairy free cook book and a book about diets suitable for different blood types were mentioned.

Conditions such as lactose intolerance were thought to have been better recognised in recent years through coverage in, for example, women's magazines.

"I drilled down even into ethnicities and how things like dairy affected you from a genetic point. So I did a lot of research then, but to be honest, for my day-to-day things, no. Not necessarily, I don't. But I did at one stage, went into it in quite a bit of detail, actually, and I bought a couple of books as well as regards to that, and it's quite useful. And again, they said people of Afro-Caribbean descent really, you know ... a lot of people with O-type blood were lactose intolerant, and shouldn't necessarily eat things like dairy and eggs. You really had to be very careful about the quantity of eggs you ate. So that's kind of what I live by." (Lactose intolerance. Med. diag. England)

"I read an awful lot and I have had, I've got hold of lots and lots of different books over the years and I don't tend to so much now because I'm already in the groove, if you know what I mean, but at the beginning I sought anything I could find that told me anything about it... But if I'm unsure about something I check it out online. I just type in the actual thing and then it comes up." (Milk allergy. Med. diag. Wales)

Another source of information for a couple of consumers was an organised 'Health Event' at which one or more health professionals were available to answer questions and address concerns.

The general picture gained was one in which after initial diagnosis or investigations, patients were not seeing a health professional on an ongoing basis, unless they were a child or had another chronic condition that required monitoring, such as diabetes, epilepsy or weight loss. Even for the children, consultations might come to an end once the condition seemed under control.

"We used to see the dietician on a six monthly basis but that sort of tailed off. It was probably just for the early years when he was weaning and stuff, and really I thought, 'Oh my goodness, how am I going to do this?' It seems like a huge insurmountable problem but after a while it does become second nature and I would now find it very difficult to go back to the other way, to be honest." (Parent of child with Milk allergy, Med. diag. N. Ireland)

3 Understanding of, and Attitudes to, Conditions involving a Sensitivity to Milk: The Health professional Perspective

3.1 Experience of Milk Sensitive Patients

Most health professionals were seeing relatively few milk sensitive patients; for those in non-specialist roles it could be an infrequent presentation, and hence not one with which they were familiar. Within this, they reported that they saw some conditions more often than others, although management was broadly the same for all conditions. Babies and children with milk intolerance or milk allergy (that they often outgrow) were the patient group seen most in primary care and for some health professionals, experience beyond this was limited, as they saw milk sensitive adults only rarely. In particular, it was felt that most 'truly allergic' (with IgE mediated food allergy) people would be picked up as children, and most struggled to think of a milk allergic patient that had presented for the first time as an adult. Even in the context of a specialist allergy clinic it was unusual to see adults with true milk allergy. Both Practice Nurses conducting baby clinics and Health Visitors were core in the provision of advice to parents of babies and infants who reacted to milk.

"The true allergies I don't get because they are picked up as children and wouldn't be seen in adults." (Dietician)

"It affects babies under one, and once we switch to a product that doesn't contain a milk protein, then they soon get better." (Practice Nurse)

"It is pretty unusual for people to have what I would describe as serious allergic reactions to milk." (Specialist)

The main adult patient group seen was lactose intolerance. Health professionals also saw adults with temporary/secondary intolerance; post antibiotics, post surgery, in relation to a different condition like colitis or Crohn's Disease, or as a short term result of Coeliac disease. Perhaps not surprisingly, none of the participants in this study had experienced a galactosaemic patient.

However, as would be expected, those in more specialist roles, and those with patient populations that were more likely to suffer from milk sensitivity, saw these patients on a more regular basis, and had a more developed repertoire of advice and information. So, for example, a Practice Nurse in a multi-cultural area reported seeing milk allergy and intolerance among children and babies on a weekly basis. Dieticians, particularly those

in focused roles such as running a specific gastroenterology clinic, also saw milk sensitive patients more routinely. However, even for these specialists, milk sensitive patients represented a relatively small proportion of their case load.

Thus, the main symptoms reported and associated with milk sensitivity were those stemming from intolerance; bloating, wind, diarrhoea, abdominal pain. For children, failure to thrive/gain weight, colic, reflux and being unable to settle were the main symptoms reported, along with diarrhoea. Consistent with rarely seeing milk allergic patients, only a minority recalled presentations with symptoms such as skin reactions, eczema, excess mucus in the saliva and face tingling/swelling, (also sometimes accompanied by diarrhoea); again, these were particularly associated with presentation by babies and young children. Although the most unusual condition, with some in primary care having never experienced a milk allergic patient, milk allergy was recognised as the most acute condition, with the more immediate symptomatic response, and as a scenario to which the health professional needed to respond quickly. These patients were felt to receive full support and information provision from childhood, and therefore to be used to managing their condition themselves by avoidance.

Even among professionals, the terminology surrounding these conditions could be far from clear, with some health professionals using allergy and intolerance interchangeably. More specifically, there was considerable debate as to the distinction between lactose and milk intolerance, with many thinking of milk intolerance in the context of babies, and as a largely temporary condition, and many not able to call to mind any 'milk intolerant' as opposed to 'lactose intolerant' patients. Indeed, some refuted the existence of 'milk intolerance', understanding that patients either experienced an immune reaction to the protein in milk or an enzyme deficiency leading to failure to break down and absorb lactose.

"I'm not sure if we're terribly good at telling the difference between the two, that I'm making a diagnosis between milk intolerance and lactose intolerance." (GP)

"Intolerance more permanently there, allergic, less of, but it depends on the patient's perception of their symptoms."(GP)

"Milk intolerance and lactose intolerance, for all intents and purposes in everyday practice, are the same thing." (GP)

“You’re either allergic to milk protein or you’re not, and you’re either metabolising lactose or you’re not. Patients that try to tell me that they’re milk intolerant, I delve into a bit deeper to find out what the actual problem is. There’s no evidence for it.” (Dietician)

There were also felt to be patients for whom the existence or extent of their allergy or intolerance was a bit of a ‘grey area’, particularly as diagnosis was largely via exclusion rather than a more objective test. Health professionals were also aware that there may well be a significant patient body that do not present, recognising that patients often self diagnosed food intolerances, or were diagnosed by alternative or complementary medicine practitioners. Indeed, some of these patients presented subsequently, having already received a diagnosis; it appeared variable as to whether that diagnosis was reconfirmed. For example, one community dietician reported that if patients had already been avoiding relevant foods and were not particularly symptomatic, then she would advise them to continue with the diet they had been following. However, some patients might be referred on to have their diagnosis reconfirmed, for example if their symptoms were severe or unresolved, or if they requested referral.

“I think that lactose intolerance is very underreported, because a lot of people are aware that they’ve got a problem with milk and milk products and they just exclude them from their diet.” (Community Nurse Practitioner)

“It’s very difficult with intolerances and allergy and whether or not it’s a proven allergy isn’t it, or whether it’s a proven intolerance.” (Nurse Practitioner)

“I wouldn’t send them on to confirm their diagnosis unless they asked.” (GP)

There was also a concern among some health professionals that there may be a group of patients that simply tolerate their symptoms, and in being unaware that they may have an intolerance, are missing the opportunity to receive help. This was confirmed by some of the consumers interviewed, who had experienced symptoms for some time before seeking help.

3.2 Diagnostic ‘Journey’

The various stages of the process of diagnosis were seen by health professionals as windows of opportunity in which advice and information could be given to patients. Initial presentation was typically to the GP, who might initiate investigation of IBS and/or exclusion of more serious conditions, depending upon the severity of the symptoms. Indeed, severe symptoms may lead the GP to refer patients to secondary care – to paediatrics, gastroenterology or dermatology depending on the patient’s age and

symptoms – but investigation and diagnosis were also carried out in primary care. However, ongoing unresolved symptoms were likely to lead to a secondary care referral. Both primary and secondary care might refer the patient on to specialist allergy centres if they required further investigation or if they had a severe/distinct allergic reaction where it was uncertain whether the symptoms they were experiencing were due to allergy, or where the patient/a complementary medicine practitioner has suggested allergy and advice/validation was required regarding this. However, the vast majority of adults were found not to have true allergy, unlike paediatric practice where milk allergy was more of an issue.

“If there is a risk of compromising airways I would want the confirmation by the allergy specialist, and then we can pick up and carry on with the education from there on.” (Community Nurse Practitioner)

Whilst some GPs also advised and informed the patient themselves, in other practices the patient may then see the Practice Nurse for advice and information. Indeed, the Practice Nurse may well have been the first point of contact; as with other therapy areas, Practice Nurses reported that some patients mentioned their symptoms to them in passing when being seen for other conditions, and it could be the Practice Nurse that suggested to the patient that they saw their GP.

Referral to a dietician was not routine for most, and regularity of referral depended on which services were available in that area, and the links with that service. In one PCT, a community based Nurse Practitioner performed a similar role, giving bespoke dietary advice to patients.

“They’re very good at telling people what’s in what food and at making sure that the calcium intake is maintained. So where I feel that the patient is not going to manage very well, dieticians are good at explaining to people how to read the labels and what it is that they should really worry about and showing people examples.” (Specialist)

Diagnosis was predominantly via an exclusion diet, often following the use of food diaries as a diagnostic tool to identify potential problem food groups. For adults, therefore, the initial advice was to completely cut any milk/dairy product from their diet for a set period of time, then to cautiously reintroduce milk and see if their symptoms recurred. Diagnosis could therefore take time, as different food groups were taken out, rested and reintroduced to identify the cause of the problem. A minority mentioned the existence of a tablet that provided lactose intolerant patients with the enzyme that they

lacked, but none had prescribed or had patients taking this medication. There was also some awareness of a lactose tolerance test but no experience of it being used. For babies/infants, management was typically to prescribe a trial of soya milk (or in some cases, goats' milk or rice milk) and to see if the symptoms stopped.

More diagnostic tools were available in secondary care, such as the hydrogen breath test for lactose intolerant patients and blood and skin prick/antibody tests for allergy detection.

3.3 Advice and Information

3.3.1 The Opportunity for and Provision of Advice

Although patients might be seen by several health professionals, or by the same health professional more than once, the window for advice and information seemed to be during the diagnostic journey rather than there being an ongoing opportunity to inform/reinforce the advice given. Once the patient had been diagnosed and/or received dietary advice, other than an initial review to see if the symptoms had been resolved, it was down to the patient to manage/evolve their diet and they tended not to be seen again by health professionals. The exceptions were a couple of community based health professionals (a community based Nurse Practitioner and a Community Dietician) whose roles involved giving patients more ongoing support. Patients were likely to re-present only if their symptoms were unresolved, or in the event of an unexplained or severe recurrence, and many health professionals reported that they never or rarely saw milk sensitive patients after initial diagnosis. The patient was therefore reliant upon the advice and information provided initially. The consistent exception was babies/small children who were followed up routinely and received ongoing management and advice until their symptoms had resolved and their health had improved.

"We don't see them very often because they tend to sort themselves out after diagnosis." (GP)

"You can only offer advice, you can't tell them what to do, you can just inform them." (GP)

"We have to let patients look after themselves, my job isn't to lead their lives. I tell them to look at the packaging and what they eat, to be a bit of a detective and work out what they can and can't eat, put the ball back into their court. People

will learn self regulation. If they have a milk allergy and they have milk they will have diarrhoea the next day, they will learn to self regulate." (GP)

"I think part of the problem as well, is the fact that you don't see that many, so you give somebody the advice and whatever and they tend to, they may come back for a return visit just to make sure everything is okay, but they tend to disappear and deal with their own either allergy or intolerance." (Dietician)

The advice and information given fell broadly into three categories; advice about their condition, advice about the foods they could/couldn't eat and suggested substitutes, and advice about food labelling. Experience was greatest around providing advice about intolerance generally, and lactose intolerance in particular. This tended to cover an explanation of the condition/why the patient was intolerant, an outline of the variability of intolerance, whether they need to avoid lactose/milk completely or might be able to tolerate them to some extent. The nature of the variation in intolerance also had to be explained e.g. whether they could tolerate small quantities, or if milk/lactose was taken only infrequently, or if it was taken with other foods.

Thus, there was no 'blueprint' for the patient to follow in terms of which foods to avoid, or what they would and would not be able to eat without experiencing symptoms. Although initial advice was exclusion from their diet, in the longer term it was not that simple, and was not seen as necessary for many patients. Rather, it was down to the patient to evolve their diet through a process of trial and error. This education was felt to be key to enabling the patient to understand their condition and the implications for the foods they could/couldn't eat, and also to be important for motivating them to work out how they were going to go forward.

"They very quickly begin to learn which products they can take and which will give them terrible symptoms, which will give them no symptoms, it depends on the degree of lactose intolerance." (GP)

"It may be that they have a threshold so that they can only tolerate one small portion of one food per week." (Dietician)

"It's a common thing that they (intolerance patients) will say, 'well I know I can have this and I know I can have that, and I know how much I can have of this', so they've obviously worked through it and they're aware of their limitations, and so they're often a lot easier to manage." (Nurse Practitioner)

Those seeing allergic patients emphasised that although the same areas would be covered in advice to them, the tone would be different, as allergic patients/their parents needed to avoid milk protein completely and to be more vigilant in the changes they

made to their diet. For these patients, the advice was permanent exclusion from their diet, the need to identify all forms of milk/milk products, and help in how to do so.

“If they are truly allergic to milk which is a minority of my patients, then we would say that they should try and avoid it. If it’s an allergy, it’s usually the milk protein, so dairy products generally. If they are intolerant of something then it’s more ‘suck it and see – do you want to avoid large quantities of milk? If there’s foods that you try and you’re okay with, then that’s fine, you’re not going to do yourself any long term damage’. If their symptoms are not life threatening but are just inconvenient then they tend to want to take a risk every now and then.” (Specialist)

“Milk allergic patients do have to be careful but they tend to have a lot of information from the Dieticians.” (Practice Nurse)

“If they are just going to get a windy tummy it’s up to them if they want to have that chicken korma and suffer the consequences the next day, it’s not going to have any long term impact on them. But if it was someone who was going to suffer respiratory problems then they have to be very, very careful. To be much stricter in what they eat.” (GP)

“It is very important that allergic patients follow the advice given, we had one patient in this week, her whole face swelled up. Eventually we had to call an ambulance.” (Practice Nurse)

When considering food labelling, health professionals appreciated the difficulties of finding a solution in this area because of the diversity in patients’ conditions and the varying level of avoidance required. Several health professionals mentioned that they also try to circumvent the problem by encouraging patients to prepare their own food more, and some had milk free recipes that they downloaded for patients.

There was also some variability in the advice given to lactose intolerant patients regarding reintroducing milk/lactose to their diet. Dieticians often provided very specific advice regarding reintroducing low lactose foods such as cheddar cheese, double cream and pure butter first to see if they could be tolerated. However, for some it was felt to be more straightforward for patients if they were simply advised to avoid all milk/dairy.

“We advise complete exclusion of lactose for 6-8 weeks. Then they can maybe reintroduce a few low lactose products one at a time e.g. cheddar because some people will tolerate a small amount of lactose, so we advise them to introduce that and then monitor their symptoms over a day or two.” (Dietician)

Health professionals were also often concerned that the patient should not become over anxious – they wished to convey that the patient just needed to remove something from their diet and carry on with their lives. For lactose intolerant patients there were few

safety concerns, their condition was not life threatening and the implications of making a mistake were short term. However, it was felt to be important that patients were given advice about the need to replace milk with other sources of calcium in their diet or calcium supplements.

3.3.2 Specific Dietary Advice

The advice given by health professionals about the types of food to avoid ranged from the general - to avoid milk/cheese/yoghurt/cream/ice cream, to more detailed advice. Those most involved also tended to highlight other key foods like cakes, biscuits, ready meals, sauces, coatings and the need to be aware of how milk based products may be used to pack/fill foods. It was here that advice regarding what could be eaten was felt to become more complex, as there are a wide range of foods with milk/lactose as a 'hidden' ingredient. It was also felt to be difficult for patients to distinguish whether the ingredient listed on the label referred just to milk protein, or contained both milk protein and lactose. However, opinion also varied as to how critical it was for those with an intolerance to identify milk/lactose at this level, from those health professionals who felt it was vital that patients were able to identify milk/lactose within these foods, to those who felt that, for this condition, this level of vigilance was not needed.

"In terms of lactose mixed into other food products, I don't go as far as that because there's never going to be enough, unless it's predominantly milk based, to cause a problem." (Dietician)

"You do find that these patients very much know how far they can push the parameters themselves by trial and error but I would certainly advise them against milk and all dairy products really, with the exception of eggs, because they are all milk based." (GP)

"I warn them about packers, fillers in foods such as that the sauce in baked beans may have lactose in, things with crumb on may have lactose in, crisps may have lactose in the powders they use, those sorts of things." (Dietician)

"I just tell them to avoid dairy and assume they know what that means... maybe they don't, I presume that they do." (GP)

These were not sufficiently prevalent conditions for this to be an area where most (non-specialist) health professionals had pre-printed patient information to hand, but professionals are now quite well served in terms of generic sources of patient information like EMIS (Egton Medical Information Systems Ltd) that provide easily accessible and printable information and advice on any condition. Several health professionals had also identified key websites that they used to download and print off

information to give to patients. However, one Practice Nurse reported that she had not been able to find information for non-English speaking patients, and had asked her local Dietician if she knew of any. Dieticians had their own/Trust bespoke information sheets prepared and emphasised the importance of printed, take away information. It was felt to be key that the patient had a 'guide', as implementing a milk/dairy/lactose free diet was felt to be complex, especially at first, with a lot of different food terms for the patient to remember. Dieticians felt that the level of information they provided was adequate for patients' needs. There was, however, no standardised information used to guide and advise these patients.

"The information we give them is quite comprehensive and usually enough for people." (Dietician)

"They will leave with all the information they need to make informed choices." (Dietician)

Those who saw patients on a more ongoing basis reported that patients could struggle initially to know what to buy, and there was recognition that working out which foods could and couldn't be eaten was difficult and time consuming for patients/their parents. Interestingly, in one PCT, dieticians offered a group supermarket tour; whilst this had been set up primarily for diabetics, milk allergic/intolerant patients had also been sent on it to help them navigate their way around the supermarket.

"I like to feel that I'm approachable and can fill in any gaps of knowledge once they're back in their houses and have actually started cooking and shopping, but it's the shopping that's the biggest challenge, that I get the most queries about." (Community Nurse Practitioner)

Health professionals identified some common areas of difficulty or misunderstanding among patients, including:

- the difference between intolerance and allergy
 - *"People come in and tell you they are dairy allergic and they are lactose intolerant." (Practice Nurse)*
- whether patients who are sensitive to cows' milk can have other forms of mammalian milk
- whether products that contain milk such as cheese and cream contain lactose

- whether other products that are not obviously made from cows' milk can contain lactose
- how to decipher the ingredients list, and how to remember the range of hidden/milk products that they need to avoid
- the fact that ingredients that they haven't heard of and that are not obviously related to milk, like whey, are a milk product

"They haven't heard of it [whey] so they don't relate it as being something to do with milk." (Practice Nurse)

- how to deal with processed and compound foods – this was felt to be particularly problematic in those patient groups that depend more heavily upon processed foods and ready meals

"It's when they are buying processed food that they come unstuck. I think it would be a good idea to have something on the front." (GP)

- the amount that can be tolerated including whether they need to avoid food with traces of milk in

"I do get asked, 'should I avoid things that may contain traces of milk?' For an intolerance I would say, 'no, it's really a quantity issue, it's not about traces, that labelling is for people with serious allergies who are affected by very small quantities'." (Specialist)

- the relationship between 'lactose free' and 'dairy free'

"Lactose free' and 'dairy free', some people get confused, it's not the same thing. Even the labelling can be confusing for patients." (Practice Nurse)

- the relationship between 'fat free' and 'milk/lactose free'
- for some parents of milk sensitive babies, the fact that formula milk contains cows' milk.

3.3.3 Food Labelling

Again, there was huge variation in the extent to which, or whether, health professionals discussed the specifics of food labelling with patients. However, those who were most involved and who saw these patients most often, would discuss food labelling in depth, explaining where to look for information, how to decipher food labels, which terms to

look out for, and the fact that the ingredients were listed in order of amount, with the first accounting for the highest proportion. These health professionals often had examples of food labels to hand to illustrate and explain further, and sections in their printed information dealing with food labelling. Health professionals reported that some patient groups, particularly those where literacy levels were an issue, became anxious when confronted with labels, adding a further dimension to the education and advice required. It was also highlighted that label and typeface sizes can be problematic for patients, including older patients with poorer eyesight. It was suggested that more widespread use of examples and take away lists/materials was likely to benefit patients.

"I don't go heavy on the labelling because I don't think it's something that the food people have to label as yet. There aren't, as far as I'm aware, labels that say 'suitable for a lactose free diet', so I couldn't tell them to look for that. I would just have to tell them to avoid things that contain lactose rather than look for things that give them the green light." (GP)

"I explain that if you are buying something from a shop, you do need to check the label because quite a lot of things have lactose in that they're not aware of. To stick as much as they can, to a lactose free and a milk free diet, if they can." (Practice Nurse)

"I teach them that an ingredients list is listed in terms of the ingredient in the greatest quantity is listed first, and then it goes down line from there, so looking in the first three ingredients, if that's milk, then that's a product they need to be concerned about and they need to think about the amount of lactose in it." (Dietician)

"I tell them – 'try and read the labels, look for anything that says milk or milk products in it, look for all the ways to describe milk, milk curd, milk whey, milk products'." (GP)

Some (particularly the nurses) said they discussed products making a 'free from' claim with patients, advising patients to look for 'dairy free' foods, particularly in the context of bakery products. Some also felt that this kind of clear guidance could be more widespread, saving patients the trouble of working their way through the ingredients list. Others gave broader advice that the supermarkets have special sections where they can find foods that are suitable for people with their condition.

"Things like cakes, cookies, biscuits, they have got alternatives." (Nurse Practitioner)

"I follow on by looking at the details of what might be on the label, what might mean that it may contain milk, that supermarkets have special areas now." (Practice Nurse)

"The area in the supermarket, saying 'free of dairy product' or 'free of lactose' or whatever. It makes it easy for people who want to go there and explore and see what choices are there for them." (Nurse Practitioner)

However, in the main, the focus was on the ingredients list and specific guidance of what to look out for - whey, casein, curds etc. It was more about what to exclude from their diet, rather than what foods could be included/or to look out for 'green light labelling' such as 'dairy free'. It was felt that signposting patients towards 'free from' products was not a replacement for telling them about how to read/use the ingredients list.

"It can be quite misleading and sometimes I think you can fall foul sort of saying to a patient, give them quick things to look for, because if you do they may not read the whole thing." (Dietician)

"They need to be willing to put the time in to read... it's very time consuming and tedious." (Nurse Practitioner)

"I mean everybody recognises milk, milk powder don't they, and cheese and butter and yoghurt and cream and ice cream, but then we have to look at information on labels such as casein, the milk protein, and people don't recognise that that's on labels, and lactose and milk sugar, and non-fat milk and whey." (Nurse Practitioner)

"I think it's better if they just quickly read everything and just look for the stuff that's on the list that they shouldn't have, that is much better." (Dietician)

Adults might be directed towards soya milk, as for infants/babies, but although some were advising patients regarding the existence of 'lactose free' milk, others had not encountered it. Similarly, whilst the most involved had specific information regarding 'lactose free' foods, others did not, and they might well group 'lactose free' and 'milk free' together as claims, assuming them to be essentially the same.

