



Gluten Free Prescribing

January 2017

1. Introduction

Healthwatch Devon is the local consumer champion for health and social care. We aim to ensure that the voices of service users are heard by decision makers, and are taken seriously.

Healthwatch Devon was approached by North, East and West Devon Clinical Commissioning Group (NEW Devon CCG) to support their survey regarding the prescription of gluten free products.

People in the area covered by NEW Devon CCG can be prescribed gluten free foods if they have a confirmed diagnosis of coeliac disease or dermatitis herpetiformis (DH). In 2015/16, NEW Devon CCG spent more than £560,000 on prescribing gluten free foods.

In recent years, awareness of coeliac disease and DH has increased and gluten free products have become more readily available to buy from supermarkets and online. Whilst gluten free foods can be more expensive to buy than their gluten containing equivalents, direct purchase from supermarkets tends to cost significantly less than the NHS price.

NEW Devon CCG therefore were seeking views on the prescribing of gluten free foods on the NHS for adults and children with coeliac disease or DH.

The survey was developed by NEW Devon CCG and Healthwatch Devon, and reviewed by Coeliac UK's Exeter and East Devon local group.

The survey was made available through Healthwatch Devon and promoted to appropriate local groups.

621 people completed the survey. The demographics of those who responded are included at the end of this report.

Healthwatch Devon also received a formal response from Coeliac UK and a number individual letters and emails highlighting people's concerns should a change in prescribing be the outcome.

The Executive Summary sets out the key findings from the responses gathered, and the subsequent Findings section summarises the responses to all the questions included within the survey.

2. Executive Summary

2.1 Respondent profile

Most respondents to the survey (63%) were people with a diagnosis of coeliac disease or dermatitis herpetiformis (DH). The second largest group of respondents (18%) was health professionals.

Of those with a diagnosis, half (48%) had been diagnosed within the last ten years, and two thirds (64%) within the last twenty years.

Responses came from all parts of the county, with two-thirds of respondents living in rural or "edge of town" areas. 81% live within 20 minutes travel from a shop selling gluten free food.

2.2 People receiving prescription food

Two thirds (64%) received gluten free foods on NHS prescription. Within the multiple choice answers, the most common reason given was that supermarket alternatives are too expensive. The second most common reason was that gluten free prescriptions are a right.

Within the free text comments, the two most common themes were the lack of availability of gluten free products and the poorer quality of products not on prescription. Respondents commented that they couldn't get prescription brands in the local shops, and that these brands were considered to be higher quality, either in terms of taste or nutritional value.

Another related comment was that many of the supermarket gluten free products contain high levels of sugar, which can cause additional problems. The other common comment was the cost of products at supermarkets.

The most commonly used prescription foods were flour, pasta and bread. The least common were sweet biscuits and cakes.

2.3 People not receiving prescription food

One quarter (26%) of survey respondents did not get gluten free food on prescription. Of those respondents diagnosed with, or caring for someone diagnosed with coeliac disease or DH, only 11% do not receive gluten free products on NHS prescription. Within the multiple choice answers, over half (55%) said that they did not agree with gluten free food being prescribed, or were happy to pay for it in the shops. Over a quarter (28%) said that the choice in the shops was better than on prescription.

78 people responded within the free text comments. However, the majority (44) said that the question was not applicable as they were not coeliac, or were a healthcare professional.

2.4 Opinions and perceptions

Responses to the CCG's prescribing options showed that most people anticipated significant impact on health from "no gluten free prescriptions" (78% with significant impact) and "restriction of prescriptions to under 18's" (63% with significant impact). Reaction to "limited prescription" was more evenly spread, and 70% anticipated no impact from non-prescription of luxury items.

Most respondents felt that there was sufficient information on managing coeliac and DH conditions, and that there was sufficient food available in supermarkets or on-line. However, three quarters saw supermarket gluten free food as unaffordable. Two thirds anticipated difficulties and complications if prescriptions were restricted. Over three quarters thought it appropriate that the NHS should provide gluten free food on prescription. Three quarters saw prescription of gluten free food as being of high importance to the management of their condition.