"I don't think there's anything that says on food labels 'lactose free'." (GP)

"I wish it was clearer. The 'lactose free' milk - is really clear, easy to find in the supermarket. People can go, 'right I can take that milk' without having to look down 20 things that are in it." (Practice Nurse)

"To look for foods that are 'lactose free', now they can get 'lactose free' milk, that's super." (Practice Nurse)

Some also mentioned allergen advice, telling patients to look out for the 'contains milk' warning on the label. Indeed, several suggested that this should be expanded to include 'contains milk products', thereby helping patients who struggle to read the ingredients list or saving them the need to do so. It was recognised that this can be a lot to take in

for patients and, depending on the patient, some allowed for a follow-up appointment to clarify any points or answer any further questions they might have. Some primary care clinicians would refer on to a Dietician for more advice regarding interpreting labels if the patient was struggling to avoid the necessary foods and control their symptoms.

There was a general perception that food labelling has improved significantly over the last few years, making decision making for patients easier now than it used to be. However, it was felt by some that milk sensitivity labelling lags behind that for other allergies/intolerances. One Dietician highlighted that there is no requirement for food to be labelled for possible contamination from milk, as with nuts, (*sic*)¹ and that whilst this is unnecessary for intolerance patients there may be milk allergy patients for whom it is an issue.

"They should learn from nut allergies. They could learn a lot when they're talking about dairy and milk allergies about making it clear." (Practice Nurse)

3.3.4 Further Support and Information for Patients

There was only sporadic awareness of further information or support for patients, with health professionals unaware of any support groups or associations for milk sensitive patients, unlike the support for patients with gluten or wheat intolerance. One Practice Nurse mentioned a Digestive Disorders Foundation charity that provides a fact sheet for patients and also the Galactosaemia Support Group website to patients. A range of websites were mentioned to patients by individual health professionals and used themselves to find information for patients – Allergy UK, patient.co.uk, foodreactions.org, kidswithfoodallergies.org, babycentre.co.uk, the FSA website and supermarket websites. However, some would simply tell patients seeking further information to Google their condition.

Patients had often also searched for information on the internet themselves before presenting to a health professional, and some reported that they sometimes needed to clarify and correct misunderstandings as a result.

¹ There is actually no legal requirement for the 'may contain nuts' or similar warning to be used if there is possible nut contamination but the phrase is frequently used and this may be why this health professional thought it must be compulsory.

“But there would certainly be, if you put in ‘lactose intolerance’, it would come up with all sorts of websites, probably too many.” (GP)

“I use the Allergy UK website an awful lot, because it’s very, very practical and it’s very sensible.” (Nurse Practitioner)

4 Food Choices: the Industry Perspective

4.1 Introduction

This section looks at what the businesses in the research sample are doing with respect to meeting the needs of consumers who are sensitive to milk. It considers their activity in the marketplace in terms of their products, the claims they are making for them and the ways in which they communicate with their customers. It also looks at what the claims mean in terms of the measures taken to support them.

4.2 Serving the Milk Sensitive Consumer

There was general recognition that the market for products that offer an alternative to dairy based products has grown over the last decade, among both those who have been medically diagnosed and those who have self-diagnosed or prefer 'dairy free' products for reasons of well-being and other perceived health benefits. The supermarkets were seen as being particularly active in developing this market in recent years.

*"In terms of sort of target consumer groups, I think we would go along with the supermarkets in the belief that there are a significant number of persons who require these foods, 'dairy free'. I think dairy allergy and lactose intolerance affects a fairly large number of people and there's research to support that."
(Niche manufacturer)*

However, not everyone was convinced about the scale of the demand and some were sceptical about whether there was a genuine need for such products or whether marketing was creating a need for them.

'Gluten free' (followed by 'nut free') products were seen as leading the way in terms of 'free from' products and as catering for a larger and more clearly defined market than 'dairy free'. It was also seen as far easier to work with 'gluten free' products because of the thresholds that have been set for permissible levels of gluten in 'gluten free' and 'very low gluten' products.

Most of the large manufacturers who took part in this research are not catering for the milk sensitive market (or for consumers with a specific sensitivity to nutrient food); their interest is the mainstream and in the absence of clear market demand, a legal standard/guidance to which they could confidently conform and the ability to produce the products at the right price for the supermarkets, they were not participating.

"We do have a general approach that we don't go in for 'free from' labelling, so 'free from milk', 'free from lactose', 'free from wheat'. The reason for that is because the effective impossibility of having a product that is totally free from one of these materials. So unless there's a clear legal standard or guidance from the authorities, say the Food Standards Agency, we've taken the approach not to put those sorts of statements on the packaging, because of the lack of agreement on what the terms mean." (Large manufacturer)

The niche manufacturers had different origins. They may have developed products for the 'free from' market out of a general product base (commonly bakery goods) and therefore not all their products are 'dairy free'. They may have come to the market from an originally vegan platform, or personal reasons may have driven their commitment to an exclusively 'free from' range. Out of six niche manufacturers, two were producing not only their own branded products but products for retailers' own label 'free from' ranges.

While all four retailers carried some own brand 'free from' products, two confined these to 'gluten free' products although they both also listed products on their websites with qualifying explanations such as 'suitable for those avoiding milk'. However, the other two supermarkets saw this market as an important part of their health and nutrition offer and did make 'dairy free' or 'lactose free' claims on their own brand products.

"We have committed to our customers to be their first choice, if they've got an allergy, to be their first choice supermarket for the place they would prefer to come. That obviously means that we have to have a good product offer, clear labelling and clear ways of communicating. So for example, the product lists that a customer can request, if they have a particular allergy, they can say I need to know about 'nut free' or 'milk free' products and we can provide that information and clarity for them." (Retailer)

One of these retailers had just begun trialling a separate chilled area for products aimed at those avoiding dairy, recognising that currently finding such products is not straightforward. It was acknowledged that a problem with the 'free from' range for the milk sensitive consumer is that the 'free from' banner has come to denote 'gluten' and 'wheat free' and it is therefore difficult to introduce within this umbrella banner products that only omit dairy/milk (but contain gluten).

"So you can get, and this is one of the things, because our 'free from' range started being 'wheat free' and 'gluten free', is how can you have a range of products that are 'milk free', or were 'milk free' but not 'gluten free' and 'wheat free', and not confuse everybody? Because 'free from' already has a meaning in the business. 'Free from', probably across all the supermarkets, means 'gluten free' and 'wheat free'." (Retailer)

Developing and marketing products that make a 'dairy free' or similar claim was not seen as a straightforward matter, both from the standpoint of defining the market place and then deciding what claims are appropriate, while working within the boundaries of what is legally and technically possible.

Businesses were often aware that consumers of such products will include not only those with a medically diagnosed allergy or intolerance but will often extend to others who think that they will benefit from them or wish to consume them for ethical reasons, e.g. vegans, menopausal women, people from certain cultures and people who think they might be sensitive to milk in some way. They do not wish to constrain the market by defining too prescriptively who might benefit from such products.

"It's difficult to know why people are buying in to these ranges, because you do get people who believe have read something that says some kind of weird symptom they have must be because of a lactose intolerance, and therefore they avoid milk. You obviously have people who genetically, because of the culture they come from, can't tolerate milk in high levels and they were just not buying milk before, and they will move to these sorts of products, because actually that's a better option for them, than going straight to soya to avoid that. But other products ... there's been a lot of advertising from Alpro, and Alpro does a lot of work, a lot of it is around the fact that it's low fat, low in saturates, and you've got high in soya protein." (Retailer)

Nor do they feel they are in a position to be able to advise on suitability, even if they wish to, because of the range of conditions and their varying seriousness. All that they can do is explain about the properties of their product and leave the consumer to decide.

"In our internal policy, we've graded the 14 allergens in terms of risk into very high risk, high risk, medium risk and low risk and milk is one of the high risk ones, so it is one of the more serious ones. So yeah, people who have milk allergy will react to very, very low levels. Galactosaemia, my understanding is people with galactosaemia, if they consume galactose or lactose, it builds up in the blood because they can't metabolise it so again, pretty low levels will make them ill, I don't think it's quite as sensitive as the allergy thing but they really do need to avoid it in their diet. Milk intolerance, I don't know, by definition, it's an intolerance and not an allergy, so not as serious. Lactose intolerance, from what you read, they can tolerate an amount of lactose so there's a sort of degree of sensitivity to people's conditions and they're all reacting to different things, so really complicated, trying to give advice to consumers, one of those sets of consumers, without misleading the other, can be quite difficult." (Large manufacturer)

"We prefer to base our claims on what we can say about the product because although we have a strong scientific interest in the conditions affecting the consumers for these products, we're not medically trained and qualified. We're bakers rather than physicians." (Niche manufacturer)

"We feel that it is a big trust area. People have to know that what we're saying is what they're getting. People's food suffering can range from a bit of mild bloating through to anaphylaxis. It's a very serious area so we take it very seriously. That comes at a business cost to us but we don't see it as an option for us." (Niche manufacturer)

The range of conditions, the requirements of each and the different sensitivity levels of individuals, make very specific claims a minefield and they are therefore mostly avoided. They may provide very general information about the various conditions but consumers will be advised to seek guidance from health professionals if they are uncertain about the suitability of a product.

"So, we work very hard in terms of our education message on the differences between lactose intolerance, milk allergy, and I think milk intolerance is something where there is a lot more work to do in understanding what milk intolerances are. And whether they are actually allergic to milk, or intolerant to lactose." (Large manufacturer)

4.3 Information and advice

All the food businesses were using a variety of channels to market and sell to their consumers. The internet was an increasingly important interface and for some of the niche manufacturers, orders via the internet were a key part of their business. Businesses might 'talk to' the consumer about the philosophy of their company, their products, as well as sometimes providing more general information about the health conditions for which they might be suitable. Indeed, some of the retailers in particular, spoke of a responsibility to provide clear and accurate information to customers.

"There are huge amounts of inaccurate information available for people to kind of pick up as well, but I think it is a useful service that supermarkets and the Government is providing to customers, to try and .. you know it's very consumer targeted information as well and to help them shop with more confidence. I mean I know that we've produced specifically a leaflet on calcium actually and you know we get a lot of questions about people who are rightly or wrongly cutting milk out of their diet and then calcium becomes a great concern." (Retailer)

For supermarkets, these channels included:

- a customer care line / nutrition advice service.
- information online; this might be about product content – at least one website allows customers to filter lists of products by dietary need. It could also be about allergies and intolerances – this is sometimes provided to help in the absence of a diagnosis.

- printed lists that are mailed on request (made in store, online, by phone).
- printed fact sheets (the information would also be available on their website) or leaflets e.g. on sources of calcium.

Manufacturers often use similar channels:

- customer care line.

"We are also quite proactive in speaking to people - they phone us regularly, email us regularly, with questions, queries, general ... it shows how people feel, how isolating it can be, that they feel they want to put pen to paper, pick up the phone or email us over something as simple as a nice biscuit." (Niche manufacturer)

- information online about product range and content (where it can be kept easily updated) including FAQs.

"We also on our site are very particular because even when consumers go to purchase a product, you get a nice pretty picture of the front of the pack but you also can have with just a click of a button, see the back of the pack and the back of the pack gives all the allergy information... it means that we, as a company, can update information and ensure the consumer is actually receiving the correct information. One of the bad things about communication of allergens is that information can become outdated quite quickly." (Niche manufacturer)

- customer forum to discuss experiences and views.
- email contact.
- content may also be aimed at health professionals to help them understand the condition and make them aware of their products (some are available on prescription).

Several businesses spoke of the problem for themselves and the milk sensitive consumer of there not being a single organisation that represents the needs of those with these conditions, in the same way that Coeliac UK performs a key role as a conduit between people with a gluten intolerance and those serving their needs.

"To my knowledge, there's not the same infrastructure [as the Coeliac UK] for dairy, there's so many people with problems and there's nothing really to support them." (Niche manufacturer)

"When you sit down and you talk about gluten, you go to Coeliac UK for their guidance on what that means, but when you sit down and talk about milk there's

no one central point. And to some extent I think that's why, you know, the provision for these people has actually been quite poor.” (Retailer)

4.4 Pack Labelling and Use of Claims

Most of the large manufacturers and some of the niche players produced own label brands for the supermarkets as well as branded products and in addition to any legal requirements, were accustomed to meeting the specification of the supermarkets with respect to labelling. They might then choose to carry over this specification into the labelling of their own brands. They often made the point that safety is a key priority – they wish to inform and protect consumers so they understand the risks and make an informed choice. Some of the principles governing labelling in this area were identified as follows:

- The allergens and ingredients declaration were seen as fairly straightforward; milk is the allergen listed. If lactose is included in the list of ingredients, they may identify ‘lactose (from milk)’ to clarify its source.

“Our policy is to give very clear information, allergen information. We say ‘free from gluten, wheat and milk’. ‘Contains egg’ and ‘made in a factory that handles nuts’ and then we say that the ‘product is suitable for coeliacs and dairy allergy sufferers’.” (Niche manufacturer)

- It was critical however that all information elements were consistent

“If you are putting a claim on front of pack, well anywhere on pack, you’ve got to have it right, so there is definitely more focus on that, there’s got to be. But that’s not to say that any focus on any other allergens is insignificant and indeed the ingredients list and the allergen advice box actually have to be given the same amount of attention. It’s disastrous if you end up having to withdraw a product because of the same information doesn’t appear in both.” (Niche manufacturer)

- Milk does not have to be listed as an allergenic ingredient on products containing the word ‘milk’ or where milk is clearly the main ingredient (e.g. cheese, butter, cream); however, examples were given of where milk was identified in such products anyway.

“Now the guidance we say is where the product name obviously is the allergen, so on milk, it wouldn’t have an allergen box that says ‘contains milk’. But where it’s not so clear I think, so on cheese I think it does say ‘contains milk’. But like strawberry, I think on our strawberry milks and our banana milks we were having a debate actually whether to say ‘contains milk’ [she checks and finds that milk is listed as an allergen on these products]”. (Retailer)

- One retailer had a policy of not using the phrase ‘may contain’ to denote a risk of contamination because they considered it unhelpful to the consumer; they preferred to use ‘not suitable for’ if there was a significant risk of allergen contamination.

“We don’t use the words ‘may contain’ because we don’t think they are helpful to customers, but we do, when absolutely necessary, put a ‘not suitable for’ statement on pack where we know that the factory is such that there is a significant risk of an allergen contamination.” (Retailer)

- Products that would never contain an allergen such as ‘milk’ would not be labelled as ‘free from’.

4.4.1 ‘Precautionary labelling’

Several of the large and niche manufacturers and the retailers described how, at times, they needed to take a more precautionary approach to labelling because they could not be certain of the ‘free from’ status of their products. This might be due to the difficulty of ensuring that bought-in ingredients are ‘free from’ a constituent or because, in the absence of a legal threshold, they do not wish to establish the allergy management processes and testing regime that a ‘free from’ claim requires.

Among the large manufacturers was one that had been challenged on a ‘gluten free’ claim in the past and while the product in question conformed to the Codex standard, technically it was not free of gluten. They changed the claim to say the product was ‘suitable for a coeliac diet’.

“If we are making a ‘dairy free’ claim, then it has to be an absolute claim, so we have to be certain there is no trace of dairy materials in that product. So we tend to not make those claims unless we are absolutely sure... if we are making a ‘free from’ claim, then I think you are putting yourself up for somebody to test the product to find a minute trace of whatever you are claiming it’s free from and that then invalidates your claim. In our view, and as I said, we make very few of those.” (Large manufacturer)

The sort of claims that these producers were prepared to make were ‘suitable for vegans’ or ‘suitable for those with special dietary requirements’.

“Making a ‘suitable for vegan’s claim, you are not flagging it to say, ‘if you suffer from an allergic reaction to these ingredients, you can eat this product’. I think that’s the mindset that the client would take on that. So if we are saying it’s ‘free from milk’, with gay abandon, and if there is a trace of milk, the consequences of that are potentially more serious; could potentially be serious. I think if we are just

saying it's vegetarian, or it's vegan, then we are not flagging it as necessarily suitable for sufferers of milk allergies." (Large manufacturer)

This approach was also adopted by certain retailers and niche players; again 'suitable for ...' was sometimes seen as providing guidance without promising 'free from' guarantees (e.g. 'suitable for those avoiding milk', 'suitable for dairy allergy sufferers'). A distinction was also drawn between claims on-pack which need to be exact and concise, and claims made online or on printed lists where there is space for a more detailed explanation.

"Partly it's due to space on packs, we have a number of messages and icons and things that have to go onto the back of the pack or the front of the pack. It's just the way the kind of allergen friendly foods are going. You know we are not doing the checks to ensure that it doesn't contain any traces of milk in the production line, we don't ask, other than for the dark chocolate issue. Our general supplier guidance is that we have to have allergens kept separate during food processing, because they don't make that statement and this is where all the gluten free labelling has kind of tied itself up in knots as well. We say that it doesn't deliberately contain any milk containing ingredients but we can't guarantee that it is milk free ... going through those tests... Rather than over claiming, we will say that products are 'suitable for someone avoiding milk' through our website and through our list and if they phone up and ask us or ask the customer service desk, they can say whether a product is 'free from milk' or 'doesn't have a milk containing ingredient in', but we are not flagging it up on the packs." (Retailer)

"It's slightly different when you've got a claim on-pack that says 'milk free' whereas – it says, 'care and attention has gone into ensuring that these products are free from the above to the best of our knowledge. However, we cannot guarantee that trace amounts may not be present at some point during the manufacturing process.' This is the list given to customers who are asking 'is this product made without milk or lactose?' and saying 'yes, this is made without it but we can't guarantee that there are no traces'." (Retailer)

4.4.2 'Free from' claims

Interestingly, among the businesses who were making 'free from' claims about dairy/milk/lactose, their accounts of the claims they were using did not always accord with what was found on their products. This seemed in part down to the involvement of different members of the team.

On the basis of what was said in the interviews, niche manufacturers mainly use 'dairy free' although 'milk free' appears too.

"Our belief is that this [dairy] is a widely used, widely accepted phrase which people who need this type of product easily understand." (Niche manufacturer)

"We've had debates – is it ... are people avoiding gluten or are they avoiding wheat? We've had another one about are you avoiding milk, or are you avoiding

dairy? Lactose really has only come into it in the last year or two... Lactose was never - if you speak to somebody, they've either got a dairy intolerance or a milk intolerance. Most people actually say 'dairy'." (Niche manufacturer)

Retailers talked mainly in terms of 'milk free' except for one who preferred 'dairy free'.

The reasons given for the choice of 'dairy free' were:

- it has the greatest coverage; a 'dairy free' product should be suitable for all kinds of sensitivity to milk.

"It's the overarching, because obviously milk allergy is the one that would cause literally a fatality if we were to get it all wrong. If you manage that one, by definition, all the sort of intolerances should also be managed for those customers. So, dealing with the top one, that automatically manages all the others with it." (Retailer)

- it is the term that has most meaning for the general public.

"My preferred route is 'dairy free' because we have looked into it extensively for ourselves and we believe that the phrase is one which is widely understood, it's widely recognised and it covers what we're trying to tell people about our products. We've gone through quite a lot and that was our conclusion. It's trying to work with what people are already beginning to become familiar with - it's better to work with people's existing understanding and develop that than reinvent the wheel and say no, that's not right, now it's going to be this." (Niche manufacturer)

The choice of 'milk free' was based on focusing on the allergen in question and because it excludes eggs.

"If you say 'dairy free' to some people, they think milk and eggs - they actually think milk and eggs. So I avoid, where possible, talking about 'dairy free' to avoid confusion, but actually a lot of people do use it as shorthand. So to me, if it was 'dairy free' and 'milk free', I would be talking about casein and lactose." (Retailer)

"Where we were talking about 'dairy free' and 'milk free', we would be talking about lactose and casein. So 'milk free' to us means lactose and casein. We don't differentiate between them... So you have both, and it covers all bases, so it's more wide-ranging." (Retailer)

The idea that 'dairy' encompasses eggs was mentioned by other businesses too.

"There appears to be some confusion with consumers. There is quite a wide encompassing statement, because I have actually had people who have said 'I can't eat your product. You say it's dairy free but it's not dairy free'... And I say 'it is dairy free', and they come back saying 'how can it be dairy free, it's got eggs in it?'" (Niche manufacturer)

However, there was not a strict divide between the two terms and both might be used.

“It means that the product must not contain any form of milk or any derivative or ingredient manufactured from milk and it must be manufactured in such a way that it cannot be contaminated with milk containing ingredients...”

...So would ‘dairy free’ be interchangeable with ‘milk free’, would you use the two terms to mean the same thing or do they mean something different?...

*...They effectively mean the same thing. Our actual policy is to use the word ‘dairy’ but sometimes in communications with customers you might refer to ‘milk’ specifically, but ‘dairy free’ is the wording that will appear for example, on pack.”
(Retailer)*

‘Lactose free’ was not a claim that was generally used because these businesses were not, by and large, producing products that were only ‘lactose free’ as they wished to reach out to as wide a market as possible.

“It [dairy free] tends to be a catch all and I think that’s quite widely understood, if we said that it is ‘dairy free’, that means all those individual things. I think if you just say ‘lactose’, it can be a little bit confusing to those, ‘what if I have galactosaemia?’” (Niche manufacturer)

‘Lactose free’ was seen by the retailers as aimed at a smaller portion of the market with fewer products suitable just for them. ‘Lactofree’ was generally seen as being responsible for bringing the ‘lactose free’ claim into the marketplace. The products in its range are clearly labelled and it was felt that consumers who have been diagnosed with a lactose intolerance were likely to know what they were looking for.

“So if we had a policy, a very clear policy, for labelling ‘milk free’ stuff, and it’s really only soya milk, then it would be milk free, and it would be lactose and casein. Just like all our gluten free stuff is always gluten and wheat. Because at the end of the day the very specialist products that might be suitable for lactose intolerance, things like ‘Lactofree’ and things like goat’s milk, but they are very clearly labelled, and that’s a very small kind of market, and most people go completely milk free.” (Retailer)

“I think it’s first of all the number of words that you can actually put on a pack and getting a clear message as concisely as possible, but also, compared with ‘dairy free’ and the people trying to avoid dairy as a whole, lactose is a much smaller sub-group and generally speaking, if you are genuinely looking to be lactose free, you understand the milk origin from that, and therefore the one message can clearly and concisely get down to that sub-group as well.” (Retailer)

The difficulty, it was suggested, might arise with other consumers who may be confused by the new term ‘lactose free’.

“I think consumer perception, until obviously their marketing, I think the consumer perception is that probably lactose is dairy and they niche market themselves into saying it’s the lactose bit, ‘if you’re allergic to lactose’. And I can see that, I can’t

see any problems with their description. I think just generally, prior to that, consumers' perception was that lactose is dairy, dairy is lactose." (Niche manufacturer)

"The difficulty with that of course, is whether consumers, if they see a product labelled 'containing milk' and it still says it's 'lactose free', whether that potentially sets off confusion in ordinary consumers' minds." (Large manufacturer)

One of the retailers described confused responses in-store.

"I know people working in our branches get a bit confused about that as well when customers come in and ask for 'milk free' products and then they don't know whether that product is suitable for them." (Retailer)

4.5 Support for claims

The measures that underpinned the 'dairy free' and 'milk free' claims being made were a combination of strictly enforced manufacturing processes, allergen management policy and procedures, and testing. Several of the niche manufacturers had dairy free factories in which milk or dairy ingredients were not permitted, reinforced by practices such as back checking of suppliers, working with them to ensure chocolate is genuinely 'dairy free' and testing to ensure 'dairy'/'milk free' status 'at the door'. The retailers also played a part where manufacturers were producing own label 'free from' products with measures such as audits, risk assessments and surveillance testing.

Setting in-house management thresholds was seen as fraught with difficulty in the absence of legal limits. The ever lower thresholds demanded by the supermarkets which were possible because of increasingly sophisticated equipment and more sensitive detection levels were not always welcomed or viewed as essential but the two niche players who were producing own label products for the supermarkets were working to their exacting standards.

"The only thing we can, the thing we dictate to our suppliers, is that products must, if you are going to make a claim, products must be manufactured as if you were aiming at absolute zero because that's the right thing to do. We don't think it's ethical to manage it at 1mg below the limit or whatever. But obviously, when it comes to testing and validating, you can only work as good as the best technology available. So, looking at whatever the best tests on the market are, to validate that you are actually achieving at least non-detectable levels in the product." (Retailer)

Where respondents were able to be specific about testing and thresholds, the constituents being measured by ELISA (Enzyme Linked Immunosorbent Assay) were variously casein and beta lactoglobulin, and casein and lactose. The supermarket

favouring the former felt that measuring lactose was less effective than beta lactoglobulin.

“Predominantly it’s casein and beta-lactoglobulin and lactose is sort of held there as a useful test but it’s not as, well traditionally, it’s not been as effective as beta-lactoglobulin testing and the reason for having the two of them there is obviously to pick up things like whey proteins, casein is the main protein in whole milk, but some of the milk derivatives don’t have a lot of casein in them...”

And from what you are saying, under that testing regime it would have to effectively come out as zero?

Yes, it would have to come out as ‘not detected’. Laboratories these days are very careful with their wording but yes. Zero is what I’d like them to say but they won’t say that, they’ll say, ‘not detectable less than the limit of the test’.”
(Retailer)

Test levels of casein (2.5ppm) and beta lactoglobulin (5ppm) were cited by one of the niche manufacturers (they in fact tested for total milk allergen content at 2.5ppm) as being those set down by one of the supermarkets. A retailer quoted casein at 2.5ppm and lactose at 20ppm and one manufacturer referred to a detection limit of 10ppm for ‘dairy’ (although the respondent was not from the technical side of the company and was not entirely sure she had represented this properly). In a situation where levels are dictated by technical advances rather than set at an agreed level, certain manufacturers have withdrawn ‘dairy free’ claims because they do not meet the new lower requirements of the supermarkets.

The control of bought-in ingredients was seen by everyone as a particularly difficult area and one that called for great vigilance if a producer was to be able to support a ‘free from’ claim. One niche manufacturer spoke of how the paucity of suppliers of genuinely ‘milk free’ chocolate added greatly to the cost of their raw materials and their time, and another spoke of the impossibility of sourcing organic ‘milk free’ chocolate.

“It’s very difficult to find dairy free chocolate and to obtain it - genuinely dairy free chocolate that’s not gone down a line that’s just had milk chocolate on it or something, that it is absolutely certifiable ‘dairy free’.” (Niche manufacturer)

“We just don’t have dairy on site and we also test for dairy. We have manufacturers who supply us with ingredients for example, and the first thing we do for example, is ask them if they deal in dairy on their site, a potential for cross-contamination. If there’s no dairy on their site, then that’s fine. But if they have dairy on site then we ask them to test all ingredients that come to us to ensure that they are dairy free... that test will be based on parts per million. And where do we get that test from? Well, actually we’ve agreed with the supermarkets as

well as taking some guidance, but generally the supermarkets as to what they are happy with, so they will have taken guidance as well.” (Niche manufacturer)

“If we were making a ‘milk free’ claim, then yes, they would have to be sure. You know, our supplier would have a specification with their supplier. They would have the same audit and approaches with their supplier as we have with our supplier. At the end of the day the product we are actually testing is the one that goes on the shelf. So it’s in their interest. They don’t want their product rejected just because they have got a dodgy batch of whatever, so they need to be maintaining their standards all the way down the line.” (Retailer)

A couple of niche manufacturers spoke of holding back on making ‘dairy free’ claims if they could not be certain about the controls in factories where ingredients were produced or of reconsidering such claims where they could not be upheld. In this latter case, the manufacturer was seeing problems with milk contamination of bought-in organic chocolate at levels varying between 50ppm and 160ppm.

“The reason for not making the ‘dairy free’ claim on some of the products is when we’re unable to guarantee the complete absence of milk in some of the ingredients, some of the compound ingredients... Mainly it’s in pre-mixes that are made in factories that also handle milk... We do audit the suppliers and ensure that their controls are good enough to safeguard us from gross cross contamination but in some cases it’s impossible to eliminate trace cross contamination.” (Niche manufacturer)

Another niche manufacturer suggested that some manufacturers were not always as honest as this and continued to make ‘dairy free’ claims that could not always be substantiated.

“So other manufacturers, obviously they have their own allergy systems and they’re looking at it, some are better than others and some obviously take it very seriously but we do know that there are a number of shall we say, brands rather than manufacturers, that will buy in and I have seen this particularly, they will buy in a chocolate with a specification that says ‘may contain dairy milk’ and they have not then translated that information to their customers when they have used that product, re-melted it, made it into bars or whatever, they have not translated that information through to consumers.” (Niche manufacturer)

Several examples were cited of where contamination by high levels of milk in plain chocolate had led to the pulling of a range of products and/or the relabelling of products with a ‘May contain...’ warning.

5 Consumers' Behaviour around Food Choices and Shopping

5.1 Introduction

This section looks at how having a sensitivity to milk affects people's lives with respect to their diet and how they make choices when shopping. We found a range of behaviours in relation to the caution exercised in making food choices that were often carried through into how people approached pack labelling. We also cover the sorts of information that consumers are looking for on labels.

5.2 Changing their Diet

A range of strategies were in evidence among the consumers affected by a milk sensitivity as they altered their day to day eating patterns in order to alleviate their symptoms. These strategies might change over time as they became more confident and relaxed about what they could eat. They might also try out foodstuffs and find that they could tolerate things that hitherto had caused them a problem.

Shortly after diagnosis a high proportion of the sample had moved towards more 'cooking from scratch' so that they could be sure of the ingredients in their meals. They often described their diet in terms of the amounts of vegetables and meat they ate and therefore how healthy their diet was. However, they also often described it as very boring and many yearned for greater variety and the occasional indulgence.

When it came to drinking liquid milk, a number had opted to cut it out altogether as a drink or in tea/coffee (sometimes switching to herbal tea) or with cereal for breakfast. This might be because they found this easier than trying to find an acceptable substitute or because they seemed to have built up an aversion to liquid milk because of the discomfort and symptoms associated with drinking it. One woman described how her husband had bought her some 'Lactofree' milk to try but it was still sitting in her fridge because she could not bring herself to face it for fear of the consequences.

"I have to be honest, I don't substitute. I did buy lactose intolerant [sic] milk three weeks ago, but because I haven't drunk milk for so long, I just couldn't bring myself to drink it... I think it's just because I haven't had milk or dairy products for so long. I've got used to drinking black coffee. I don't eat cereals, I'm used to not having cereals because I can't drink the milk. It doesn't appeal to me." (Lactose intolerance. Med. diag. N.Ireland)

"I've made myself go off milk and dairy as I've not taken it for so many years, so I'll only use it [substitutes] maybe very sparingly if I have to add it in coffee or I really feel the need to have some cereal." (Milk intolerance. Med. diag. Scotland)

Most respondents had however substituted liquid milk in some form, most commonly soya or rice milk but 'Lactofree' milk had been tried or was being used by a number of those who were lactose intolerant. The extra cost of 'Lactofree' was a deterrent for some; one woman bought it occasionally as a treat.

"If I do get 'lactose free' [sic], then it's a bit more expensive than just a pint of milk, I will go a bit mental and enjoy some cereal." (Lactose intolerance. Med. diag. England)

A similar approach was taken to dairy products such as cheese, spreads and yogurts. Some had cut these out of their diet while others were substituting with the soya based version. Some felt they could 'get away with' eating limited amounts of these foodstuffs while others were prepared to put up with the consequences in order to indulge occasionally.

"We will have a bit of cheese on our spaghetti bolognese or we'll have a bit of cheese on toast. We know our allowances." (Self diagnosed and parent of child with lactose intolerance, Wales)

"I love the Edam cheese. I have it now and again, but not over, you know..."

Can you get away with it?

... I think I do and I don't really because it's not often I think I get away with it. I know I can feel the difference, there's something wrong. I'm not sure if it is mind over matter, but I know there is something wrong. The next day I'm not enjoying myself or the foods so, or eating properly, or things like that." (Lactose intolerance. Med. diag. England)

For some respondents, there were specific types of cheese, for example, that seemed to cause them fewer or no problems. For those with galactosaemia, cheeses that have been matured for many months, will have had all the lactose (and therefore galactose) leached from them so that they can be consumed.

"Because it is matured for longer than 12 months, mostly 24 months, the actual lactose is leached out. So the bit that is actually harmful to them is gone. We have done tests on this, the dieticians, we have sent ... we have had cheese analysis, quite a few done, so they are allowed. Parmesan is one of the newer ones. They are allowed Emmental because that's the same, because the lactose content has come out, you see. They are allowed Parmesan, Emmental, Gruyère, because that's made the same way. And there's actually an English cheese, the West Country farmhouse Cheddar, which is available at certain supermarkets with the PDO [Protected Designation of Origin] seal. They have

matured it for longer than 12 months.” (Parent of child with galactosaemia. Med diag. England)

When it came to foods in which milk figured as an ingredient, some would avoid these altogether, possibly choosing to buy products making a ‘free from dairy’ claim. For example, ‘non-dairy’ Swedish Glace ‘ice cream’ was bought by the mother of a galactosaemic child. Others would ‘take a view’ and decide if the amount of milk seemed to be of an ‘acceptable’ level although this was mostly judged qualitatively rather than quantitatively. Another approach used by a few respondents was to opt for substitute products that were ‘economy’ versions of the product e.g. chocolate chips or chocolate digestives because they contained little or no milk. One woman was following this practice for financial reasons and had no idea that this was why she was able to tolerate these products.

“It’s really, really interesting about the ‘Value’ foods. If I’m making buns with the children, I use xxx’s ‘Value’ chocolate because I can eat it... that’s the only chocolate I can eat without consequences.” (Lactose intolerance. Med. diag. N.Ireland)

5.2.1 Eating out

While everyday eating at home was easy to control, new hazards arose when respondents were eating out of the home in situations that they had less control over. This might be when visiting the homes of friends or family or when eating out. Eating in larger restaurant chains or more upmarket restaurants where one could ask about ingredients was seen as less hazardous than buying from a local takeaway or small café. However, even here, it depended on whether the food was actually produced in the kitchen.

“If you’re eating in a hotel, it’s not so bad because you can say you’ve got an intolerance and most decent hotels will make up something especially for you, but it’s not easy to go into an ordinary café and have say a scone or bits and pieces, cake or whatever because you can’t say, ‘hey, is there milk in here, or is there butter in here?’” (Milk allergy. Med. diag. Wales)

“When I’ve gone into the restaurant and I’ve said to the waiter, ‘can you tell me if that’s dairy free, milk free?’ And it’s, ‘oh, I don’t know. I haven’t got a clue’ and they’ve had to go and ask the chef. Some places they will come back and actually say, ‘oh, we couldn’t say because it’s all pre-packed and it just goes in the microwave’ or whatever and some will come back and say, ‘yes it does contain milk or it contains egg’... So that doesn’t really help you know what you can eat does it?” (Milk intolerance. Med. diag. Wales)

When eating out, the tendency was to stick to basic dishes that were known to be ‘safe’.

For mothers, invitations to their child's friend's house for tea or parties were a particular concern and often needed careful handling. The mother of the galactosaemic child felt that more informative labelling had made it easier for others to be able to cater for her daughter although in fact, there was only one mother among her child's friends whom she trusted to do so. Her practice was to take food for her daughter to eat at parties rather than relying on what was provided

"The labelling laws have made it so much easier, so much. Because xxx can go now to other peoples houses for tea, and I used to say 'she can have these kind of things to eat', but they can go out, or look at the packaging of things they have in the house, to see if it contains milk..."

And is it just milk that you are looking for? What are the key words?

Well, I just say to people, 'milk and lactose and milk protein', but obviously there's casein and all the other names, which can prove difficult, so she actually just goes to one person's house for tea. All her other friends come here." (Parent of child with galactosaemia. Med diag. England)

Travelling abroad was not generally seen as a major problem; respondents often simply stuck to the basic foods or they might take some ambient products (i.e. products that do not need to be kept in a fridge) with them. Some brands were also available overseas. One family spoke of returning to the same resort for their holiday where they knew the restaurants well but they also took along cards on which their dietary requirements were explained in Spanish.

5.3 Food Choices and 'Risk Taking'

It seemed that consumers followed certain patterns in their approach to making food choices, and, as we shall show in section 5.5, in how they approached food labelling. We have grouped these into 'most, reasonably and least cautious'. We offer this clustering as a means of understanding the different ways in which consumers might behave and, on the basis of our sample of 32 respondents, felt that there was a fairly even spread across the three types. Interestingly, the specialist health professional also made a comment about how patients could be divided according to how concerned they were about their condition and how this translated into how they coped with it.

We have offered a couple of 'case studies' that illustrate each type.

5.3.1 Most cautious

In this group, we would place those consumers who are most concerned about avoiding the foodstuffs that trigger a response either because of the seriousness of their condition (e.g. galactosaemia) or the severity of the symptoms they experience. They will follow their diet very carefully and a great deal of planning may go into their choices. They may buy some products from the 'free from' range. Parents would typically talk to the parents of their children's friends about what their son/ daughter could eat and similarly would discuss choices with the kitchen in restaurants.

A is 31 and has very recently obtained a diagnosis of lactose intolerance after 14 months of investigations for severe and prolonged diarrhoea, sickness and hives. Following extensive invasive tests in hospital with no result, she returned to her GP who ordered the skin prick test and further blood tests. This has shown that she is intolerant of cows' milk, lactose, dairy and mushrooms. Her symptoms have improved since cutting out dairy but not disappeared completely and she has to be vigilant. She has cut out processed foods, now cooks meals herself and is very careful about eating out. Her fear is that if she eats the wrong thing, it will have a profound impact. She has curtailed her social life and no longer goes to gigs with friends.

"I sometimes venture out a bit and try and see what happens kind of thing but I am quite strict about it now because just the thought of having to go through the whole having to run to toilets all over the place, and not being able to travel and stuff like that and to get to work on time and things, it was getting ridiculous for a while." (Lactose intolerance. Med. diag. Scotland)

B is a young Asian man in his 20s who was diagnosed with a milk intolerance in his teens after a battery of medical tests (including a 'milk challenge') at his GP and in a specialist clinic. His GP has provided detailed advice on what he should avoid in his diet and how he needs to find alternative sources of calcium. He used to use drops to break down the sugar in dairy products but hasn't done this for some time. He will drink soya milk if he really wants some milk. He finds he can eat a little Parmesan cheese but otherwise, avoids 'any milk, any lactose, any dried milk product, any whey product, sugars that are milk based or dairy based, any dairy based enzyme in the actual ingredients'. He will always ask about ingredients when eating out and usually finds that the kitchen can accommodate his needs. He is quite relaxed about living with the intolerance because he sticks to his routine and has a clear understanding of what is likely to cause him problems.

5.3.2 Reasonably cautious

While in the main following a fairly strict regime and cutting out the main foods that caused them problems, these respondents adopted a more trial and error mindset and claimed to be able to use common sense to decide whether something merited trying. They might also have ways of diluting the effects of milk-based products.

"It depends on the product. If it says it has a very little percent milk... It depends what I do with it. That's when I make up my mind whether to get it, or not... I'm sure it was xxx; we had something called xxx. It's a drinking product, and sometimes it has a bit of milk in it. Instead of putting soya in it, I put in water." (Lactose intolerance. Med diag. England)

As with the least cautious, they had often found that their own or their child's tolerance had improved with time and therefore they did not feel they needed to be as strict as they might once have been. However, if something caused an upset, they would revert to avoidance.

"I would say I am trying to sort of get her to try products now, different things, but it depends. I've got to be truthful, and if she's unwell in herself, I will go back to the non-dairy products completely then." (Self and parent of child with lactose intolerance. Med. diag. Wales)

C was diagnosed with a milk allergy (sometimes referred to by her as an intolerance) some 20 years ago by a mix of skin prick tests and what sounds like kinesiology. She tries to avoid buying anything with dairy in it and avoids lactose 'as a precaution' but has occasionally been 'caught out' by not reading the labels. She uses soya and sometimes goat's milk as substitutes for cows' milk and, 20 years ago, it was a struggle to source such products. In the past she was extremely careful but now admits to being more relaxed especially with social occasions. If eating out, she will 'negotiate' with the kitchen where this is possible but sometimes will accept that she has to take a chance.

"I was a bit precious about it to start off, but I'm not like that anymore, I've got used to it and even sometimes, I mean sometimes I even take risks because I think, especially in social sort of settings... I mean you can go so far with thinking that this will be okay and then if I have an upset stomach for a day or so afterwards, I think, 'well it was my own fault' and I would just go straight back then to being very good for about a week." (Milk allergy. Med. diag. Wales)

D was diagnosed by a kinesiologist as milk intolerant in 2005 after her GP had failed to diagnose what was causing her vomiting and diarrhoea. She then went back to her GP who referred her to a dietician because of weight loss. She has been very careful about finding substitutes for milk, cutting out ready meals and avoiding biscuits and cakes with milk in them but she has become a little more relaxed in circumstances where a milk-free option may not be available. She will allow herself small amounts of milk-containing food occasionally but would not let it build up over a short period. She will therefore plan ahead and if she knows she is going out will try and be extra careful the week before.

5.3.3 Least cautious

These respondents were particularly prominent among those who were lactose intolerant who felt that they could tolerate a small amount of milk or milk products; their downfall might be a longer glass of liquid milk or perhaps a milk shake.

"If I had a little spec of cheese, I'll not be sick with that, if I had a wee pot of yoghurt, I'm sure I'll be fine, but if I have like a big bowl of cereal or a full glass of milk, then I'll notice it. But I'll have the odd cup of tea and I'm fine, I'll not notice anything." (Lactose intolerance. Self diag. Scotland)

They might have reduced amounts of cheese, yoghurt or sauces rather than avoiding them altogether. They typically spoke of using a little cheese in cooking or 'pushing aside' creamy sauces. They might find that on occasion, they had miscalculated their tolerance and would go on to suffer the stomach cramps and diarrhoea but they were willing to take this chance.

Sometimes they felt unable to resist occasional indulgences and would rather have the 'real thing' than a poor substitute or none at all. If they tried something and the effects were disproportionate, they would not buy it again.

"I tend to go and look at things as an all-round healthy package and if I did want anything that was considered ... like Stilton or like some bread, I would know what the ramifications would be ... the other day I went to Waitrose and I was desperate for a flapjack. I scratched forever and a day. Oh my God, it was terrible. It was the oats and the chocolate. So you just indulge yourself if you really feel you want to, and ... Yes. I don't deny myself everything I shouldn't have. I mean, there would just be so many no-go areas at all." (Lactose intolerance. Med. diag. England)

"To be honest, if I thought it looked nice, I would think, I'd buy that, cook it, eat it. If we had a problem afterwards then I wouldn't buy it again. Again, common sense, if it's covered in cream and cheese then you know it's going to cause a problem but, more often than not, I'll try it before." (Lactose intolerance. Self diag. N. Ireland)

E diagnosed herself as a teenager with lactose intolerance after appendicitis was ruled out and tests proved inconclusive for IBS. Her GP said the next step was to have food allergy tests at which point she followed up his suggestion that it might be dairy related and cut out milk. Following her own research, she identified lactose intolerance as the cause and now thinks her 10 year old son is also affected.

"I just looked on Google. I went on the Internet and looked at what lactose was, only briefly but I looked at what lactose was and it was saying that it was a high content of sugar and things like that and I didn't go too deep into it. I just wanted a rough idea of what it is." (Self and parent of child with lactose intolerance. Self diag. Wales)

She has been avoiding liquid milk but has now started buying 'Lactofree' milk. She tries to keep dairy in their diet to a minimum but feels they can tolerate a certain amount such as cheese on spaghetti bolognese. She also admits to succumbing to temptation from time to time e.g. rice puddings that lead to severe cramps and will not refuse food at friends' houses though she knows she should. She will use measures to try and dilute the effects such as drinking lots of water.

She does not scrutinise labels when shopping because she feels it is a matter of common sense as to which products contain dairy and which do not. If she came across a new product which looked nice, she would try it and only avoid it subsequently if she had problems with it.

F is an Asian woman in her 30s with a young son. She was originally diagnosed with lactose intolerance by a private doctor but this was changed to a milk allergy after her symptoms changed. She has been cutting out the obvious liquid milk but has found it hard to avoid milk in other foods including bread, chocolate and sauces and views her condition as 'borderline' which means that she does not need to be so strict about her diet. For herself, she would rather take the risk and continue to eat certain foods occasionally rather than cutting them out.

"I am very careful now. When I cook myself, I know that I'm not putting any milk in. The highest level of milk is in processed foods ... I still have lasagne ... I scrape the top off.... I'm not wholeheartedly very, very careful, otherwise I'd be reading labels all the time. I think it's just products that I know contain a lot of milk, like custard pies, I don't have those any more." (Self and parent of child with milk allergy. Med. diag. England)

"When I do go [to the temple] and you've had a meal there, all you want to do is go to sleep. It's really rich in fats and clarified butter they use ... and you go to the temple and have a lovely rice pudding and I never say no. I pay for it afterwards but I never say no." (Self and parent of child with milk allergy. Med. diag. England)

However, her son is now exhibiting signs of a milk intolerance/allergy and is in the process of being diagnosed. She is following a strict regime for his food and is already beginning to substitute cows' milk for him.

5.4 Shopping

All of the consumers were using one or more of the large supermarket chains for their main shopping, sometimes combined with the occasional use of discount supermarkets. A number used health food shops/organic supermarkets to supplement their shop and several more commented that they used to do this until supermarkets began stocking a greater range of products suitable for those with a sensitivity to milk. Cost might also have been a factor in switching away from using these outlets.

A small number who were advocates of health food shops were particularly supportive of small independent outlets rather than the chains.

“There are chains of health food shops here in Cardiff and the single type health food shop is usually the best, because the person in there, it’s usually the owner serving for a start and usually they are very, very knowledgeable. If you go to an ordinary chain it’s just a shop assistant in there who might not know very much. I mean, sometimes you do find somebody who is very knowledgeable but in general, it’s the smaller locally owned places and usually people who have got problems themselves and they’ve set up in health food and they are by far the best places to go.” (Milk allergy. Med. diag. Wales)

There was a general feeling that supermarkets had improved over recent years in terms of their product ranges and the information they provided, both on pack and online. A high level of trust was evident in supermarket own brand products, in part because of the improved labelling and especially, when compared to other UK and imported brands (e.g. as found in discount supermarkets) which were felt by some to be less reliable.