When asked how people could be better supported to manage their condition, the top three comments were:

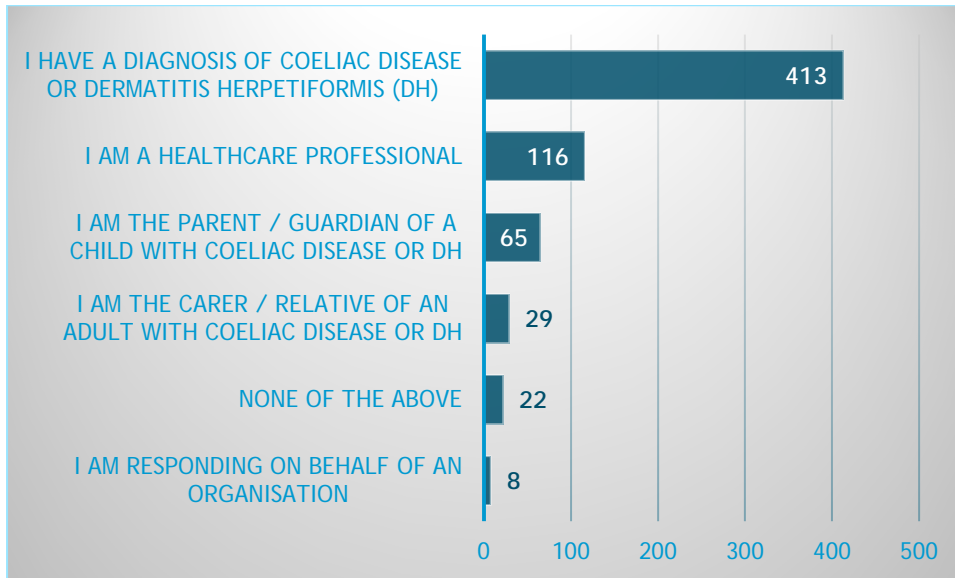
- Support and ongoing monitoring, annual check-ups, support groups etc.
- Reduce the cost; put pressure on manufacturers and/or supermarkets
- Increase awareness, including: health professionals, food retailers and the general public

"Other" comments reflected points already made in survey responses, particularly around the availability, quality and cost of gluten-free food.

3. Findings

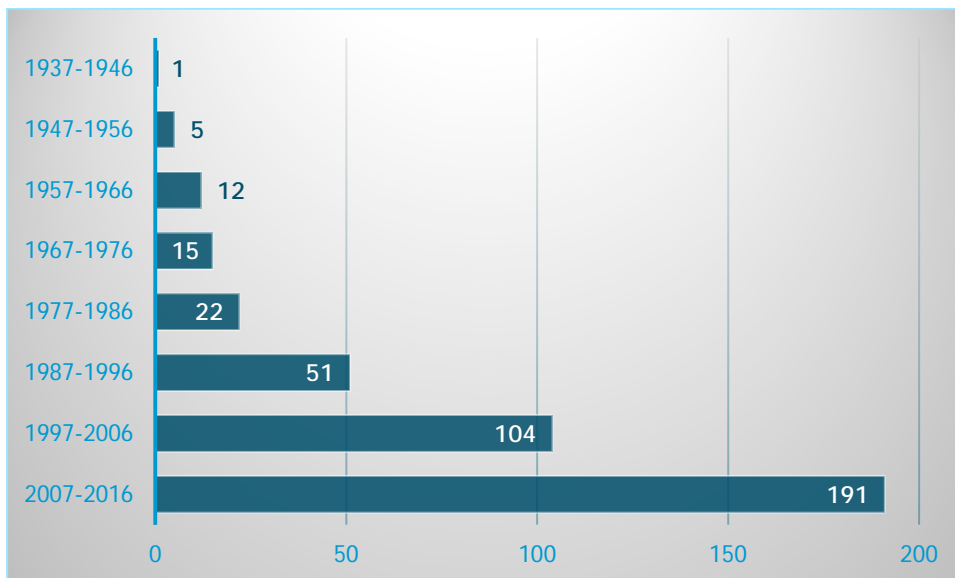
3.1 Which of the following applies to you?

620 people responded to this question.