While some respondents did some of their shopping online and might make use of information about product content found on supermarket websites, one or two spoke of taking such lists along with them to the supermarket for reference when shopping. One woman talked about how discount coupons were the incentive for her to try new products.

“It’s like trying out things, and trusting that it’s not going to... I wouldn’t mind trying things. I look out for all those little vouchers you get, Alpro milk coupons.” (Lactose intolerance. Med. diag. England)

5.4.1 Purchase of ‘free from’ products

Most consumers were aware of the ‘free from’ range of products in many supermarkets although some commented that it is not always easy to find (even staff may not know

where it is) and the section does not make for a very satisfying shop as it is limited and does not include the chilled products.

"Well, I do go to xxx [name of supermarket] because I know that's the only place that I've actually seen the products there. I did have to ask about three members of staff before they realised what I was saying ... you've got just two bays of stock of soya and 'dairy free' and it is quite jumbled so you've got to literally... I know it sounds silly, but I don't mind looking because it's for my daughter at the end of the day, but it is quite confusing on the products because you've got goat's stuff, you've got.. .you know, so you don't know where to go really." (Self and parent of child with lactose intolerance. Med. diag. Wales)

"There is a free from range but it is quite small and all the supermarkets that I've been in like just have a wee shelf kind of thing and even then it's not always 'dairy' or 'lactose free', it's more 'wheat free' stuff." (Lactose intolerance. Med. diag. Scotland)

"They have a 'free from' section but it's mainly focused on gluten and wheat, pasta, and there's some biscuits as well, but it's not really milk related, it's not like it's 'lactose free' or 'dairy free'." (Lactose intolerance. Med. diag. England)

A number of respondents were buying or had bought from the range. Some may have done so when they were first diagnosed but had since decided that they could do without them.

"I eat a lot of vegetables, I eat a lot of fish, and it's mix and match my own thing, and I'm not even making it stress me out, because when I think the kids were younger, I used to get stressed out a lot, about making sure I have this, and making sure I have that, but I'm not any more." (Lactose intolerance. Med. diag. England)

They might also have decided that these products are too expensive and there are cheaper alternatives or may be avoiding the sorts of products found on these shelves (often cakes and biscuits) in order to lose weight.

"You tend to find quite a lot of the 'Basic' ranges are 'milk free'. Like you can have 'Value' garlic bread from quite a few of the supermarkets. It's quite brilliant 'cos it's cheaper... Some of the biscuits, we have a xxx [name of supermarket] and they do ... they've got lots of dark chocolate, which is really nice and cheap. So she has some of the chocolate from there. They do dark chocolate digestives, like xxx [brand of biscuits], but they are 55p a packet. Now if I go into a health store, and buy some that are 'dairy free', they are about £2.50." (Parent of child with galactosaemia. Med diag. England)

While the range was welcomed, there was a feeling that it was aimed less at those with a sensitivity to milk and more at those requiring 'gluten free' products. Some voiced a preference for products that were 'normally' constituted other than being 'dairy free' because 'gluten free' foods lacked the taste and texture of the 'real thing'.

A few dismissed the idea of the 'free from' ranges as a marketing ploy or without trying the products, decided they would not offer a worthwhile or even healthy substitute.

*"It depends what foods would be 'dairy free'. Can you have 'dairy free' cheese, is that possible? I think that would strike me as not very healthy or safe."
(Lactose intolerance. Self diag. Scotland)*

One woman suggested that the range is helpful for those who are unaccustomed to shopping for someone with a sensitivity to milk. She would also direct other mothers to look out for the tick symbols and milk free claims of certain sweets.

*"It's good for other people, like Grandmas. We'll just go and look in the 'Free From'. It just gives us somewhere to direct them to."
(Parent of child with galactosaemia. Med diag. England)*

*"The xxx [brand] sweets, on the back they've got 'milk free' little ticks, so they are good. Any mums at Christmas, they obviously have sweets in schools, they ask what can they get, and I say, 'just check the xxx – most of them are okay'.
(Parent of child with galactosaemia. Med diag. England)*

5.5 Use of Pack Labelling

Just as we found different levels of caution with respect to choices of food, this was evident also in how consumers said they approached on-pack food labels and the use they made of these. For some, information about milk content was just one of the areas they were interested in. Those with weight issues, diabetes, gluten, egg or other intolerances or those who were vegetarian, might be looking for other nutrient information too. If they have other dietary concerns, they may be interested in what the milk has been replaced with.

*"I'm wanting a bit of confirmation because you can get stuff now that says 'free from fat' but if you look at the back and the sugar content, yeah, it might not be full of fat but it's full of sugar... if it says it's 'free from milk', I want to see that there's nothing milk based, I don't want to see milk powder in the list of ingredients, I want it to be free from milk and I want to see exactly what they've got in it to replace the milk."
(Lactose intolerance. Med. diag. England)*

5.5.1 Most cautious

Those whom we would term 'most cautious' claimed to scrutinise all food labels to check for allergens. They were aware that the milk components to which they were sensitive might take several forms and might be found in 'unlikely' products such as stock cubes or the coating of tablets. They were also aware that product recipes might change from time to time and milk might be introduced into hitherto 'milk free' products.

“But with changing on the ingredients in food you’ve got to keep on - like with salt and vinegar crisps, it’s only now they’ve changed the ingredients and they’ve added milk.” (Milk intolerance. Med. diag. Scotland)

“A couple of times I have not looked, have got it home, put it in the oven, or done whatever to it, whatever it is, looked at the labelling - ‘Oh, they’ve changed this’. I’ve never actually given her anything. I’m trying to think what I did buy; it was some seaside shapes or something, fish shapes from xxx [manufacturer], and I had put them in the oven, must have been looking at the box as I’m chucking it in the bin, and they had put milk in it, it had changed. So that’s what we say to people. I say to my mother-in-law, ‘you need to check every time you buy something’. Because they do change. It will be a ‘new improved recipe’, and you know for a fact they will have put milk in it.” (Parent of child with galactosaemia. Med diag. England)

“It was biscuits, like custard creams, and they were made by xxx [manufacturer] and they added, I think it was milk they added to them, and they had a little red thing on the outside of it, but one of their claims was they were ‘milk free’, they were ‘dairy free’. And I had been buying them for a good long time, and I bought them And really luckily, before I had opened the packet, I got a letter from the Anaphylaxis Campaign to say they had changed the recipe and it now contains milk ...So I was not impressed, not impressed at all. I actually rang them and wrote them a letter asking ‘why would you do that?’ xxx can only have about three different types of biscuit, and I asked them why they had done that, and they said they had discovered that in a blind taste test they actually tasted better with milk!! I asked, ‘what sort of people are you actually making them for?’ I thought that was ludicrous, that was ridiculous.” (Parent of child with milk allergy. Med. diag. N.Ireland)

Consumers taking this vigilant approach would tend not to trust any on-pack positive claims such as ‘dairy free’ but would turn over the pack and check in the allergen (if present) and ingredients boxes to confirm that the claim holds up. If an allergen does not appear in an allergen box, they may still check the ingredients in case the manufacturer has chosen not to declare the allergen.

“I don’t tend to trust the ‘contains’ thing up to a 100%. If it’s something new, I always check the ingredients list. If it’s something I’ve had before, then I’m just checking to see if they’ve added something.” (Galactosaemia. Med diag. England)

5.5.2 Reasonably cautious

These respondents tended to look in detail at the labelling on those products where there might be some question mark over the presence of milk rather than all product labels. One example given was where ready made sauces were yellow or creamy in colour – the respondent would either stay away from these or check out the ingredients.

This group would be particularly interested in label information when they are considering buying something new or if they are looking for very specific products, for example, the mother seeking out 'dairy free' chocolate buttons for a milk allergic child.

"I look to see if there's milk in it, but because I know a lot of what stuff does have milk in, I don't always look at the label because I know that it's there." (Lactose intolerance. Med diag. England)

"It's basically 'dairy free', 'lactose free', that kind of thing on labels is really the green light for us... unless it's a product that we are already using, my mum or partner will check it just to make sure that it doesn't have any of the other ingredients. It might be 'dairy free' but it might have whey or some kind of powdered form of lactose or milk in it, so she still has to check it." (Milk intolerance. Med diag. Scotland)

5.5.3 Least cautious

A number of respondents were fairly dismissive of labelling either because they felt that they did not need to be so very careful in their choices or making choices was pretty much 'common sense'. They might be buying some 'dairy free' or 'lactose free' products but they did not feel that they needed to check out such claims, taking them on trust. Often, if someone had developed a liking for and trust in a product, this trust might be extended across the range; the 'Alpro' and 'Lactofree' brands were given as examples of this.

A mother of a milk allergic child said that she looked for the percentage of milk in the product and made a judgement based on this.

"So you would look and say, 'well, if it's 71%, that's quite high', so no, I wouldn't give him that, whereas if it was 30 or whatever, I know I could give him it." (Parent of child with milk allergy. Med diag. Scotland)

Some in this group were not making use of on-pack information because they saw it as too much trouble and too time-consuming – they were often the men in the sample. Rather than trying new things, they claimed to be sticking to a tried and tested range.

"It got a bit of a pain with shopping looking at labels to make sure there's no dairy products in there. It was a pain... That's why when I go shopping I tend to stick to the basics and you know where you are. You haven't got time to go round looking at exactly what." (Lactose intolerance. Med diag. Wales)

"It is very difficult to be food shopping and looking at every product in minute detail really." (Milk allergy. Self diag. England)

5.6 Information sought

In terms of the specific information that consumers were seeking from labels, there was mention of all three types, the positive 'free from' claims, allergens or 'the contains box', and the ingredients list. There was not however, a clear picture of what information consumers with each condition were looking for - as noted above, they gave varying levels of attention to labelling. A few respondents were unaware that it was possible to find products that claimed to be 'milk free', 'dairy free' or 'lactose free'. Consumers' understanding of each of these terms is covered in section 6.

While some consumers were very clear about the differences between the allergen and ingredients information, others tended to say that they were looking for similar information in each. Milk would always be a term that might feature as an allergen, but respondents also mentioned milk or whey powder, lactose, butter and dairy as potential allergens. A similar list of constituents might figure under the ingredients that consumers would look out for – dairy, milk, milk powder, skimmed milk, whey, milk protein, lactose.

An interesting take on the allergens list was given by one lactose intolerant respondent who claimed that she did not take any notice of this because she suffered from an intolerance rather than an allergy.

5.6.1 Galactosaemia

The claim of choice for the two respondents affected by this condition was 'milk free' although on questioning, 'dairy free' or 'non-dairy' would also be acceptable. They might also be attracted by vegan products although as with everything, would need to check out the actual content. They would have assumed that products claiming to be 'lactose free' would be suitable for them but this is now open to question because of the 'Lactofree' range which contains a little lactose, as they understand it, and 'a lot of galactose'.

"We've had so many families emailing us [the Galactosaemia Support Group] saying 'is this okay?' because obviously saying it's 'lactose free', but it's not 'galactose free'. But because we tell people to look for the lactose content..."
(Parent of child with galactosaemia. Med diag. England)

Further communication with the GSG resulted in the following explanation for the situation with respect to 'Lactofree' and galactose; it comes from one of the dieticians who consults to the charity.

"'Lactofree' milk is made by removing half of the lactose and then converting the other half by enzyme to its simple parts (half glucose and half galactose). Thus the milk has little lactose present, but will still have galactose and glucose. Anything made with 'Lactofree' such as yoghurt or cheese will therefore also contain lots of galactose, but very little lactose. This makes it unsuitable in galactosaemia (but suitable for lactose intolerance)."

The allergens they would look out for were milk and lactose, and similarly, the ingredients were milk, milk powder and lactose. Galactose itself is not listed on products (the mother of the galactosaemic child is a nurse and has only seen it listed on a dietary drink supplement). She explained that allergen warnings about possible contamination of plain chocolate with milk would probably be ignored because of the level at which galactose would be present if there was such contamination.

"It would only be a very minute amount of milk or butter that you could actually cross-contaminate, so the amount of galactose in that would be even less. Say if the lactose content is 1%, the galactose content would be ½ %. So you are getting a very, very small amount of a very small amount. This has come from the dieticians, not from us." (Parent of child with galactosaemia. Med diag. England)

5.6.2 Milk Allergy

Perhaps because none of those questioned with a milk allergy had experienced very severe symptoms, they presented a mixed picture of the extent to which they scrutinised labels. Hence, these respondents included those who claimed not to bother with labels because they kept to a known range of products, to more observant shoppers who would tend to look at the allergen list before moving on to the ingredients list.

"Well, really for the allergy advice. If it's contained in the allergy advice, I just look for milk and eggs in the allergy advice, and if it contains them, it's a 'no-no'... It would use those words in the ingredients list but generally under allergy advice it would just say 'milk'. But if it doesn't have allergy advice, which some products don't, things like milk proteins and whey and lactose and all those things, yes, I would have to look out for." (Parent of child with milk allergy. Med diag. N. Ireland)

"Well, if it just said 'free from milk', I would still read the ingredients because ... there are sometimes hidden things in them. It may not be milk, but might be milk products."

So would the same be true if it said 'free from dairy'?

If it said 'free from dairy', I'd feel more likely to just take it on you know... Because dairy is like a generic term and milk is a specific." (Milk allergy. Med diag. Wales)

5.6.3 Milk Intolerance

The lack of a clear-cut distinction between milk and lactose intolerance was thrown up by some of these interviews where consumers assumed that lactose was something that they should be concerned about.

"As and when I'm going to eat something I just need to make sure that it's not got certain products in it, even powdered products, powdered whey or milk products and stuff... any milk, any lactose, any dried milk product, any whey product, sugars that are milk based or dairy based, any dairy based enzyme in the actual ingredients, that is basically what I'll avoid." (Milk intolerance. Med. diag. Scotland)

"I've been told that lactose is a sugar in milk. If it said 'lactose' on the pack, I would keep away from that too." (Milk intolerance. Self diag. Wales)

5.6.4 Lactose Intolerance

For those who might look out for a product claim, 'dairy free' or 'lactose free' was most often mentioned although not everyone was aware that 'lactose free' products were available. Those who were aware of 'lactose free' products commented on the fact that there is very few of them.

"It's very difficult to see things like 'lactose free'. I remember you specially have to go and search for things. It's getting better now, in different supermarkets. In the health shop you go and find this but in the supermarket it's getting better. It's actually being labelled 'lactose free' but it's more 'dairy free'. Everything looks to be dairy, dairy, dairy free. But it's getting better where it actually has it written on now. But it was a bit of a hassle to find it with 'lactose free'." (Lactose intolerance. Med. Diag. England)

5.7 Confusions

In discussing their use of labels, it became clear that there were some areas of confusion and a desire for clarity. These included:

- the significance of the warning about manufacture on a line that has had milk products on it.

"It says that there is no milk in the product itself but it's been made on a line that milk has been near before and I never know if that's safe enough to take, because it's not actually in it, but just touched it somewhere... I've not gone near

it, but I'm just wondering would it affect you as much?" (Lactose intolerance. Med diag. Scotland)

- whether a 'free from' claim means that there is none of that constituent in the product or whether there could be a small amount.
- whether lactose always comes from milk or whether it can also come from plants?
- whether lactose is a problem for those who are not lactose intolerant?

"But if you take off the shelf, I don't know an xxx or a yyy or zzz [names of brands] or whatever, sauce, then sometimes they'll have lactose on and I'm never sure - I don't know whether I'd react to it but... I'm never sure obviously if that's derived [from plant] 'cause a lot of the time it's obviously derived from milk." (Milk intolerance. Med. & Self Diag. England)

- the various terms for different ingredients.

"You're not really quite 100% sure because a lot of them don't have anything written on to help you ... nobody has really sat and told you what all the names are for different ingredients. So it's hard to actually, it's not just the basic knowledge of the words they are and also looking up on the internet to see what other names are given for these ingredients ... You could be in the supermarket for about an hour and a half by the time you read everything!" (Lactose intolerance. Med. Diag. Scotland)

- whether dairy products are always recognised as such. Examples were given where consumers had not appreciated that products that many people would regard as obviously dairy, were derived from milk.

"It was him [the GP] that said to me, 'think, you're giving him yoghurts, think about that'. ... Things like yoghurts, you forget that there's milk in them, things that I wasn't thinking about that were quite similar, like dairy, things like, like xxx [brand of processed cheese]." (Parent of child with milk allergy. Med. diag. Scotland)

"But the one thing that does get a few people is fromage frais. Someone said to me 'Oh, has that got milk in?' but obviously that's their ignorance of not knowing what fromage frais is, because it says 'fromage frais'." (Parent of child with galactosaemia. Med diag. England)

- whether all the allergens have to be listed.

"I'd like it, but I know they don't have to, it's very helpful if milk is listed on the allergens. They don't have to put an allergen label on. They've got the ingredients, and most of the bigger companies put allergy advice, but they don't legally have to do that. That is a help, because if I pick something up, if milk is

there I know not to bother looking through the rest of the ingredients.” (Parent of child with galactosaemia. Med diag. England)

6 Understanding of Food Labelling Terms

6.1 Introduction

Each of the interviews, regardless of audience, included a section towards the end that looked at the respondent's understanding of each of the terms; 'dairy free', 'milk free' and 'lactose free'. They were asked what they thought was meant by each of these claims, the levels of dairy, milk and lactose that they would expect to find in products making each of these claims, and the suitability of such products for different conditions. In this way, we set out to gain an impression of understanding across the board although the questions might not be posed in exactly the same way because this depended on the preceding discussion.

While a few respondents might have had cause to think about some of the questions beforehand, most from all three audiences had not. It was not a straightforward task to set them and it forced them to articulate unconscious thoughts and question assumptions. For example, many would probably have used the terms fairly interchangeably rather than thinking about what differentiated them. At the end of the exercise, several consumers and health professionals ended up questioning whether they knew as much as they had thought and wanted a greater understanding that might help them in making/advising on food choices.

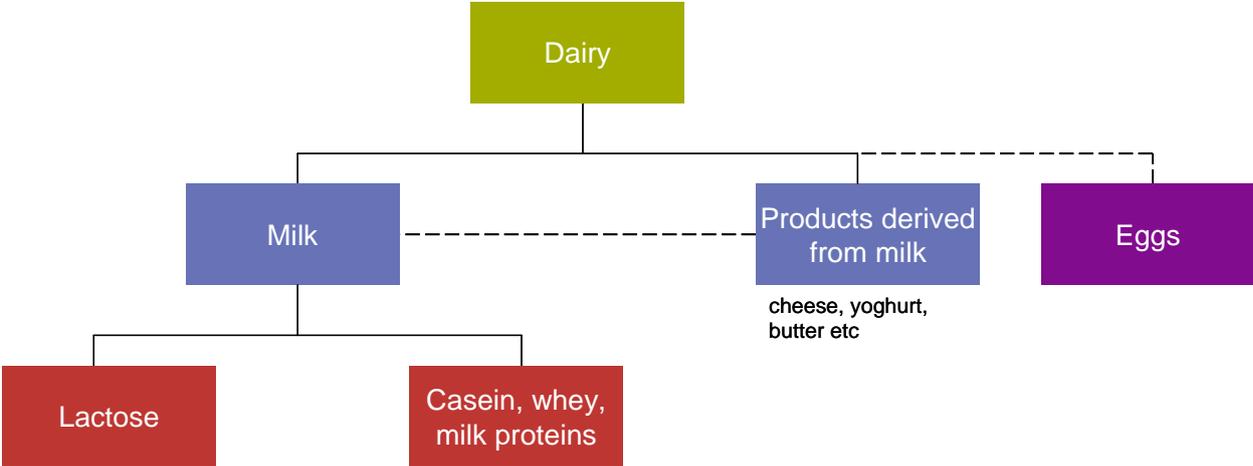
We are also conscious that the very practice of asking about the meaning of three different claims (in varying order) led to some confusion, over-rationalisation and sometimes, a need to back track and revise earlier opinion.

6.2 Underpinning Framework

Based on an amalgam of views from across the interviews, we have constructed a schematic framework (shown in figure 2) which attempts to sum up how respondents understood the various terms and the relationships between them. Few would articulate them fully in this way but their understanding might be reflected in different parts of the framework. The breaking down of milk into lactose and other constituents was mentioned by very few consumers, for example. In the diagram, the dashed lines indicate the areas of particular uncertainty – principally, whether 'dairy' includes eggs, and whether 'milk' refers to just liquid milk or includes products derived from milk too.

A key finding was that there was no agreed understanding of any of the basic terms, 'dairy', 'milk' and 'lactose'. The boundaries surrounding what was contained within 'dairy' and 'milk' varied while there was only hazy understanding among consumers at least, of 'lactose'.

Figure 2: Schematic framework underpinning understanding of the terms



For each of the claims, 'dairy free', 'milk free' and 'lactose free', we consider in this section, the different ways in which it is understood, what it means in terms of the presence or absence of dairy, milk and lactose, and for whom products making such a claim would be suitable. It should be noted that galactosaemia was a condition that was unknown to nearly all the consumers and had not been seen by any of the health professionals, so there was little comment on whether claims were suitable for people with this condition.

In what follows, we have combined the often very similar response of the consumers and health professionals and summarised the view of businesses after this.

6.3 'Dairy free'

6.3.1 What does 'dairy free' mean?

It was universally agreed that 'dairy' includes both milk and products derived from milk such as cheese, butter, cream, yoghurts. 'Dairy free' therefore denotes products that are free from these things. The immediate response seemed to be that this meant that there was no cows' milk in 'dairy free' products although some consumers and health professionals felt that 'dairy' might also cover other types of mammalian milk; thus,

there would be no goats or ewes milk or cheese from these sources either in 'dairy free' products.

"It would have nothing in it which was from a cow, so it wouldn't have milk, it wouldn't have butter, it wouldn't have cream. That's what I would take as dairy free." (Milk allergy. Med. diag. Wales)

"That the ingredients included in that product don't include any product, any ingredient that may come from cows, goats, sheep. You know, dairy to me is milk, cream, yoghurts, it won't include any of those ingredients in it." (Milk intolerance. Med. diag. Scotland)

For about a third of consumers, 'dairy' also included eggs and a number of the health professionals also thought this themselves or thought their patients might assume that eggs were included.

"That it's got no milk in, that it's got no - dairy I think, is eggs as well, so I would assume it's got no eggs in either, no cheese or milk." (Milk intolerance. Self diag. Wales)

"To me it means that it's free from all dairy products, milk, cheese, butter, eggs, cream and anything I associate with dairy products." (Milk intolerance. Self diag. N.Ireland)

The common assumption was that 'dairy free' meant that products making this claim were **completely free of both dairy and milk**.

"If it has milk in it I would expect it to be a milk substitute. I'm not expecting it to be milk. I would be livid if it was milk because by inference, it's not." (Lactose intolerance. Med. diag. England)

"If it's 'dairy free' I would assume that it meant no milk products, full stop." (GP)

Two consumers were less certain about the presence of dairy; one, on the basis that they knew of similar claims such as 'sugar free' which actually meant a very low percentage of sugar was present; the other, because she found it hard to envisage how foods such as chocolate could be completely free from dairy. A similarly small number were uncertain about the presence of milk, again because they found it hard to envisage how a dairy type product could be made without having some form of milk (possibly from sheep or goats) in it.

"I would suspect a tiny little bit, but enough not to have consequences." (Lactose intolerance. Med. diag. N.Ireland)

Most consumers and many health professionals assumed that a 'dairy free' product would be **completely free of lactose** because this was derived from milk but there was uncertainty here too.

*"I would assume it had no lactose because the lactose to me is relative to dairy."
(Lactose intolerance. Self diag. Scotland)*

Among the consumers this was based on a lack of understanding of what lactose was. It was questioned whether lactose might be present but from a source other than milk, or whether, as a sugar, it could be added. One woman claimed to have seen a 'dairy free' product containing lactose.

"I would say no [lactose in 'dairy free'] but I have come across products that've said 'dairy free' and it's got lactose on and I wasn't sure... and again, I didn't buy it because I thought is it derived from plants or is it actually from milk? But then I thought 'well it can't be from milk' because they'd put 'dairy free' on the label - so that is confusing." (Milk intolerance. Med. & Self diag. England)

Some health professionals also thought it was possible to have lactose in non-dairy products and that a product labelled 'dairy free' would not therefore necessarily be lactose free.

6.3.2 Who is 'dairy free' suitable for?

All consumers thought that they should be able to eat/drink 'dairy free' products although, as noted above, some would still check the on-pack information about allergens and ingredients. Most also thought that people with other conditions could also eat/drink 'dairy free' products although there was a question over those with a lactose intolerance regarding the feasibility of 'dairy free' products containing lactose. However, most of those who were lactose intolerant thought they could eat 'dairy free' products.

"That's ['dairy free'] what I would go for first straightaway because it proves it's got none of the added extras that I've been told about as well sort of thing, like eggs, and you don't get that with just 'milk free'." (Lactose intolerance. Med. diag. Scotland)

Some health professionals thought along similar lines and were concerned that the meaning of a 'dairy free' claim would be unclear for lactose intolerant patients who might be misled into thinking it was suitable for them.

“There might be a derivative, it may have lactose in it, they would have to check.” (Practice Nurse)

“I would say look at the small print because I’ve had this in the past, because of the flavouring.” (Practice Nurse)

“The main source of lactose is milk but it will be found in other substances.” (GP)

Some in this sample also highlighted that the claim, ‘dairy free’ did not relate to a condition, that patients were not ‘dairy’ intolerant, rather they are lactose intolerant or milk allergic.

“Say ‘lactose free’, I don’t understand a diagnosis of dairy intolerance.” (GP)

“If it’s ‘dairy free’, then are they talking about ‘lactose free’? I find that confusing. ‘Lactose free’ is a different scenario, don’t lump it in, this is where patients get confused when they go to the supermarket.” (Practice Nurse)

However, it was recognised that truly allergic patients needed to know that products were free from all types of dairy products as they contain the same proteins.

“If you are allergic you need to know that it is ‘dairy free’.” (Specialist)

6.4 ‘Milk free’

6.4.1 What does ‘milk free’ mean?

A claim of ‘milk free’ was probably the least known and most confusing of the three claims and several among the consumers and health professionals raised the question of why a manufacturer would use this claim rather than the more familiar ‘dairy free’ and ‘lactose free’.

The boundary around the term ‘milk’ was uncertain for many. Often it was assumed that it referred to liquid milk but then respondents wondered if it could include powdered milk or even other forms such as condensed. A further critical question was whether ‘milk free’ excluded products made from milk as well as the liquid form and therefore would essentially mean the same as ‘dairy free’.

There were also questions around the source of the milk. While the first response might be for consumers and health professionals to think in terms of cows’ milk, they often went on to query:

- could it include milk from other animals (goats, sheep)?

- moreover, could it include ‘milk’ derived from plants (soya, rice, almond) and how about coconut milk?

“That it’s free from all kinds of milk, be it cow’s milk, soya milk, rice milk, whatever milk.” (Lactose intolerance. Med. diag. England)

“It doesn’t have milk in it I presume, the proper term, what we would presume is milk, any relative milk, coconut milk, condensed milk, cream. That is what I would presume.” (Self and parent of child with lactose intolerance. Self diag. Wales)

While respondents felt that ‘milk free’ meant **completely free of milk**, they were uncertain as to just what this meant. While some concluded that it meant that it had no milk or milk derived products (and was therefore the same as ‘dairy free’), others focused on it being free of just milk (liquid or powdered).

Opinion was therefore divided among both consumers and health professionals as to whether ‘milk free’ products were also **completely free from dairy** or not, with those who saw it as referring just to milk, feeling that the product **could still have other dairy products/derivatives** in it (such as cream, cheese and eggs).

“If it says ‘milk free’, I wouldn’t believe it to be completely free from dairy because even if it doesn’t have milk, it may have some other form of dairy product in it, powdered milk, some sort of soft cheese could be in there, some whey products.” (Milk intolerance. Med. diag. Scotland)

“I would say that particular product does not contain milk but again, it’s big terminology because if it doesn’t contain milk, does it not contain milk protein, milk products, the artificial flavours?” (Practice Nurse)

“Does it have milk based products such as butter and cream is more tricky. It could imply that is not made with any milk but doesn’t mean it’s not got a milk product in it. It makes it hard to answer the question about suitability - I don’t know, it’s confusing that label. Not clear for me or patients.” (GP)

“If it says ‘milk free’ you automatically think ‘milk (only) free’ but patients wouldn’t know whether it meant it had no butter or cheese in it.” (Dietician)

There was a similar divide in opinions about the presence of lactose. About two-thirds of consumers (most of whom were lactose intolerant) and some health professionals thought it would be **completely free of lactose** but **many were unsure**. This lack of certainty was mainly based on a lack of understanding of what lactose is but for a few, there was the same uncertainty as with ‘dairy free’ products about whether lactose could still be present.

6.4.2 Who is 'milk free' suitable for?

Apart from the respondents with galactosaemia, 'milk free' was not the claim of choice for other groups although most consumers assumed that they would be able to eat/drink 'milk free' products. This was largely because they readily made a connection with 'dairy free' products. They also assumed that people with other conditions could also consume products making this claim.

"The stuff that gives us the problems is in the milk, so if it was 'milk free' I know I could eat that then, because there's nothing in it that would cause us problems." (Self and parent of child with Lactose intolerance. Self diag. Wales)

"I'd probably look into that more than a 'lactose free' one. Because that covers all the proteins and lactose as well, because it just sounds like that all the particles are taken away altogether." (Lactose intolerance. Med. diag. Scotland)

The health professionals were largely in agreement; 'milk free' products would certainly be suitable for milk intolerant and milk allergic patients. While they also thought that they could be suitable for those with a lactose intolerance, some health professionals along with several consumers (including a few who were lactose intolerant themselves), questioned whether those who are lactose intolerant might have a problem because lactose could be present.

6.5 'Lactose free'

6.5.1 What does 'lactose free' mean?

Most consumers understood that lactose is part of milk but beyond this, there was often a lack of knowledge or confusion about the nature of lactose. Many, especially among the lactose intolerant, were aware that it was a sugar but on several occasions it was also referred to as an enzyme, and by one respondent, as being 'secreted' by milk and dairy. One lactose intolerant respondent thought it was to do with proteins in milk.

Those who were able to give some explanation of what 'lactose free' meant suggested that the sugar in the milk had been removed but they did not necessarily have a clear picture.

"I did know what it was and I had a brief look on the Internet and it said something about sugar and that's it. That's basically my knowledge of lactose..."

... So when it says 'lactose free'?...

... I'm just assuming they've taken the extra sugar out of it." (Self and parent of child with lactose intolerance. Self diag. Wales)

"I thought lactose was the sugar in milk, am I wrong?... so the lactose wouldn't be in eggs because they are not made with milk – do they add it to milk? Gosh, I don't know as much as I thought I did! I know that not all of it, some of it, would be 'lactose free'. If it is 'lactose free', then it doesn't contain sugar so it must be added. I don't know, I am going to check when you've gone! Butter is 100% butter - has that got lactose in it?" (Lactose intolerance. Self diag. N.Ireland)

However, a large number of consumers admitted ignorance about how lactose related to milk and dairy, with a few equating it with one or other. For those who knew of 'Lactofree' milk, the cow on the pack could variously help and confuse – it suggested that the milk came from a cow but had the lactose removed yet some could not envisage how one could have cows' milk without lactose.

"It ['Lacto free'] tells me that it's milk that's been processed to take the sugars out and what's left is actually cow's milk. It's not a different form of milk, it's not like soya or anything like that, it's not made with anything else. To me 'lactose free' means cow's milk with the sugars taken out. It says to me I can have that and not have the side effects of drinking cow's milk without the sugars taken out." (Lactose intolerance. Med. diag. England)

"If, for instance, somebody gives me a bar of chocolate and says it's 'lactose free', or 'dairy free' which I'm associating the two with, then I would say they have used another product other than milk to put in there, but if you tell me here is a glass of milk, and it's lactose free, and it's not soya, then I would say 'How come it can be lactose free?'" (Lactose intolerance. Med. diag. England)

One respondent was able to draw an analogy with 'gluten free', meaning that the gluten is removed from cereal. While some were unaware of 'Lactofree' milk, for most others, this was the only product that was known for claiming to be 'lactose free'.

The natural assumption would be that for galactosaemics, a claim of 'lactose free' should mean that galactose has also been removed because galactose is a part of lactose. However, this may not be the case, especially if an enzyme has been added to the product to break down the lactose into its constituents (glucose and galactase). 'Lactofree' products have created confusion for galactosaemics (see 5.6.1) because they contain galactose and are therefore unsuitable for them.

"If it was me, I would have said it is free of milk but when you have products like that ['Lactofree'] that I know I can't have, it makes me think, 'hang on, is it free of milk or isn't it?'" (Galactosaemia. Med diag. England)

It was generally assumed by consumers and health professionals that 'lactose free' products would be **completely free of lactose** but there was **uncertainty over milk**

and dairy content. Many thought there could be some milk in a lactose free product – in part because they know that lactose is only part of the milk and also because of their knowledge of ‘Lactofree’. Health professionals were often more specific about the milk components that might be present. Similarly, many thought that low or normal levels of dairy could be present, for similar reasons.

“But in my own mind I think to myself, if it’s ‘milk free’, there shouldn’t be any lactose in it. But if it’s ‘lactose free’, I don’t think it’s guaranteed that there’s no dairy products.” (Milk allergy. Med. diag. Wales)

“I would say it could possibly still have the normal levels of dairy in it. I’m thinking of that lactose free milk that you do get. I presume that is normal milk with the lactose removed.” (Parent of child with milk allergy. Med. diag. N.Ireland)

“It’s probably got some milk in it but it hasn’t got the sugars that make up milk in it, but it’s probably got some kind of milk in there but is okay to consume.” (Milk intolerance. Self diag. Wales)

“There is no milk sugar in it but there may be other products like casein, whey, curd.” (Dietician)

“There could still be dairy content in it but the lactose part has been modified and removed.” (Practice Nurse)

“It should have no cows’ milk but it could have other forms of milk.” (Nurse Practitioner)

6.5.2 Who is ‘lactose free’ suitable for?

As mentioned above, while consumers with galactosaemia felt they should be able to eat/drink ‘lactose free’ products, ‘Lactofree’ has given them pause for thought. All those who were lactose intolerant recognised that products making this claim should suit them.

All those with a milk allergy were unsure or believed that ‘lactose free’ would not suit them and one woman was able to articulate that this was because her allergy is due to a milk protein rather than the lactose in milk. Her knowledge may have been based on the fact that she had previously been diagnosed as lactose intolerant and due to a change in her symptoms this had been changed to milk allergy.

Half of those who were milk intolerant thought that they could eat/drink ‘lactose free’ products. In part this seemed to be due to a lack of knowledge of what it meant but it could also be in part down to an unclear definition of their condition.

“I think I would still be a little bit wary of trying it myself because it doesn’t tell me that it’s milk free or dairy free because I don’t really understand what part is the lactose.” (Milk intolerance. Med. diag. Wales)

Similarly, ‘lactose free’ products were understood by health professionals to be suitable for lactose intolerant patients but not for those with a milk intolerance or allergy. However, in line with the confusion over what ‘lactose free’ meant, a proportion of health professionals felt that such products would be suitable for those with milk intolerance/allergy.

6.6 The Business View

As noted above, the businesses included both those who were featuring ‘free from’ claims on products that they manufactured or sold, and those that did not. Their responses to the questions about the meaning of ‘dairy free’, ‘milk free’ and ‘lactose free’ were informed by different types of experience and variously drew on their corporate or professional experience, consumer research and their own personal views on the subject.

6.6.1 ‘Dairy free’

The immediate response tended to be to think of ‘dairy free’ as equivalent to ‘milk free’ but when forced to articulate the meaning, some questioned the definitions. The large manufacturers who were not making use of claims often anticipated the confusion that consumers might feel.

“To me, both ‘milk free’ and ‘dairy free’ would mean the same, which means you don’t have anything present that has been made from milk. But my personal perception is maybe consumers would see ‘milk free’ as being free from milk, the liquid white stuff, whereas ‘dairy free’ I think everyone would assume, means complete absence of anything that comes from dairy, that’s a personal view.” (Large manufacturer)

The team at one manufacturer contrasted the ‘corporate’ definition with their personal understanding.

*“No milk or derived products actually... or ingredients, milk derived ingredients...
... I just know from my experience - if I think about my family, I’m thinking outside of work even - ‘dairy’ can be a very poor term. It can encompass eggs for some people. You know they think butter, milk, cheese.” (Large manufacturer)*

Interestingly, on the question of whether eggs would be included under dairy, for one manufacturer at least, eggs were included within the dairy category within their business.

It was generally assumed that a claim of 'dairy free' would be interpreted by consumers as meaning the product was completely free of dairy but the best that industry could do would be to ensure that whatever component featured in the claim would not be detectable above the level to which equipment was sensitive (and as set down by retailers) and would be at a level that would not cause harm to consumers.

"This is very much where the difficulty comes in. It's my perception, I think ordinary people, if you say something is free from something, obviously people think it is free, but from a practical perspective, that total absence can be very hard to achieve and in the case of lactose intolerance, may not actually be necessary." (Large manufacturer)

"The point is, we might be able to accept that sort of claim in our products if we were satisfied that the amount of dairy ingredient, milk derived ingredient was actually so small as not to pose a risk basically..."

...So it may not be completely free but it's so small?...

...Yeah because completely free is - how I always think of that is as a challenge to an analytical chemist and you tell them it's free and they'll find a way... Yeah, there'll be one molecule!... Let's put it this way, I would expect it to be undetectable by a sort of routine test but maybe something would be detectable by really advanced analytical techniques I should really say, something like that. And it would be so low that we would judge it not to pose a risk." (Large manufacturer)

It was also assumed that the same undetectable amounts of milk and lactose would apply to 'dairy free' products because 'dairy' encompassed these constituents. One of the large manufacturers was less certain, feeling there might be some exceptions to this.

"Do you think 'dairy free' would be totally free of lactose?"

Um...it is an interesting one, because I know lactose is in things like coating of tablets and medication, so... I would probably go back and say, potentially it could still contain lactose." (Large manufacturer)

One of the niche manufacturers who had observed consumers talking about this topic in research commented that it was those who had been diagnosed and understood their levels of tolerance who would also be better informed about the levels of constituents in products making 'free from' claims.

“As far as the consumer’s viewpoint, from the groups I have been at, because it says ‘free from’, they assume it’s free from, so there is nothing in it and many are confused when they find out that actually, we are allowed to put some in, regardless of how little or how large. They are confused we can do that. ‘If it’s free from, why are you allowed to put some in?’ The people who do understand it are the people who are fully aware of their intolerances or their allergies. The people who have done a lot of research on it do understand it, and they are aware of this allowance, but as I say, the majority of our market place are people who are avoiding for reasons other ... well for health reasons, but they are not fully diagnosed reasons, so I would say again, that the majority of people don’t fully understand that we are allowed to put some of whatever it is free from in, in certain areas.” (Niche manufacturer)

It was also expected that ‘dairy free’ products would be suitable for all consumers with a sensitivity to milk.

“I think I would link milk and dairy together. If I saw messages about milk or messages about dairy, I would assume they meant the same thing... so if I had a problem with lactose and I saw ‘dairy free’, I would assume that was okay for me.” (Retailer)

6.6.2 ‘Milk free’

While those using ‘milk free’ saw it as essentially the same as ‘dairy free’, it was seen by several businesses as potentially confusing for consumers because the term lacks clear definition and they are unsure why some use it.

“We use the term ‘dairy free’ because we think that embraces those areas [‘dairy free’, ‘milk free’, lactose free’]. Whereas, if you say ‘milk free’, what does that mean? There are a lot of question marks from a consumer point of view in my opinion. It’s not got milk in it but if it’s ‘milk free’, is it free of cheese? Has it got butter in it? I don’t know what they’re meaning when they say it’s not got milk in it. Do they really know what they mean? Has it got whey protein in it? I have a lot of questions straight off the bat when somebody says it is ‘milk free’.” (Niche manufacturer)

“‘Milk free’ would just mean that it doesn’t contain the actual liquid form of milk.” (Large manufacturer)

“Well, a number of the manufacturers and indeed the private label people use ‘milk free’, some of them still do...”

What would your understanding of ‘milk free’ be? Would it be the same as ‘dairy free’ or would it be different?...

“...I don’t know, I can’t answer that because I don’t know what ‘milk free’ means either. I mean ‘milk free’ should be the same as ‘dairy free’ unless they’re trying to avoid the confusion with eggs.” (Niche manufacturer)

Given this uncertainty, some were unsure whether ‘milk free’ products might contain some other dairy ingredient. Moreover, while most thought that ‘milk free’ products

should be free of milk, some questioned (as with 'dairy free') whether they might contain some lactose.

6.6.3 'Lactose free'

'Lactose free' products were often associated with the 'Lactofree' product range and it was understood that this was milk with the sugar removed and served the needs of a particular market that had probably had a diagnosis of lactose intolerance.

"Like 'lactose free milk', if you know it's specifically lactose that you have the problem with, then understanding that it's 'lactose free' and you can have it, that's brilliant, you don't need to get rid of all the milk proteins. So that's a very specific product." (Niche manufacturer)

However, there was some concern that 'lactose free' was not well understood as a term unless a consumer had been 'educated' in its meaning. It was generally accepted that there could be both dairy and milk components in 'lactose free' products and that this could also confuse the consumer.

"I think it could mean something else because potentially you could have something like butter present which is very low in lactose, but would obviously still be a significant dairy ingredient." (Retailer)

"It might mean the product is completely free from dairy but you cannot be sure without knowing more. It might still contain milk allergens." (Niche manufacturer)

"Because you can get lower lactose products can't you and lactose free cows' milk because they've done something to it, to the sugars. So I would assume the protein was still in those products, so if I had a milk allergy I would avoid it and would recommend customers to avoid it." (Retailer)

Most thought that 'lactose free' products would be completely free of lactose in terms of detectable levels, with some noting that 'Lactofree' does not claim to have removed all the lactose. They were unsure whether this was necessary anyway.

"I would say they would have to be very low rather than totally absent actually..."

... Yeah. I would as well, 'cause again, if you get 'lactose free' milk, I think they state on it, don't they, that it's like 99% lactose removed. It's not absolutely free from...

...Yes, I mean the thing is, once there is some information about what are the amounts that people react to and the dangers for people who have got lactose intolerance or even galactosaemia of very small, very low levels of lactose - it would not be as dramatic as for those with milk allergy." (Large manufacturer)

6.7 Preferences

6.7.1 Consumers

Consumers were asked to put the three claims in order of preference – their choice did not signify that other claims would be ignored by them; simply, that the one they chose first had greatest resonance for them.

For all conditions except galactosaemia, **‘dairy free’** was most often, but not exclusively, preferred. This was because:

- it was seen as a more accessible term especially when compared to the more ‘technical’ ‘lactose free’.

"I think it's more... simple. It's much more understandable. Everybody can look and say it's dairy so, dairy, dairy, yes." (Lactose intolerance. Med. diag. England)

- this is often the term that health professionals have used.
- it is broad ranging in its coverage – including eggs for some. This was perceived as useful where consumers also had an intolerance to eggs (although technically, eggs are not dairy so there may be potential for egg allergic consumers to misunderstand a ‘dairy free’ claim if this does not encompass eggs).

"Because it encompasses everything, if it is really ‘dairy free’, it doesn't contain any milk, any lactose, anything." (Lactose intolerance. Med. diag. England)

"If it said ‘dairy free’, that would indicate that it's completely suitable but if it said ‘milk free’ I would have to read on further and make sure." (Lactose intolerance. Self diag. Scotland)

Very few opted for **‘milk free’** as their preferred choice because of the uncertainty around what it covers.

"‘Milk free’ is a bit confusing because you do wonder what's in it, ‘lactose free’ is milk without the sugars, ‘dairy free’ is no milk at all, so I don't understand ‘milk free’. It would tell me there's no lactose because there's no milk but what products would be ‘milk free’ without being ‘dairy free?’ If I saw three items, one said ‘lactose free’, one said ‘dairy free’ and one said ‘milk free’, I'd probably go for the dairy or lactose knowing that I understood what they were trying to tell me." (Lactose intolerance. Med. diag. England)

Those who opted for ‘milk free’ were those with galactosaemia and a few others who felt that ‘milk free’ was more precise than ‘dairy free’. For those affected by galactosaemia,

'dairy free' is wider ranging than they feel it needs to be and might therefore cut out eggs which are not a problem for them.

"The problem with 'dairy' is people tend to think, for some reason, that it tends to be the whole farm. So a lot of people ask if xxx [name of child] is okay with eggs. Because she can't have dairy, they tend to think there's a lot of things she can't have... or she can't have meat." (Parent of child with galactosaemia. Med diag. England)

"Because it's just milk, it's clearer, whereas dairy could be yoghurt, cheese, butter, so many different things, ice cream. And lactose, I don't really understand what 'lactose free' entails... Dairy is a whole bigger picture that you've got to think about, whereas milk's milk." (Parent of child with milk allergy. Med. diag. Scotland)

'**Lactose free**' was selected by about half of the lactose intolerants – it 'spoke to their condition' and meant that they could have products that otherwise might have been out of bounds to them. However, the fact that 'lactose free' is seen infrequently on products meant that a number with this condition were unaware of 'lactose free' products.

"I would go for 'lactose free' because I associate that as my problem. I could still have a problem with the milk but I associate that as being our problem is the lactose." (Self and parent of child with Lactose intolerance. Self diag. Wales)

"Because that's what my doctor says my intolerance is, that's what I've been told to watch out for. It would be good to see that on the pack - I've never noticed it on the front of anything." (Lactose intolerance. Med. diag. Scotland)

"And there's a comfort factor I think, when I buy something that's 'lactose free', it's always tended to be around milk products. But 'dairy free' - it's cheese, it's biscuits, it's a load of other things that falls under that umbrella. It seems that lactose is a little bit more specific." (Lactose intolerance. Med. diag. England)

6.7.2 Health professionals

The health professionals commented on any concerns they had about how the various claims might be understood by consumers.

While '**dairy free**' seemed to be suitable for most conditions and to cover the broadest range of possible allergens, health professionals queried whether the term 'dairy free' would be clear for all patients. It was felt there may be some confusion as to whether the product was therefore also 'lactose free', and uncertainty as to whether it did or did not include eggs. Health professionals were also unsure whether patients would think about the full spectrum of products that might be included within the umbrella of 'dairy free', or whether they would think about just cows' milk, or, alternatively, think about other 'dairy' products and not cows' milk.