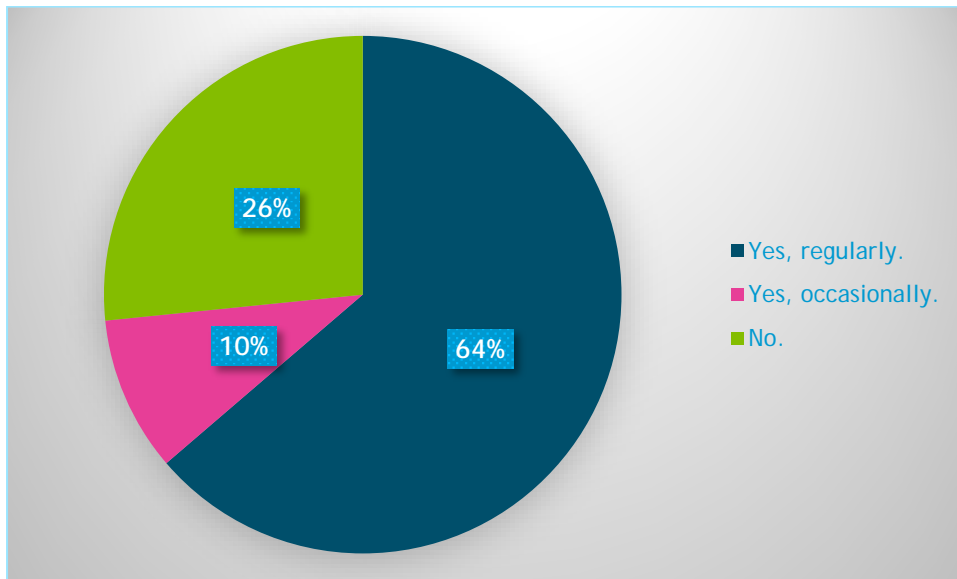
3.2 Do you (or someone you care for) have a diagnosis of coeliac disease or DH? If so, when were you diagnosed?

513 people responded to this question.



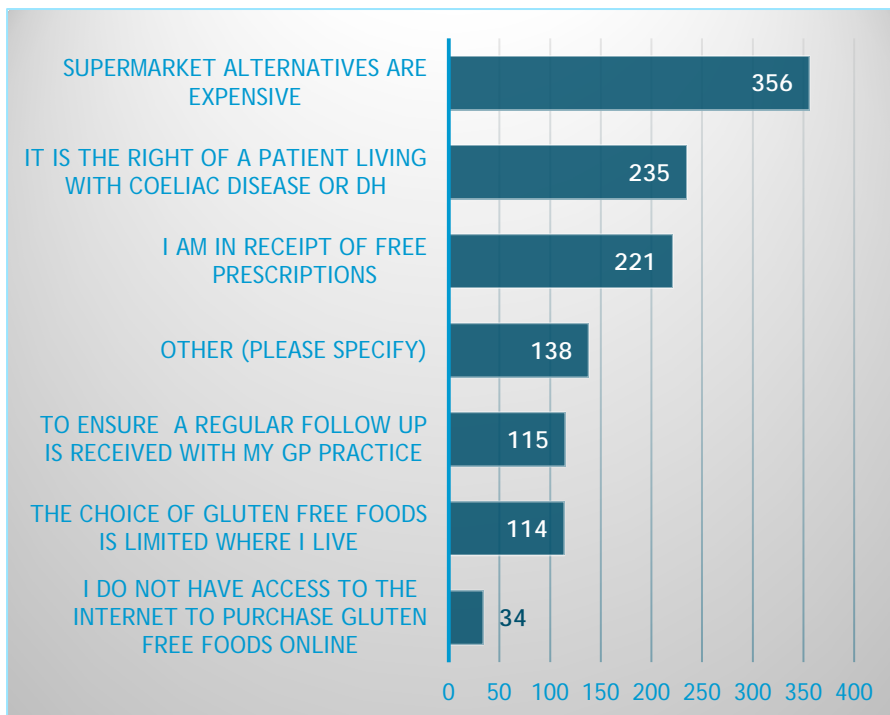
3.3 Do you (or someone you care for) receive gluten free foods on NHS prescription?

609 people answered this question.



3.4 If you answered yes to the question above, please tell us why you get gluten free foods on prescription?

454 people answered this question.



138 people provided an additional comment in response to this question.