“Patients might think it meant ‘milk free’, and perhaps yoghurt and cheese free but I don’t think ‘lactose free’, so there may be some confusion.” (Dietician)

“I think you have to make it clear what is ‘dairy free’ and what is ‘milk free’. I think sometimes they get muddled, think that if it’s ‘dairy free’ it’s ‘milk free’, ‘lactose free’.” (Practice Nurse)

“To say ‘dairy free’...if they actually used the word ‘milk’ maybe and ‘products’, they would understand it, but ‘dairy’ covers a large range.” (Practice Nurse)

Given the similar potential variation in understanding of the claim **‘milk free’**, it was felt by health professionals to be an unclear term for both patients and themselves. One suggestion was that it would help to make clear that it refers to cows’ milk.

“It’s not a useful label to put on things, it’s too generalised, people are not milk intolerant, they’re mammalian milk intolerant, they can have soya milk.” (GP)

“I think it’s got quite a few ambiguities but I don’t know if that’s because I’m a dietician and I’m thinking about components.” (Dietician)

“It’s broad, it can be misleading, you probably need to stipulate it is cows’ milk, patients would just think it had no milk in it.”(Dietician)

“‘Milk free’ is ambiguous because if the patient is allergic to milk protein it may still be there in another form, not milk form. That’s concerning, if you were allergic to milk protein and interpreted it incorrectly.” (Dietician)

From a patient perspective, health professionals felt that **‘lactose free’** was both clear and extremely useful for patients who had been diagnosed and received advice, but that it would mean nothing to patients who had self diagnosed or not received advice about their condition, what lactose is, and what this means in terms of the foods they can and cannot eat. It was therefore felt that it may be confusing for those patients who do not realise that the product could still contain some milk protein/milk product. It was also felt to be too complex and technical a term for some patients, particularly those with low literacy.

“People who have been diagnosed with lactose intolerance are fully aware of their condition. The general public don’t need to know it because the general public don’t have lactose intolerance. It’s far more definitive than to say it’s ‘dairy free’ because dairy covers other things.” (GP)

You would need to have had information, to know the difference between ‘lactose free’ and ‘dairy free’, not to have self identified. I see plenty of patients who have been diagnosed but have never received any written information or been given advice.” (Dietician)

“I think they would understand, because that’s part of the teaching that it comes from milk and it’s the way it’s broken down in the body etc. Hopefully, they would

have an understanding of that and they would be able to see that but maybe not. They may think it means there are no milk products and no milk derivatives.” (Dietician)

“They would understand that it was free of lactose but they wouldn’t have a clue what lactose means.” (GP)

“If you have gone through it and know you are lactose intolerant, then yes, if it said ‘lactose free’, then that would be very easy for them to understand.” (Practice Nurse)

6.8 Views on a Way Forward

6.8.1 Consumers

Towards the close of the interview, consumers were asked whether there was anything that would help them to make appropriate food choices for their condition. Listed below are some of their suggestions.

Label information

- A more comprehensive listing of allergens i.e. identify milk as an allergen even on those products where it might be assumed that people would know they are dairy products. We have noted above reports of ignorance about fromage frais and yoghurt being dairy products. There was also a suggestion that galactose should be listed as an allergen/ingredient. It was suggested that imported products should also conform.
- The ideal for many would be a more positive assertion about the suitability of a product for people with specific conditions e.g. ‘galactosaemic friendly’, ‘suitable for people with a lactose intolerance’.
- Use of the term ‘lactose free’ on more products such as ready meals would be helpful for young people as they start to fend for themselves.
- Colour coding of the allergens in the ingredients list on pre-packed foods might be used in combination with either of these more positive claims, to have immediate impact.
- Larger type for allergens/ingredients if other measures to help visibility are not taken on board.

- More information about the amount of particular ingredients/allergens in a portion of a product, presumably so that those with some tolerance could make a decision about whether the level was acceptable to them.
- If a recipe changes, flagging up on the product that this is the case.

“I think definitely, when a recipe is changed it should be, regardless whether it’s from the ‘free from’ range or not, ‘this now contains any allergens at all’. It should be made quite noticeable on the front ... because you can’t go round reading every label every week when you are doing your shopping of every item.” (Parent of child with milk allergy. Med. Diag. N.Ireland)

Provision of other information

- More information available in-store as to ‘dairy free’ or ‘milk free’ products, possibly in each area or via a terminal.
- Clearer signposting on supermarket websites as to where to find information about products.

“I have quite a big family, eight of us here with children, and when I go shopping I go for probably the cheapest but best branded item I can find. If there’s something there that I need that I could eat, that the rest of my family could eat, for example coleslaw, yoghurts, I would buy them but because I can’t, I can’t.” (Lactose intolerance. Med. diag. N.Ireland)

- A source of information about what terms and symbols mean on packs.

‘Somewhere online that you can check what all these symbols and labels actually mean, to find out what you can and can’t have.’ (Lactose intolerance. Med. diag. Scotland)

- More leaflets to explain in simple language about the condition and dietary restrictions for children/young people growing up with the condition or relatives to read.

“For me, I think it’s sufficient, but for people just finding out, because with my son, there are a lot of things he didn’t understand, because he automatically thought that he could still drink milk even though he’s lactose intolerant. And things like that. So I think for younger people just finding out, I think there should be more information.” (Milk intolerance. Med. diag. Wales)

- Allergens listed on menus.

Product availability

- Less expensive 'free from' products.
- More products that are 'milk' or 'dairy free' without necessarily also being 'gluten' or 'wheat free'.
- These might also be available with other products of the same type in the main aisles (rather than just on the 'Free From' shelves) but they would need to be clearly signposted.

"There's nothing else there to grab your attention and say 'actually I'm free from milk, I'm good for people who have dairy intolerances'... You've got to go out of your way to go to the 'free from' aisle whereas the 'Lactofree' milk is above the normal milk... out of the corner of my eye I see the 'Lactofree' and I think 'oh, I'll pay a bit more and get that'." (Lactose intolerance. Med. diag. England)

6.8.2 Health professionals

Health professionals were asked about measures that might be helpful to their patients in making food choices. There was a general feeling that signposting on the front of the pack was helpful for patients, as reading the ingredients was often difficult and always time consuming. There were many suggestions for clear, colour coded symbols/information that would enable patients to identify products more easily.

"I know we have got the red, green and yellow, but it would be nice to say 'lactose free' is blue, or pink or whatever, so that people know exactly what they are looking for, rather than trying to read, or for those who cannot read." (Nurse Practitioner)

"Colour coding would be better and would help these patients more – it is hard to read the small print for ingredients, especially for older people. Make it more obvious, they would be directed more quickly to the potential contents or lack of." (Practice Nurse)

"Something that they can look at and know that that colour means it is completely free of milk products. Something that is staring people straight in the face, as soon as they pick it up, easily recognisable so that patients feel secure in what they're taking" (Practice Nurse)

However, health professionals also emphasised that it was key that patients were still educated as to the specific terms to look out for and how to read the ingredients list, so that nothing was missed. Moreover, the point was made that the packaging should not become so overloaded that the really important messages for patients with severe allergies are lost.

"I think proportionality is the issue here, it's about getting the key messages across in a simple graphic symbol type of approach and recognising that it's not going to apply to everybody, it's just getting the balance right. So if it's a really serious dangerous problem then you need to be more careful about it than you do if it's just an inconvenience. You can't label in a way that will cover everybody's individual range of intolerances. What we don't need is six different words to describe the same thing, being used by different people." (Specialist)

Many emphasised the importance of the industry settling on one or more terms, the meaning of which are very clear, if patient confusion is to be minimised.

"I think that the labelling is absolutely crucial, if it's clear, concise and the people understand it, regardless of which intolerance or allergy it happens to be, that I can have this, because it says it quite clearly on it." (Dietician)

'Lactose free' products were felt to have a definite role for lactose intolerant patients, clearly identifying the product concerned as suitable for people with their condition. However, it was emphasised that understanding is reliant upon education as to what lactose is, and the implications of lactose free, but that not all people who suffer lactose intolerance receive that education.

"It's easier to use the proper terminology, to say 'lactose free', because anybody who has got these allergies will have spoken to a specialist, been told what to avoid. They only need to know the one name to avoid so keep it simple and succinct and have it in a relatively bold colour on the front of the packaging." (GP)

"Then it's the job of doctors and health visitors and government to make people understand what lactose intolerance is so that people actually understand the name of their illness, rather than just saying 'I can't have dairy products'." (GP)

Some also suggested that it would be helpful if there were designated lactose free areas in the chiller cabinets.

However, many health professionals suggested alternative forms of labelling. In particular, several suggested that 'contains milk products' could be added to the front of the pack, and there were also several suggestions that 'suitable for....' would be clearer and more user friendly.

"'Suitable for' is actively telling you that this is a safe food for you, is a definite green light whereas patients might get confused between 'milk free' and 'dairy free'. 'Suitable for' is telling you it's safe rather than leading you to have to think, 'is that still okay for me?'" (Dietician)

"If it just stated that it was suitable for which condition, then it makes it a lot easier for them, they won't have to read every detail, they can just pick it up and put it in their trolley." (Practice Nurse)

6.8.3 Businesses

While businesses were not asked explicitly to suggest developments they would like to see in this area, during many of the interviews, there was a spontaneous request for clarification and the setting of a threshold. However, this was not just for a threshold for managing 'lactose free' but more widely, for 'dairy free' also. It was suggested by some of the businesses who are not participating in this market place that this would be one of the measures that would make them reconsider entry.

"That [setting a threshold] would be extremely helpful because there's a clear standard that everyone can buy into and ... we know we're safe in making that statement because it's been properly investigated, that we're not going to make somebody ill and also we know we're legally compliant, we're not going to get into any disagreement with any enforcement authority." (Large manufacturer)

"I think we would like the FSA to tell us what those thresholds are..."

Would you welcome that if that happened?...

...Oh yes. And not just for lactose or milk... The establishment of a threshold, however low, would be preferable to the circumstances at the moment where, if we test the products, if there is some doubt as to the supply chain, and the manufacturing controls of a product, and we test just to make sure, and we find an infinitesimal amount of an allergen, there is nothing against which we can measure whether that product is acceptable or not. The default position is we had better not send it, or we had better not manufacture that product." (Large manufacturer)

For the niche players in the marketplace, they would also know whether the assumptions they are making about thresholds are the right ones. For those who do not currently meet certain standards set down by the supermarkets, it would also give them a clear target to aim at.

"I would welcome that from the manufacturer's perspective although I do appreciate the difficulties involved in arriving at a suitable threshold in view of the different degrees of sensitivity amongst the consumer group. It's just from a manufacturing perspective, you can really only control what you can measure and unless we have a target value to aim at, it's very difficult to set our controls so we've taken ... in general terms we've taken the approach taken by organisations like the Anaphylaxis Campaign who say that in the absence of thresholds, you need to manage the risk to the lowest possible level." (Niche manufacturer)

The point was made that it would be most helpful to international businesses if any thresholds are internationally applicable.

“It would be an advantage I think, to have a particular standard rather than a situation where we have nothing at the moment or where different countries interpret things differently.” (Large manufacturer)

Several businesses voiced the feeling that any threshold that is set should be one that is helpful to consumers rather than aimed at manufacturers or retailers; in this context, they were unsure whether the needs of affected consumers were well known. Overall, there seemed to be two schools of thought.

Most seemed to feel that there should be just one level and that ‘free from’ or ‘dairy free’ etc. should mean just that, or as near to zero of that particular constituent as detectable. This, it was assumed, was what the consumer expected and it made it easy for him/her to decide about the suitability of the product for them. Setting thresholds at a higher level so that some products had levels just below the threshold could lead to a consumer taking in more than they could tolerate over the course of a day (the ‘body burden’).

“If it’s down to 1 part per million, 2 parts per million or whatever, then as manufacturers, we should be making products that fit into that, rather than having this level, that would make it easier for everyone.”

Would you actually prefer a level to be set?

Yes. In conjunction with consumers and the manufacturers. I think it’s right that you just set a level that is ‘free from’, ‘lactose free’ or whatever, and anything above that ‘Contains’. And then that way, there’s no ambiguity about it... I think, as manufacturers, rather than turn around and say, ‘well, let’s educate the consumer to understand this’, that’s a bit sort of arrogant as well - to say, ‘just because we make it this way, so let’s educate the consumers to do that.’ Actually you should be doing what the consumers need and want.” (Niche manufacturer)

The other school of thought was that there may be room for more than one threshold level because not all consumers need the lowest level. The point was made that in setting the threshold as low as possible, one was ensuring that the few thousand consumers who might suffer anaphylaxis would be safe. Perhaps there could be a second level that would cater for the far larger number with greater tolerance or that would be acceptable to vegans.

“It may be that there needs to be another kind of chunk which is pretty close but this issue’s [contamination] still there. So for example, I can’t remember what the criteria are for the Vegan Society – there’s another kind of category for the other 5 million or so people who are interested in ‘dairy free’ for some reason or another... You have to have some positive claims, not ‘no dairy’ but ‘low dairy’ or

some other words that say less than 200 or so – it's basically 'dairy free' but it might have a bit in." (Niche manufacturer)

One respondent followed up the discussion with an emailed suggestion for a standardised system involving several levels.

"A simple traffic light system or for example, 1-5 or 1-10 values of 'risk or content' would be more helpful. Manufacturers could advise the risk/content on the scale using a number, and consumers could judge for themselves where on the scale they personally are, purchasing products accordingly... The advantages of this system would be enduring, allow for all the principles of allergy management to be taken into account, as well as end product testing at the producer, and would, possibly correctly pass some of the 'risk assessment' to the individual. Value descriptions could be changed over time, if required, without disruption to consumer understanding." (Niche manufacturer)

Such an approach would clearly put greater onus on the consumer to decide which level they could tolerate but the point was made that consumers are probably already using trial and error to decide what works for them. Moreover, apart from those who are milk allergic (who will require the highest 'free from' level), their condition is not life threatening.

"An individual with an intolerance needs to be aware of their own intolerance and interpret labels accordingly to their own specific needs, it is very difficult for a manufacturer to judge how for instance, how safe their product is for each individual with an intolerance." (Niche manufacturer)

If a threshold is set for making a 'lactose free' claim by the EC and it becomes more common, it was anticipated that consumer-directed communication will be necessary to help them understand how they can make use of it. For example, it may be necessary to inform those with a lactose intolerance that they may be able tolerate some lactose. The picture with respect to those with galactosaemia and those with a milk allergy/intolerance will need clarifying.

"I think first of all need to get to the bottom of what the consumers concerned want themselves, whether this is a big issue with people with lactose intolerance or maybe they ... I just don't know, maybe they know they can consume a certain amount of milk and they just use their common sense .. As we've been discussing, the thought does occur that if you do have a standard like that for 'lactose free', the worry about people with galactosaemia, although I think that's quite a rare condition, we're talking about something detected at a very young age, as a baby and those people are under such strictly controlled regimes, but there is a worry that if you say 'lactose free' then anyone with galactosaemia ... But one way may be to have a standard for 'lactose free', but it would need careful research to establish the effect on other groups. I don't think people with milk allergy or milk intolerance would see 'lactose free' as meaning it's suitable

for them but ... that's my thoughts. Or perhaps you've got to say 'lactose free, not suitable for galactosaemia!'" (Large manufacturer)

The suggestion was made by several respondents that the confusing situation with wheat and gluten should not be repeated with dairy and lactose in terms of firstly, the availability of two levels ('gluten-free' and 'very low gluten') and secondly, the need to signal that the product contains the higher level ingredient (wheat or dairy) when the allergenic ingredient (gluten or lactose) has been removed e.g. the requirement for the manufacturer to label gluten containing ingredients such as wheat starch when it meets the threshold to be labelled as 'gluten-free'.

"Now we, as a manufacturer, argued it should just be 'gluten free'. We don't need this very low, but I know that other manufacturers wanted this middle ground, this very low ground. But all I think is it confuses consumers because it's either 'free from', or it's not 'free from'. And if you are saying it's 'free from' ... 'But most people can have it and some people can't', how do they know if they can or they can't have it, again, without making it like a pharmaceutical product?" (Niche manufacturer)

"We have a problem at the moment where you can, in theory, have a product which can be labelled 'gluten free', but you've got to label it as 'containing wheat', which is extremely complicated and the authorities are thinking about that! Because the definitions are so different and there's a big problem with consumers becoming confused." (Large manufacturer)

7 Conclusions

7.1 Use of the Terms: 'dairy free', 'milk free' and 'lactose free'

The research found a general recognition that food labelling and other forms of information aimed at consumers with a sensitivity to milk have improved greatly in recent years. The availability of milk substitutes (e.g. soya milk), the bringing together of 'free from' products in particular ranges or sections of the supermarket, improved allergen and ingredients labels, and the use of claims such as 'dairy free', 'milk free' and 'lactose free' have all made life easier for those who are diagnosed with lactose or milk intolerance, milk allergy or galactosaemia.

A high proportion of milk sensitive consumers are scrutinising labels on-pack to help guide their food buying, at least on an occasional basis, and they are looking for a variety of information. However, while positive claims such as 'dairy free' are helpful to many, allergen and ingredient information are often more important. This seems to be in part because many people are unaware of products making such claims or because they may not buy them for reasons of cost. It was also the case that while some welcomed the 'green light' given by such claims, they might still wish to check out the back of the pack for allergens and ingredients. The claims have therefore not yet established themselves as a device that everyone feels they can rely on.

This picture is reflected in the practice of the health professionals who tend to focus on educating patients about excluding specific ingredients rather than seeking out the positive claims made on 'free from' products.

Among the food industry, a mixed picture was also evident with respect to the adoption of 'free from' claims, in particular the 'dairy free' claim. While some manufacturers and retailers are actively developing the market, others are holding back from entry and some established niche suppliers are reconsidering their position. One of the reasons for this difference in perspective is the uncertainty over the threshold levels that manufacturers should work to in order to support a 'dairy free' claim. At present, the supermarkets seem to be setting the standards by insisting on a threshold that is as close to zero as can be detected by the latest test methods that are available. There is a strong desire for an agreed threshold for 'dairy free' so that everyone is aware of the

target that they need to reach. The fact that EFSA is considering a threshold for lactose, rather than dairy, was not seen as a priority for most of the businesses.

7.2 Understanding of and Preference for the Terms

Understanding of what constitutes 'dairy', 'milk' and 'lactose' is far from clear and in the context of the terms, 'dairy free', 'milk free' and 'lactose free', these meanings become more ambiguous and confused. This applies not only to consumers, but also to health professionals and food businesses. Moreover, there is a high degree of overlap across the different audiences in the confusion over the meaning of the various terms, with health professionals and businesses anticipating, and to a degree, empathising with, the difficulties faced by consumers.

The terms 'milk free' and 'dairy free' are often used interchangeably (by all audiences) and until the entry of 'Lactofree' to the market, it was also suspected that 'lactose free' would not have had a specific meaning for consumers.

For the most part, 'dairy free' is the term that seems to have broadest appeal across the audiences and is most readily understood (certainly in terms of being free of milk and milk-derived products) although this understanding can at times be inaccurate when 'dairy' is seen as including eggs. The term 'dairy free' is liked for its familiarity and the fact that 'dairy free' products should be suitable for everyone with some form of sensitivity to milk. It is generally seen as meaning that a product making this claim is also 'milk free' although there is some uncertainty over whether it might contain lactose from a non-milk source.

Apart from terms such as 'non-dairy' and 'suitable for vegans', consumers are not actively seeking other claims although a number of them, backed up by some of the health professionals, would like to see more positive statements such as 'suitable for people with a lactose intolerance'. The provision of such statements is not how manufacturers and retailers would like to see the market developing, in part because of the difficulty of making such very specific claims but also due to the lack of space on-pack to accommodate them. Ironically, such statements (e.g. 'suitable for those avoiding milk') are sometimes now used by manufacturers and retailers as a more precautionary claim rather than the positive assertion that consumers and health professionals would like to see.

In the UK market, 'lactose free' products are not present in great numbers in the UK market but there is some sign that, in the form of the 'Lactofree' range, they are beginning to establish themselves with lactose intolerant consumers and that in part, based on the information provided on-pack, there is some understanding of the product in terms of what it is and who it is suitable for. However, this does not extend across the milk sensitive market however and many are confused about the nature of 'lactose free' products and who they are suitable for. The products seem to represent a particular difficulty for consumers who are galactosaemic because they retain galactose when the assumption would be that galactose would be removed with the lactose and therefore would be suitable for them.

Greater guidance was felt to be needed to help consumers understand what the terms mean if they are to make appropriate use of them.

7.3 Increasing Understanding of the Terms

Some consumers feel that the supermarkets and some manufacturers are performing an important role in educating affected consumers and helping them make informed food choices. This is done principally through online product and health information. Some retailers and manufacturers also see themselves as supplementing the advice given to the public by the health profession and even, as having a role in informing health professionals about what may be poorly understood conditions.

Health professionals acknowledge that they see only a small proportion of those affected by these conditions, particularly the intolerances, and that many may suffer adverse effects because they either do not present or do not receive a diagnosis that helps them. Alternative information sources or sources that prompt those affected to seek professional help may therefore be of value. Even where a diagnosis of an intolerance is achieved, it is often difficult for the practitioner to provide clear guidance because of the individual nature of the condition, and the need for the patient to work out for themselves where the limits of their tolerance lie.

Looking ahead at the potential need to harness existing communication channels to inform consumers about the meaning of claims, both health professionals and businesses offer useful routes. With respect to health professionals, any such information would need to be given around the time of diagnosis, along with guidance

about food choices and what to avoid. This is because, apart from those with other ongoing health problems or for whom symptoms remain unresolved, there seems to be little ongoing management of their condition.

The consumers who spoke of an effective relationship with their health professional, as well as the most knowledgeable health professionals, often described clear, printed guidance that could be taken away and referred to, although currently there is not a standard piece of information that performs this task. Consideration might be given to the development of such material.

Finally, the establishment of an expert information resource/charity comparable with Coeliac UK could be helpful for all parties.

Appendices

Appendix 1: Research Method

The research was conducted using a mix of telephone and face to face interviews. Sixty-three interviews were conducted in total, approximately half of these with consumers (32) and the other half split between health professionals (15) and businesses (16). Consumers and health professionals were recruited by a recruitment agency using a mix of recruiters on the ground and in the case of the health professionals, databases. The recruitment screening questionnaires developed to ensure the eligibility of these respondents are included below (appendix 2). Businesses were identified using a variety of methods including internet searches and help from the FSA, trade associations and the editor of a food website. Tailored letters introducing the research and Creative Research were provided by the FSA to reassure each audience. These can be found at appendix 3.

Face to face interviews (25) lasted up to an hour while the telephone interviews (38) varied in length by audience but were typically 30-45 minutes. Interviews were conducted between 4 February and 25 March 2010. More detail about each of the samples is provided in the following sections.

Consumers

Sixteen face to face and the same number of telephone interviews were carried out with consumers; the distribution across the four different conditions is shown in the table below.

Table 5: Consumer sample by medical condition

Condition	No. of respondents
Lactose intolerance	15
Milk allergy	7
Milk intolerance	8
Galactosaemia	2
Total	32

About a third of the respondents lived in England; the rest were fairly evenly spread across Scotland, Wales and Northern Ireland. The majority of the sample were women and most were aged under 50, with about a quarter aged less than 30.

Tables 6, 7 and 8 show how respondents were distributed within each nation by condition and by gender.

Table 6: Consumer sample by location and condition

		Condition				Total
		Lactose Intolerant	Milk Allergic	Milk Intolerant	Galactosaemic	
Location	England	4	2	3	2	11
	Wales	3	1	2	-	6
	Scotland	5	2	1	-	8
	N Ireland	3	2	2	-	7
Total		15	7	8	2	32

Table 7: Consumer sample by location and gender

		Gender		
		Male	Female	Total
Location	England	2	9	11
	Wales	1	5	6
	Scotland	2	6	8
	N Ireland	1	6	7
Total		6	26	32

Table 8: Consumer sample by condition and gender

		Gender		
		Male	Female	Total
Condition	Lactose Intolerant	2	13	15
	Milk Allergic	2	5	7
	Milk Intolerant	1	7	8
	Galactosaemic	1	1	2
Total		6	25	32

Most of the consumers were from socio-economic groups C1C2 with smaller numbers from groups AB and DE. Tables 9 and 10 show the sample by social grade, condition and gender.

Table 9: Consumer sample by socio-economic group and condition

		Condition				Total
		Lactose Intolerant	Milk Allergic	Milk Intolerant	Galacto-saemic	
SEG	AB	1	1	1	-	3
	C1C2	10	6	4	2	22
	DE	4	-	3	-	7
	Total	15	7	8	2	32

Table 10: Consumer sample by socio-economic group and gender

		Gender		
		Male	Female	Total
SEG	AB	1	2	3
	C1C2	4	18	22
	DE	1	6	7
	Total	6	26	32

Just over a quarter were of BME heritage. Tables 11 and 12 show the distribution of respondents by ethnic group, condition and gender.

Table 11: Consumer sample by ethnicity and condition

		Condition				Total
		Lactose Intolerant	Milk Allergic	Milk Intolerant	Galacto-saemic	
Ethnicity	White British	8	4	6	2	20
	White Irish	2	1	-	-	3
	Indian	-	2	1	-	3
	Pakistani	1	-	1	-	2
	Caribbean	2	-	-	-	2
	Black African	1	-	-	-	1
	Mixed White/Asian	1	-	-	-	1
	Total	15	7	8	2	32

Table 12: Consumer sample by ethnicity and gender

		Gender		
		Male	Female	Total
Ethnicity	White British	3	17	20
	White Irish	1	2	3
	Indian	2	1	3
	Pakistani	-	2	2
	Caribbean	-	2	2
	Black African	-	1	1
	Mixed White/Asian	-	1	1
	Total	6	26	32

Most of the respondents had the condition themselves but in six cases, the mother was interviewed about a child with the condition. In at least a further three cases, other respondents also had a child with the same or suspected same condition. Moreover, several reported other family members with the condition.

The sample included a mix of consumers who had been medically diagnosed with their condition (23) and those who had either self-diagnosed or been diagnosed by an alternative or complementary practitioner (9). The numbers for each condition are shown in Table 13

Table 13: Consumer sample by diagnosis

	Medically diagnosed	'Self' diagnosed or diagnosed by an alternative practitioner	Total
Lactose intolerance	9	6	15
Milk allergy	7	0	7
Milk intolerance	5	3	8
Galactosaemia	2	0	2
Total	23	9	32

Health Professionals

Four face to face and eleven telephone interviews were conducted with a range of health professionals across the four nations who treated patients with some form of sensitivity to milk. The distribution of the health professionals across the four nations is shown in Table 14.

Table 14: Health professionals by role and location

		England	Wales	Scotland	N. Ireland	Total
Role	Practice Nurses	4	-	2	-	6
	GPs	3	1	1	-	5
	Dieticians	-	1	1	1	3
	Secondary care specialist	1	-	-	-	1
	Total	8	2	4	1	15

Businesses

Five of the 16 interviews with this part of the sample were conducted face to face, the remainder by telephone. The sample was made up of a mix of trade associations, retailers with a presence in most, if not all, the four nations, large food manufacturers with a range of products and/or product brands, and niche manufacturers of products aimed at consumers with a sensitivity to milk. While most were based in England, half of the niche manufacturers were in Wales and Scotland. The number of interviews conducted in each category is shown in Table 15. Respondents had various roles in their company including Managing Director, Commercial, Technical, Regulatory Affairs and Quality and Compliance Director or Manager, Brand Manager, Nutritionist and Science Lead.

Table 15: Business Sample

Type of organisation	No. of interviews
Retailers	4
Large manufacturers	4
Niche manufacturers	6
Trade associations	2
Total	16

Discussion Content

Copies of the discussion guides for each of the audiences are provided in appendix 4. While each of the three is tailored to its audience, there was a shared element that was covered towards the end of each interview which asked respondents about their understanding of each of the terms, ‘dairy free’, ‘milk free’ and ‘lactose free’. This can be found in the discussion guide for consumers.

Appendix 2: Recruitment Screening Questionnaires

Consumer recruitment screener

Food Labelling Research

Hello, I'mfrom Creative Research, an independent market research company. I wonder if you would be interested in taking part in some market research we are conducting on behalf of the Food Standards Agency about food labelling to help people who are sensitive in some way to milk, other dairy products (such as cream, yoghurt, butter, cheese) or lactose. It involves taking part in an informal interview in your home / by telephone to discuss your experience and views. This should last for about an hour / half an hour. In return for your time, I can offer you £30/£20 as a contribution towards your expenses.

Recruiter: please fill in the following details

RESPONDENT DETAILS

Explain that you need to record the respondent's contact details so that they can be contacted in the event of a change of plans (e.g. the moderator is ill) and also for quality control procedures. Reassure respondents that no personal details or responses will be passed on to anyone not directly concerned with the research without their express permission

Name:	
Address:	
Postcode:	
Telephone:	

METHOD OF RECRUITMENT

- VIA HEALTH CARE PROFESSIONALS
- FROM CLIENT-SUPPLIED LISTS
- FROM RECRUITER'S DATABASE
- SNOWBALLING
- FREE FOUND (In Street/House to house etc)
- OTHER (PLEASE WRITE IN): _____

RECRUITER DECLARATION

I DECLARE THAT THIS IS A TRUE RECORD OF AN INTERVIEW WITH THE NAMED RESPONDENT WHICH WAS CONDUCTED IN ACCORDANCE WITH THE INSTRUCTIONS AND THE MRS CODE OF CONDUCT. I AGREE TO BE BOUND BY THE DATA PROTECTION ACT 1998.

SIGNATURE: _____

PRINT NAME: _____ DATE: _____

For Creative Research use only Respondent ID

KEY DEMOGRAPHICS

D1 SOCIAL GRADE OCCUPATION OF HEAD OF HOUSEHOLD:						
ASK THE FOLLOWING FIVE QUESTIONS TO CLARIFY HEAD OF HOUSEHOLD INFORMATION:						
IF RETIRED, ASK FOR PREVIOUS OCCUPATION, IF PRIVATE PENSION RECEIVED			IF LOCAL AUTHORITY OR CIVIL SERVICE OR ARMED FORCES, ASK GRADE/RANK			
IF SELF-EMPLOYED OR MANAGERIAL, ASK FOR NO. OF EMPLOYEES RESPONSIBLE FOR			ASK FOR DETAILS OF TRAINING/QUALIFICATIONS			
INDUSTRY (WRITE IN)						
NOW CODE SEG	AB	1	C1C2	2	DE	3
D2 Gender			D3 Age – write in			
Male	1		18-30	1		
Female	2		31-50	2		
D4 Ethnicity (Use Show Card D)			51-65	3		
White British	1		66+	4		
White Irish	2					
Northern European	3		D5 Condition: Complete after going thro' Q1-6			
Southern European	4		Lactose intolerance	1		
Other White background	5		Milk allergy	2		
Mixed – White & Caribbean	6		Milk intolerance	3		
Mixed – White/Black African	7		Galactosaemia	4		
Mixed – White & Asian	8		Non-specific	5		
Any other mixed background	9		D6 Diagnosis: refer to Q4/Q5			
Indian	10		Clinically diagnosed	1		
Pakistani	11		Alternatively or self-diagnosed	2		
Bangladeshi	12		D7 How affected by the condition: refer to Q2			
Any other Asian background	13		Person with the condition	1		
Caribbean	14		Parent of child with condition	2		
Black African	15					
Any other Black background	16					
Chinese	17					
Other: write in	18					

SCREENING

S1. SHOW CARD A Can I just check, do you or any of your immediate family work in any of the following professions or occupations?					
Market Research or Marketing	1	CLOSE	Healthcare	4	CLOSE
Public Relations or Journalism	2		Food manufacturing	5	
Advertising	3				
			None of these	6	CONTINUE
S2a. Have you ever attended a GROUP DISCUSSION or IN-DEPTH INTERVIEW before?			S2b. What was the subject under discussion?		
No	1	GO TO Q1	IF PREVIOUS SUBJECT RELATED TO THIS PROJECT, THANK & CLOSE. OTHERWISE ASK Q2c		
Yes	2	GO TO S2b			
S2c. How long ago was that?			S2d How many group discussions & depth interviews have you attended in the last 3 years?		
Less than 6 months	1	THANK & CLOSE	1-6	1	GO TO Q1
More than 6 months ago	2	GO TO S2d	7 or more	2	THANK & CLOSE

Q1. Do you look at food labels for information about milk, other dairy products (such as cream, yoghurt, butter, cheese) or lactose when shopping for food because of an intolerance or allergy?					
Yes	1	CONTINUE			
No	2	CLOSE			
Q2. Who are you shopping for?					
Myself	1	Recruit to Quota			
My son/daughter	2				
My husband/wife or partner	3	THANK & CLOSE			
Other (please write in)	4				
Q3. What type of sensitivity to milk, other dairy products or lactose do you have / does your child have?					
Lactose intolerance	1				
Milk intolerance	2				
Milk allergy	3				
Galactosaemia	4				
Other - please write in	5	Consult office to see if eligible			
Don't know	6				
Q4. Have you / they been diagnosed by a medical practitioner?					
Yes	1	Ask Q5 then classify as directed			
No	2	Go to Q6a-6c then classify as directed			

If respondent's/child's condition has been diagnosed by a medical practitioner, ask Q5 and then classify as shown below

Q5. Which type of medical practitioner was involved in giving you / them a diagnosis? (Code all that apply). Please note that diagnosis by a nutritionist would not count as a medical diagnosis. If a nutritionist is mentioned, treat as an alternative therapist and skip to Q6

GP	1	These would all count as a clinical diagnosis – you may recruit
Practice nurse or health visitor	2	
Medical consultant (usually hospital based) – if possible write in speciality eg. paediatrician, allergy specialist	3	
Dietician	4	
Other – please write in	5	Consult office to see if eligible

Now classify here and at D5 as

Lactose intolerance	1	If condition has been diagnosed as such by a medical practitioner – Code 1 at Q3 and Q4
Milk intolerance	2	If condition has been diagnosed as such by a medical practitioner – Code 2 at Q3 and Code 1 at Q4
Milk allergy	3	If condition has been diagnosed as such by a medical practitioner – Code 3 at Q3 and Code 1 at Q4
Galactosaemia	4	Only if condition has been diagnosed as such by a medical practitioner – Code 4 at Q3 and Code 1 at Q4
Non-specific	5	If condition has been diagnosed as such by a medical practitioner – Code 5 or 6 at Q3 and Code 1 at Q4

If respondent/ child has not had their condition diagnosed by a medical practitioner, ask Q6a-c and then classify as shown below		
Q6a. Have you/they been diagnosed by someone other than a medical practitioner or have you arrived at a diagnosis yourself?		
Diagnosed by someone other than a medical practitioner	1	Continue
Diagnosed by myself	2	
Q6b. How have you/someone other than a medical practitioner arrived at a diagnosis?		
Alternative therapist/nutritionist – please write in	1	These would all count as alternatively or self-diagnosed Continue at Q6c to check symptoms
Test bought over the counter eg. the York test – please write in details	2	
Based on own research	3	
Other (please write in)	4	
Q6c. SHOW CARD B Which of these groups of symptoms, if any, comes closest to describing what happens when you eat/drink food that contains milk, other dairy products or lactose?		
A	1	Lactose intolerant
B	2	Milk intolerant
C	3	Milk allergic
None of them	4	CLOSE
Now classify here and at D5 as		
Lactose intolerant	1	If symptoms match A (Code 1 @ Q6) AND Code 1 at Q3
Milk intolerant	2	If symptoms match B (Code 2 @ Q6) AND Code 2 at Q3
Milk allergic	3	If symptoms match C (Code 3 @ Q6) AND Code 3 at Q3
Galactosaemia	4	This is a very serious potentially life threatening condition and must have been diagnosed by a medical practitioner – if respondent has self-diagnosed - CLOSE
Non-specific	5	If condition coded at Q3 does not match symptoms coded at Q6c OR If condition is coded 5-6 at Q3 irrespective of which symptoms are coded at Q6c OR If respondent is unable to choose between option A or B at Q6c irrespective of condition coded at Q3

Give to Respondent or read out Show Card C

The group discussion or interview you take part in will be audio recorded and a transcription will be produced.

This card describes how the information you provide will be used and the steps that will be taken to protect your confidentiality.

Please indicate your agreement with this procedure.

Respondent agrees with the procedure	1	Continue
Respondent does not agree with the procedure but is willing to be interviewed without it being recorded	2	
Respondent unwilling to take part	3	CLOSE

SHOW CARD A

Market research

Marketing

Journalism

Public Relations

Advertising

Healthcare

Food manufacturing

SHOW CARD B

- A: Symptoms develop within 1-2 hours and include abdominal pain, bloating, wind and diarrhoea.
- B: Symptoms may develop very quickly or may take several days and include feelings of nausea, abdominal pain, bloating, vomiting and diarrhoea.
- C: Symptoms include hives (red itchy bumps), swelling of the skin, an eczema type of skin reaction, vomiting and diarrhoea, difficulty breathing and possibly anaphylaxis.

SHOW CARD C

The Data Protection Act requires that we collect and use the information you provide to us in a manner that respects and protects your confidentiality.

Your personal details (such as name, address, phone number) will not be disclosed to anyone else without your permission other than Creative Research, the company carrying out the research.

In most cases the recordings/transcripts will be heard/read **only by the transcriber and researchers from the research company.**

The recordings/transcripts will only be listened to/read for research purposes and only to pursue the aims of the study. Excerpts from the recordings/transcripts may be used to illustrate the research findings. This will always be done in a way to protect your identity (e.g. comments will not be attributed).

The recordings/transcripts will not be used for non-research purposes, such as promotion or direct sales activities.

In exceptional cases the recordings/transcripts will be listened to/read by people from the client organisation working on this project. In these circumstances, where possible we will go through the material first to delete any references to people's names or anything else that could identify them.

Anyone from the client organisation who listens to/reads the recordings/transcripts will sign an undertaking that they will respect the anonymity of those taking part. Thus, if anyone recognises you, (s)he will immediately stop listening or reading.

Any other material or information generated by you, such as ideas written down on paper, will be subject to the same strict controls.

You have the right to **withdraw your consent** at any point in the interview/discussion. You may also withdraw from the interview/ discussion at any point. Please sign below to indicate your agreement with this procedure.

SHOW CARD D

White British	Indian
White Irish	Pakistani
Northern European	Bangladeshi
Southern European	Any other Asian background
Other White background	Caribbean
Mixed – White & Caribbean	Black African
Mixed – White & Black African	Any other Black background
Mixed – White & Asian	Chinese
Any other Mixed background	Other

Recruiter Instructions

This research is on behalf of the Food Standards Agency and is about how people who have an allergy or intolerance to milk make use of labels on food packs to help them decide what they can buy and eat. We have provided a letter of reassurance from the FSA that can be given or sent to respondents.

There are three conditions that we are particularly interested in – lactose intolerance, milk allergy and milk intolerance although the bias is towards lactose intolerance.

In total, we wish to conduct 30 interviews with people who are affected by one of these conditions or who is responsible for buying and preparing food for someone who is affected. 16 of the interviews are face to face and the other 14 are by telephone. The interviews are to be spread out across the four nations as shown in the table below. The numbers in **underlined bold** refer to **face to face** interviews.

Sample Group	England	Scotland	Wales	N. Ireland	Total
Lactose intolerant	<u>2</u> + 2	<u>2</u> + 2	<u>2</u> + 1	<u>2</u> + 1	14
Milk allergic	<u>1</u> + 1	<u>1</u> + 1	<u>1</u> + 1	<u>1</u> + 1	8
Milk intolerant	<u>1</u> + 1	<u>1</u> + 1	<u>1</u> + 1	<u>1</u> + 1	8
Total	16 f2f / 14 telephone				30

We expect the face to face interviews to last about an hour and they should take place in the respondent's or recruiter's home. The telephone interviews should take between half an hour and an hour. We will give £30 as a thank-you for the face to face interview (given at the time) and £20 for the telephone interview (a cheque will be sent out on the day of the interview).

Using labels when shopping

It is vital that everyone taking part shops for food for someone with one of these three conditions and regularly uses the on-pack labels to help decide whether to buy certain products (code 1 @ Q1).

Which condition? – Classify at D5 after asking Q1-6

The way to classify respondents depends on whether or not they have been diagnosed by a medical practitioner (code 1 at Q4) in which case, classify according to the answer given at Q3. If the answer at Q3 is 'other' or 'don't know', classify as 'non-specific'.

If the condition has not been diagnosed by a medical practitioner (code 2 at Q4) then you should classify the condition on the basis of the answer coded at Q3 and the symptoms coded at Q6c. You must have a match between the condition coded at Q3 (e.g. code 1 'lactose intolerant' and the symptoms i.e. symptoms A). If these do not match, you should classify them as 'non-specific'.

No more than 4 respondents should be classified as non-specific irrespective of whether or not they have been diagnosed by a medical practitioner.

Please note: we have included at D5 and Q3 the condition known as Galactosaemia. This is a rare and potentially life threatening condition and the chances of finding someone are small. If you do come across someone who has been diagnosed by a medical practitioner, you may be able to recruit them for a telephone interview **but you must check with us first.**

How has the condition been diagnosed? – Classify at C2

We do not expect everyone to have been diagnosed by a medical practitioner and therefore to count as clinically diagnosed (code 1 @ Q4) however **20 of the 30 interviews should be with respondents where the condition has been clinically diagnosed.** Identify which medical practitioner(s) was (were) involved in giving the diagnosis at Q5. More than one type of professional may have been involved.

If someone has not been clinically diagnosed but 'knows' which condition they have, ask Q6a and Q6b to find out how they have arrived at this diagnosis. They may have consulted an alternative therapist or used a test that they bought in a health food shop or pharmacy, or they may have decided themselves based on their own research. Please give some detail on this or write in at code 4 @ Q6b if they have used some other means to diagnose themselves.

Who is affected? - Classify at C3.

Of the 30 interviews, we would expect **15-20 to be with people who are themselves affected by one of the conditions** (code 1 @ Q2).

The interviews with people who are responsible for buying and preparing food for someone else who is affected, are likely to be with the mother of a child with one of the conditions (code 2 @ Q2), most probably a milk allergy. If they are with a partner or other person (code 3 or 4 @ Q2), we would only wish to include up to five people in this position. We are happy to include the child/person with the condition in these interviews but they will not receive an additional incentive.

Ethnic Background

Lactose intolerance is particularly prevalent in people from Asian, African, Chinese and Mediterranean backgrounds and we would therefore expect a number of respondents to be from such groups. It is important that respondents speak good English to allow us to conduct a face to face or telephone interview. If their English is not very fluent and they speak one of the South Asian languages, then it is possible that we may be able to arrange for them to be interviewed in their first language **but please ask before recruiting.**

Please aim to recruit

- 8-10 BME respondents with lactose intolerance
- 1-2 BME respondents who have a milk allergy
- 1-2 BME respondents who have a milk intolerance

Exclusions

Please exclude anyone who works (or who has close family who works) in marketing or market research, PR, journalism, advertising, healthcare (as a medical practitioner or in pharmaceuticals) or in the manufacture of food.

Data Protection and Confidentiality

Please make sure every respondent has read/been read Card C and given their consent.

Front Page

Finally, please complete the details on the front page:

the respondent contact details

the method you have used to find people

the recruiter declaration.

Good luck!

Health professional recruitment screener

Record category		
GP	1	
Practice Nurse	2	
Nurse Practitioner	3	
Health Visitor	4	
Dietician	5	
Record geographical location		
England	1	Recruit to Quota
Scotland	2	
Wales	3	
N Ireland	4	
Record interview type		
face to face	1	Recruit to Quota
telephone	2	
Record Respondent details		
Health professional name		
Address		
Postcode		
tel number		
mobile		
Appointment Details		
Q1. Do any of the following apply to you personally?		
I have a special interest in food allergies/food intolerances	1	If codes 1 or 2 apply, go to Q3
I am personally involved in running an allergy clinic and seeing patients at that clinic	2	
I am personally involved in giving advice to patients diagnosed with food allergies/food intolerances	3	If only codes 3 or 4 apply, go to Q2a
I am personally involved in giving advice to the parents of babies or children diagnosed with food allergies/food intolerances	4	
none of the above	5	Ask Q2b

Q2a. Do you tend to take the lead in your practice in giving advice on food allergies/food intolerances?		
Yes	1	Skip to Q3
No	2	Ask Q2b
Q2b. Is there anyone else within your practice who takes the lead in giving advice on food allergies/food intolerances or who has a special interest in food allergies/food intolerances?		
Yes	1	Record details below
No	2	If codes 3-4 @ Q1, ask Q3 If code 5 @ Q1, CLOSE
Record below details of those involved and try to recruit one of these (you should double check by taking this person through the screener).		
Q3. And do you personally see and advise patients who are...		
Lactose intolerant	1	All health professionals must see and advise at least one of these patient categories Ensure that across the sample we have included those advising all 3 main categories - lactose intolerant, milk intolerant and milk allergic.
Milk intolerant	2	
Milk allergic	3	
Galactosaemic	4	
None of the above	5	Thank and close
Q4a. How often do you see such patients?		
Rarely	1	Thank and close
Occasionally	2	Ask Q4b
Frequently	3	
Q4b. When was the last time you advised a patient with one of these conditions?		
In the last month	1	Please recruit
Between one and three months ago	2	
Longer than three months ago	3	Thank and close
Q5. Would you describe your patient population as...		
A mostly informed patient population	1	No quotas but ensure a mixture of patient populations across the health professional sample
A mixed patient population	2	
A mostly less well informed patient population	3	
DK/Not sure	4	

Recruiter Instructions

This research is on behalf of the Food Standards Agency (FSA) and is about how people who have an allergy or intolerance to milk, including milk products (dairy products) and components of milk (such as lactose), make use of labels on food packs to help them decide what they can buy and eat. This part of the research is about the guidance given by health professionals to patients with one of the conditions about what they should eat/drink and therefore the information on food labels that is relevant to them. We have provided a letter of reassurance from the FSA that can be given or sent to respondents.

In total, we wish to conduct 14 interviews with health professionals who are involved with patients who have an allergy or intolerance to milk, including milk products (dairy products) and components of milk (such as lactose). 4 of the interviews are face-to-face and the other 10 are by telephone. The interviews are to be spread out across the four nations as shown in the table below. The numbers in **underlined bold** refer to **face-to-face** interviews. You should aim to arrange the face-to-face interviews in Scotland, Wales and Northern Ireland to coincide with the face-to-face interviews there with consumers.

Sample Group	England	Scotland	Wales	N. Ireland	Total
GPs	1	1	1	1	4
Nurses/health visitors	<u>1</u> + 1	<u>1</u> + 1	1	1	6
Dieticians	1	1	<u>1</u>	<u>1</u>	4
Total	4 f2f / 10 telephone				14

We want to talk to health professionals who are at least reasonably well informed about milk/lactose allergies/intolerances and give advice on a regular basis, including advice on what to look for on food labels. It is vital that everyone therefore sees and advises patients with one of the conditions that we are especially interested in - lactose intolerance, milk allergy, milk intolerance or galactosaemia (codes 1-4 @ Q3). They should see patients with one or more of these conditions on at least an occasional basis (codes 2 & 3 @ Q 4a) and they should have seen such a patient in the last three months (codes 1 & 2 @ Q 4b).

Dieticians - We assume that they will say that they have a special interest in food allergies/intolerances (at least code 1 @ Q1) and therefore you just need to check whether they advise patients with the conditions at Q3 and whether they do this frequently and recently enough (Q4) .

When approaching GP practices to identify practice nurses, nurse practitioners, health visitors or GPs, please seek out the professional with the greatest experience or who takes the lead on allergies/intolerances – hence Q2a and 2b. If someone only gives advice to patients or parents of children with food allergies/intolerances (codes 3-4 @ Q1) but does not take the lead on this in the practice (code 2 @ Q2a) and there is nobody else who does (code 2 @ Q2b), you need to check that they are seeing and advising patients with one or more of the conditions we are particularly interested in (Q3) and they are doing this frequently and recently enough (Q4).

Given that lactose intolerance is particularly prevalent in people from Asian, African, Chinese, Latin American and Mediterranean backgrounds, health professionals in practices located in areas with large BME populations are likely to have greatest experience. We would therefore expect a number of such practices to be involved.

We only wish to see one practitioner from each practice unless you feel there is good reason to include more. Please discuss with us before recruiting. Please do not approach single handed practices.

Appendix 3: Letters of introduction

To consumers

www.food.gov.uk



To whom it may concern

Research about food labelling for people with a sensitivity to milk or milk components

The Food Standards Agency (FSA) is a non-ministerial Government department set up to protect the public's health and consumer interests in relation to food. It is concerned not only with the safety of the food we eat but also how it is labelled to make sure that people get accurate information in an understandable form.

The Agency is currently interested in how people with an intolerance or allergy to milk or milk components (including lactose) make use of food labels to help guide them when deciding which foods to buy and eat. We have commissioned Creative Research, an independent research company, to conduct this research on our behalf. They will be carrying out a series of interviews either in your home (lasting approximately 1 hour) or by telephone (lasting approximately 30 minutes to 1 hour) to discuss your experience of, and views on, current on-pack information.

Creative Research is bound by the Code of Conduct of the Market Research Society. This means that your interview will be conducted on an anonymous basis and although your comments may form part of the feedback to the Food Standards Agency, they will not be attributed to you personally. Any personal details (for example, names and addresses) will be kept confidential and will not be used for any purpose beyond this specific project, unless you give permission. All these details will be deleted upon completion of the project, unless you have given permission for them to be retained for recontact purposes.

If you wish to talk to someone about this research, you can call me here at the Food Standards Agency on 020 7276 8509, or Ros Payne at Creative Research on 020 8567 6974.

I hope that you will be interested in taking part in this valuable research and thank you for your contribution in advance.

Yours sincerely

A handwritten signature in blue ink, appearing to read "Sue Hattersley", with a long, sweeping flourish extending to the right.

Sue Hattersley

Head, Food Allergy Branch

To health professionals

www.food.gov.uk



To whom it may concern

Research about food labelling for people with a sensitivity to milk or milk components

The Food Standards Agency (FSA) is a non-ministerial Government department set up to protect the public's health and consumer interests in relation to food. It is concerned not only with the safety of the food we eat but also how it is labelled to make sure that people get accurate information in an understandable form.

The Agency is currently interested in how people with an intolerance or allergy to milk or milk components (including lactose) make use of food labels to help guide them when deciding which foods to buy and eat. As part of this work, we also wish to talk to health professionals who give guidance to patients who are lactose intolerant, milk intolerant, milk allergic or galactosaemic, on how to make safe food choices for their condition. One of our aims is to find out how helpful the information currently provided on packs is.

We have commissioned Creative Research, an independent research company, to conduct this research on our behalf. They will be carrying out a series of face-to-face or telephone interviews with a range of health professionals, some of whom will have more regular contact with such patients than others. We expect these interviews to last between half an hour and an hour. They will be conducted at a time that is convenient for you.

Creative Research is bound by the Code of Conduct of the Market Research Society. This means that your interview will be conducted on an anonymous basis and although your comments may form part of the feedback to the Food Standards Agency, they will not be attributed to you personally. Any personal details (for example, names and addresses) will be kept confidential and will not be used for any purpose beyond this specific project, unless you give permission. All these details will be deleted upon completion of the project.

If you wish to talk to someone about this research, you can call me here at the Food Standards Agency on 020 7276 8509, or Ros Payne at Creative Research on 020 8567 6974.

I hope that you will be interested in taking part in this valuable research and thank you for your contribution in advance.

Yours sincerely

A handwritten signature in blue ink, appearing to read "Sue Hattersley", with a long, sweeping tail.

Sue Hattersley

Head, Food Allergy Branch

www.food.gov.uk



To whom it may concern

Research about food labelling for people with a sensitivity to milk or milk components

As you will be aware, the Food Standards Agency (FSA) is a non-ministerial Government department set up to protect the public's health and consumer interests in relation to food. It is concerned not only with the safety of the food we eat but also how it is labelled to make sure that people get accurate information in an understandable form.

You may be aware that the European Commission (EC) has indicated that it may wish to consider setting community-wide management thresholds for lactose in foods with a view to potentially setting common rules for the use of labelling terms to indicate the absence or reduction of lactose. For this reason, the EC has requested that the European Food Safety Authority (EFSA) issue a scientific opinion on lactose intolerance and galactosaemia (now expected to be published in June 2010). The Agency would represent the UK in any discussions in this area to ensure that any developments are appropriate for the UK food industry and UK consumers who could be affected.

In order to best input into these discussions, the Agency would like to determine the understanding in the UK of current labelling terms that indicate the absence or reduction of lactose, milk or dairy in foods. As part of this work, we will be talking to consumers with lactose intolerance, galactosaemia, milk allergy and milk intolerance as well as health professionals who give guidance to such patients on how to make safe food choices. We would also like to talk to businesses that manufacture and sell foods that carry labels advising on their suitability for such consumers. This research would provide evidence on which the UK could base its position, to help ensure we can act to protect the interests of the UK food industry and UK consumers.

We have commissioned Creative Research, an independent research company, to conduct this research on our behalf. They will be carrying out a series of face-to-face or telephone interviews with food manufacturers of different sizes and with different product ranges, and with large food retailers. We expect these interviews to last between half an hour and an hour. They will be conducted at a time that is convenient for you.

Creative Research is bound by the Code of Conduct of the Market Research Society. This means that your interview will be conducted on an anonymous basis and although your comments may form part of the feedback to the Food Standards Agency, they will not be attributed to you personally. Any personal details (for example, names and addresses) will be kept confidential by Creative Research and will not be used for any purpose beyond this specific project, unless you give permission. All these details will be removed from records upon completion of the project.

If you wish to talk to someone about this research, you can call me here at the Food Standards Agency on 020 7276 8509, or Ros Payne at Creative Research on 020 8567 6974.

I hope that you will be interested in taking part in this valuable research and thank you for your contribution in advance.

Yours sincerely

A handwritten signature in blue ink, appearing to read "Sue Hattersley", is written over a light blue horizontal line.

Sue Hattersley

Head, Food Allergy Branch

Appendix 4: Discussion guides

Consumer discussion guide

The following will be adapted for interviews with parents of affected children e.g. the child's symptoms, how it affects the child and the wider family with respect to food, buying food for the child, introducing the child to the idea of looking at labels

Background of condition

- What is the nature of your condition; the symptoms and diagnosis? When did it first appear and how was it diagnosed?
 - If you were diagnosed by a medical professional, how was this done – who by, what tests were necessary? How long did a diagnosis take? Is treatment only concerned with diet or does it involve other things such as medication?
 - If you were diagnosed by an alternative therapist or nutritionist, who were they and how did they diagnose you?
 - If you diagnosed yourself, how did you do this e.g. who did you consult, which websites did you use, what tests did you take?
 - If respondents are 'non-specific' ie. they are avoiding dairy in some way for a medical condition but they don't have a specific diagnosis or their self-diagnosis is at odds with the clusters of symptoms, then we will explore this by asking probing questions about their symptoms (**Moderator: refer to list of symptoms used at recruitment at end of guide**).

Nature of diet

- What advice were you given/information have you used about the diet you should follow at and since diagnosis? We will explore advice from practitioners (clinical or alternative therapist) or some other source such as a website or book, identifying sources and types of advice.
- Are there some sources you feel more confident about taking advice from – which and why?
- How does the condition affect your diet e.g. what must you avoid and what should you eat? What do you tend to eat? How have you arrived at this diet – e.g. was it a long process of trial and error or did the advice you were given seem to work?
- How does your condition affect your approach to food – e.g. are you open about what you eat within boundaries or do you tend to keep to a range of familiar foods? Does it affect eating out in restaurants or with friends?

Food buying

- Who buys the food that you eat? Who cooks it?

- When you go shopping for food, where do you tend to go; what kind of shops, how often? Are there any shops you use specifically to buy products suitable for your condition?
- Do you make use of any sources of information to guide you in what to buy e.g. lists of suitable products provided on retailer websites?
- In the store, do you look out for particular types of product or ranges e.g. the 'free from' range? Any particular products within this?
- Do you look out for particular information in-store; where (on shelf, on pack)? What information specifically are you interested in and why? **Ask about:**
 - whether and how they use the ingredients list on products or warnings about allergens
 - whether they look out for or take any notice of claims that indicate that a product does not contain or contains a reduced amount of something that they are sensitive to (**Moderator: be sure to record verbatim any spontaneous claims/product descriptions mentioned**)
- How do you make use of this information – does it give you the green light to buy and eat this product or do you need to then look for more information or take anything else into account (e.g. past experience of a particular ingredient)? What is the hierarchy of importance e.g. look for 'free from' type of claims, then check if there is any 'allergen' information but do not check full list of ingredients?
- How easy is it to find this information? Is it always available? How reliable do you consider it to be e.g. do you trust own brand products from UK supermarkets or UK food producers more than imported products?
- If you are overseas, perhaps on holiday, how do you approach shopping for food in a supermarket there? Do you assume that the same terms used by food manufacturers in Europe, for example, mean the same as in the UK?

Understanding of Labelling Terms

Moderator: in this part of the interview, you should explore what respondents understand by each of the following terms:

- 'dairy free'
- 'milk free'
- 'lactose free'

You should also explore any other terms they use.

You should start with the terms the respondent spontaneously said they make use of and then move onto any of three remaining terms that the respondent has not mentioned.

You should complete a separate '**Understanding of Labelling**' sheet for each term. Be sure to write in the term if it is not one of the above three.

Once all terms/claims have been covered, proceed as below

- At this point, prompt the respondent to think of any other term(s) they might look out for or take notice of, such as 'free from ...', 'low ...' or 'very low ...' and check their meaning

- **If 'lacto free' has not been mentioned as part of the above discussion** ask whether they have seen the term and what they understand is meant by this e.g. the same as 'lactose free' or something different. If it is something different, we will then ask them about how it differs in terms of content ie. levels of milk, dairy and lactose.
- Ask them to put the 3 claims and any other claims they mention in order of preference. Which one do they prefer and why?

Things that would help

- To finish off, is there anything that would help you to decide which food to buy and eat (or give to your child)? – this could be to do with the labels on packs or some other form of information or measure.

Recontacting

The possibility of the FSA wishing to recontact them will be explained and they will be asked for their permission for Creative Research to pass on their contact details to the FSA. The moderator will explain how their contact details will be kept. Those interviewed face to face will be given a letter and asked to sign a pro-forma giving permission. Those giving permission on the phone (this should be recorded) will be sent the letter and asked to return it.

Understanding of Labelling: 'Dairy Free'

- What do they understand by this claim/term? What does it tell them about what the product does or doesn't contain? **(Do not prompt)**
- What type of condition do you think products with this claim would be suitable for? **(Do not prompt)**
- **Ask if respondent did not spontaneously mention this term:** If you came across a product with this on the label, how would you react? For example, would you reject the product altogether or look further for other information? How would you decide whether you could eat it or not?
- **Use Showcard A** When you see the term 'Dairy Free', what do you think that means in terms of
 - the **levels of dairy** in that product? Does it mean that product is completely free from dairy, that it is very low in this, that it is low in it or does it mean something else?
 - the **levels of milk** in that product? Does it mean that product is completely free from milk, that it is very low in this, that it is low in it or does it mean something else?
 - the **levels of lactose** in that product? Does it mean that product is completely free from lactose, that it is very low in this, that it is low in it or does it mean something else?

	Completely free from...	Very Low...	Low...	DK	Something else?
Dairy					
Milk					
Lactose					

- **Use Showcard B** For which kinds of people do you think 'Dairy Free' products would be suitable?

	Yes	No	DK		Yes	No	DK
People with a dairy intolerance				People with galactosaemia			
People with a milk intolerance				People with a dairy allergy			
People with a milk allergy				People with a lactose allergy			
People with a lactose intolerance				Any other conditions (write in)			

Understanding of Labelling: 'Milk Free'

- What do they understand by this claim/term? What does it tell them about what the product does or doesn't contain? **(Do not prompt)**
- What type of condition do you think products with this claim would be suitable for? **(Do not prompt)**
- **Ask if respondent did not spontaneously mention this term:** If you came across a product with this on the label, how would you react? For example, would you reject the product altogether or look further for other information? How would you decide whether you could eat it or not?
- **Use Showcard A** When you see the term 'Milk Free', what do you think that means in terms of
 - the **levels of dairy** in that product? Does it mean that product is completely free from dairy, that it is very low in this, that it is low in it or does it mean something else?
 - the **levels of milk** in that product? Does it mean that product is completely free from milk, that it is very low in this, that it is low in it or does it mean something else?
 - the **levels of lactose** in that product? Does it mean that product is completely free from lactose, that it is very low in this, that it is low in it or does it mean something else?

	Completely free from...	Very Low...	Low...	DK	Something else?
Dairy					
Milk					
Lactose					

- **Use Showcard B** For which kinds of people do you think 'Milk Free' products would be suitable?

	Yes	No	DK		Yes	No	DK
People with a dairy intolerance				People with galactosaemia			
People with a milk intolerance				People with a dairy allergy			
People with a milk allergy				People with a lactose allergy			
People with a lactose intolerance				Any other conditions (write in)			

Understanding of Labelling: 'Lactose Free'

- What do they understand by this claim/term? What does it tell them about what the product does or doesn't contain? **(Do not prompt)**
- What type of condition do you think products with this claim would be suitable for? **(Do not prompt)**
- **Ask if respondent did not spontaneously mention this term:** If you came across a product with this on the label, how would you react? For example, would you reject the product altogether or look further for other information? How would you decide whether you could eat it or not?
- **Use Showcard A** When you see the term 'Lactose Free', what do you think that means in terms of
 - the **levels of dairy** in that product? Does it mean that product is completely free from dairy, that it is very low in this, that it is low in it or does it mean something else?
 - the **levels of milk** in that product? Does it mean that product is completely free from milk, that it is very low in this, that it is low in it or does it mean something else?
 - the **levels of lactose** in that product? Does it mean that product is completely free from lactose, that it is very low in this, that it is low in it or does it mean something else?

	Completely free from...	Very Low...	Low...	DK	Something else?
Dairy					
Milk					
Lactose					

- **Use Showcard B** For which kinds of people do you think 'Lactose Free' products would be suitable?

	Yes	No	DK		Yes	No	DK
People with a dairy intolerance				People with galactosaemia			
People with a milk intolerance				People with a dairy allergy			
People with a milk allergy				People with a lactose allergy			
People with a lactose intolerance				Any other conditions (write in)			

Showcard A

Completely free from ...

Very low in ...

Low in ...

It means something else to me

I'm not sure what it means

Showcard B

People with a dairy intolerance

People with a milk intolerance

People with a milk allergy

People with a lactose intolerance

People with galactosaemia

People with a dairy allergy

People with a lactose allergy

People with some other condition

Prompts that can be used to probe symptoms

Lactose intolerance:

Symptoms develop within 1-2 hours and may include stomach pains/cramps, stomach bloating, stomach gurgling, wind, nausea and diarrhoea.

Milk intolerance:

Symptoms may develop within 1-2 hours or several days and may include stomach pains/cramps, stomach bloating, stomach gurgling, wind, nausea, diarrhoea and vomiting.

Milk allergy:

Symptoms include hives (red itchy bumps), swelling of the skin, an eczema type of skin reaction, vomiting and diarrhoea, difficulty breathing and possibly anaphylaxis.

Health professional discussion guide

The following will be adapted for interviews with different health professionals, to reflect their role, relationship with patients and level of expertise in this area.

Background – patient population and management (NB briefly)

- Ask for a brief outline of their role, any areas of special interest, of their patient population/the profile of that patient population
- Ask for each of
 - Lactose intolerant patients
 - Milk allergic patients
 - Milk intolerant patients
 - Galactosaemic patients
- How many patients do they currently have with this condition, what is the profile in terms of adults/children/babies for these conditions, any other key features of that patient population, how often do they see those patients?
- How do these patients tend to present, how is their condition diagnosed, what referral and testing protocol/procedure, if any, do they go through before diagnosis?
- How are these patients typically managed, who is responsible for the on-going management of the patient and advice regarding their diet, who else is involved in the provision of advice?
- Do they use any support materials, direct patients towards any websites, support groups – which? Are there any other sources of information/advice available for these patients that they are aware of?

Advice for Patients

- What information and advice do they give these patients, what areas do they cover with them? For each condition explore (NB noting language/terminology used spontaneously, how the advice given varies between the different patient groups)
 - What advice do they give to patients regarding their diet?
 - What do they tell them they can/can't eat?
 - Do they offer them any written information (e.g. product lists, leaflets) or direct them to any websites, in order to help them choose suitable foods (which ones)?
 - What do they tell them to look for when choosing food, what do they tell them to avoid, where do they tell them to look for this information?
 - Specifically, do they tell them anything in particular with regard to food labelling – if so, what? What 'labels' or 'claims' on food packaging do they

tell them to look out for? Are there any food categories/labels that they particularly direct them towards, any that they warn them against/advise them to avoid/treat with caution?

- What are their key concerns in terms of the safety of these patients and what does this mean in terms of safe food labelling?
- What areas of misunderstanding/confusion, if any, do they encounter among these patients regarding food labelling? What advice do they give to these patients to clarify these misunderstandings?
- What advice do they give regarding how strictly they should/don't need to follow the guidelines given? What are the implications of this for food labelling? What information is needed to ensure adequate patient understanding?

Understanding of Labelling Terms

- Taking each labelling term in turn ('dairy free', 'lactose free' and 'milk free'), what do they, as health professionals, understand by each claim?
 - What does it tell them about what the product does or doesn't contain?
 - What do they think patients understand about what the product does or doesn't contain?
 - How clear is it – for health professionals, for patients?
- Explore further and record responses systematically (as for consumers) with respect to perceived levels of each of dairy/milk/lactose in each of 'dairy free', 'lactose free' and 'milk free'
 - Is there another way of expressing the level of dairy/lactose/milk that is more relevant?
- Returning to the conditions discussed, for which of these would products with this claim would be suitable, who would it not be suitable for, explore for each and record systematically
- What concerns, if any, do they have regarding this approach towards food labelling? Are there any issues/implications for patient safety of this approach to labelling?
- What, if any, are the benefits of labelling food in this way?

Summing Up

- Ask to summarise their thoughts on the most useful/appropriate way to label products in order to ensure understanding and safety among these patient groups.

Business discussion guide

This guide will be adapted for each of the different types of business; points may not always be explored in this order and not all points may be relevant to every type of business.

Moderator will briefly go over the objectives of the research based on the reassurance letter and explain our particular interest in how they use the key labelling terms aimed at this group of consumers and what they intend those terms to mean.

It will help to have some background understanding first ...

Background

- Outline of respondent's role, responsibilities regarding food labelling
- Extent to which they can influence what goes on-pack e.g. do retailers and manufacturers work together on this – e.g. how is the labelling of branded, own brand and the 'free from' range decided?
- In general, what are their interest/priorities in meeting the needs of consumers with particular dietary requirements – do they aim products at specific groups or ensure that they have products in their range that meet each group's needs or is their priority the general marketplace?

Products aimed at people with a sensitivity to milk/dairy/lactose

- Which products/product ranges do they make/sell that are intended for people with some form of sensitivity to milk, other dairy products or lactose?
- To what extent does the company try to meet the particular requirements of consumers with each of the four conditions (lactose intolerance, galactosaemia, milk allergy and milk intolerance) in terms of the products they make/sell? (product ranges and specific examples will be identified)
- Do they set in-house thresholds for dairy/milk/lactose? If so, what are these and how were they derived?
- Do they provide any other forms of support to these groups of consumers? e.g. product lists, leaflets, guidance on websites and what is the take-up of these?
- Do they market products to these consumers and if so, what are the key messages they seek to communicate?

Approach to labelling these products

- What is their policy in labelling products aimed at consumers with one of these conditions – how do they decide what information is provided on-pack? Is there a consistent policy or does it vary, for example with different product categories?

- What is that policy with respect to:
 - allergen information e.g. what terms are used and why? We will try to identify whether particular terms are used for people with particular conditions.
 - any claims made about the content in terms of being free from a constituent or having reduced levels of it? What terms do they use and why? Who are they aimed at?
 - any claims about the suitability of the products for people with specific conditions? What phrases do they use and why?
 - are there any labelling terms they use that would indicate that a product was suitable for people with different conditions (e.g. a term that would cover both lactose intolerance and milk allergy)?

We will ask for specific product examples that demonstrate their approach.

- How do they decide what information is provided in other information sources (i.e. other than product labels e.g. on their website)?
- Is this a company-specific approach or do they follow industry practice or other guidelines?

Understanding of Labelling Terms

We will explain that we are trying to arrive at a picture of how different audiences understand the main labelling terms and who they are aimed at – therefore, we would like to check out a few things that have not been covered so far (please note, that if appropriate, we will explore these as we discuss each term above).

- We will take **each of the terms they use** and fill in any gaps e.g. you mentioned that your organisation uses 'lactose free' because ...; can I check whether the use of this term is intended to mean that the product is completely free of lactose, has a very low level of lactose or has a low level or something else? How about dairy/milk levels in a product labelled 'lactose free'. Would the product be completely free of these things, have a very low level or a low level or something else?

We will then turn to any of the three main **terms that they do not use**

- For each one, why don't they use it? Is it because they have no products for which they can make this claim or for some other reason.
- We will check out their understanding of these terms in the same way. Responses will be systematically recorded as for consumers.

Winding up

- Which, in their experience, present fewest problems with respect to guiding consumer behaviour? For example, do they have any feedback from customers / queries that suggest issues with understanding?