The two most common themes mentioned were the lack of availability of gluten free products and the poorer quality of those products not on prescription. These two themes were often intertwined as respondents commented that they couldn't get the brands that they received on prescription in the local shops, and that prescription brands were considered to be higher quality, either in terms of taste or nutritional value.

The prescribable products are more reliable in both nutrition and availability.

Prescribed gluten free foods are not available in supermarkets, nor online. Only pharmacies can obtain most items prescribed for me.

It is the nicest bread.

To ensure it is strictly gluten free and has the correct additives not contained in supermarket gluten free foods.

Supermarket products unlike prescription foods are not fortified with key nutrients that are important to Coeliacs.

Supermarkets seem to run out of stock and it's a long time before they stickup again so you can't always get what you want when you want it.

I cannot buy Tritamyl Brown Bread mix which I have had for many years on prescription.

Supermarket GF foods are free from essential nutrients that coeliacs need as they lose more iron and calcium.

I am sensitive to 20ppm gluten so cannot buy 'free from' foods as the labels do not disclose this.

I have purchased gluten free flour at great expense and it makes very poor gluten free bread and pastry, however the prescription white mix is excellent and you cannot buy it.

Supermarket alternatives are less well fortified with essential vitamins which the dieticians say I require.

Select flour from glutafin is not available in supermarkets and is the best flour I have ever tried, where the gluten is removed from the wheat. Also, prescribed products tend to be nutritionally superior with added fibre, calcium.

Another related comment was that many of the supermarket gluten free products contain high levels of sugar, which can cause additional problems.

The products in the "free from" in the supermarkets are full of sugar.

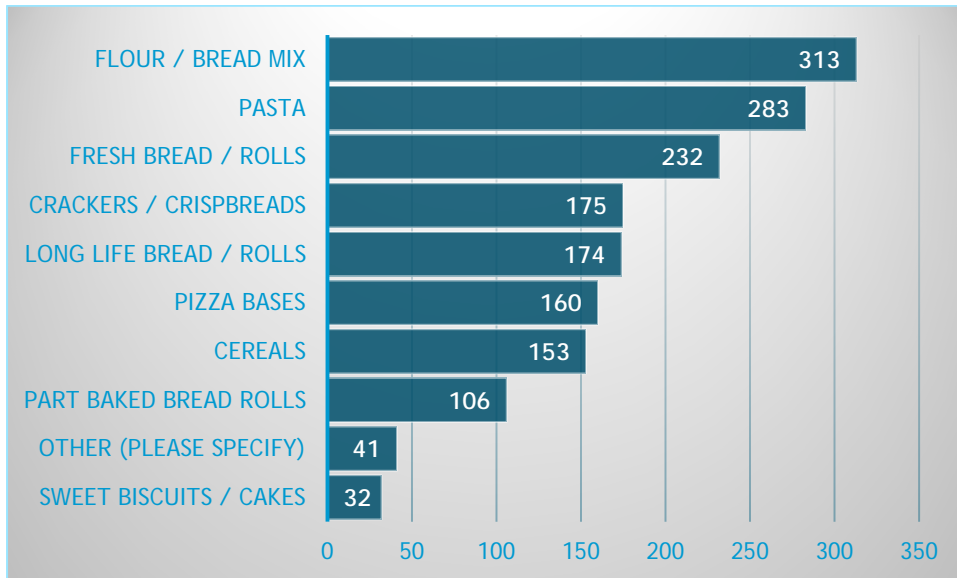
ALL supermarket food in practice GF overloaded with sugar Campaign to force Food producers to cut sugar in food by half would reduce diabetes cost to NHS.

I also have type 1 diabetes and a lot of Gluten free foods in the supermarket such as cakes and biscuits have a very high sugar content.

The other common comment, which was also the most popular response indicated in the graph above, was the cost of products at supermarkets.

3.5 If you receive gluten free foods on prescription please can you tell us which gluten free foods you use?

449 people answered this question.



Those that provided a comment in the 'other' box were often bespoke or a specific brand of product. The only 'other' comment made consistently was oats/porridge, made by 15 people.

3.6 If you answered no to question 3, please can you tell us why you do not get your gluten free food on prescription?

157 people answered this question.

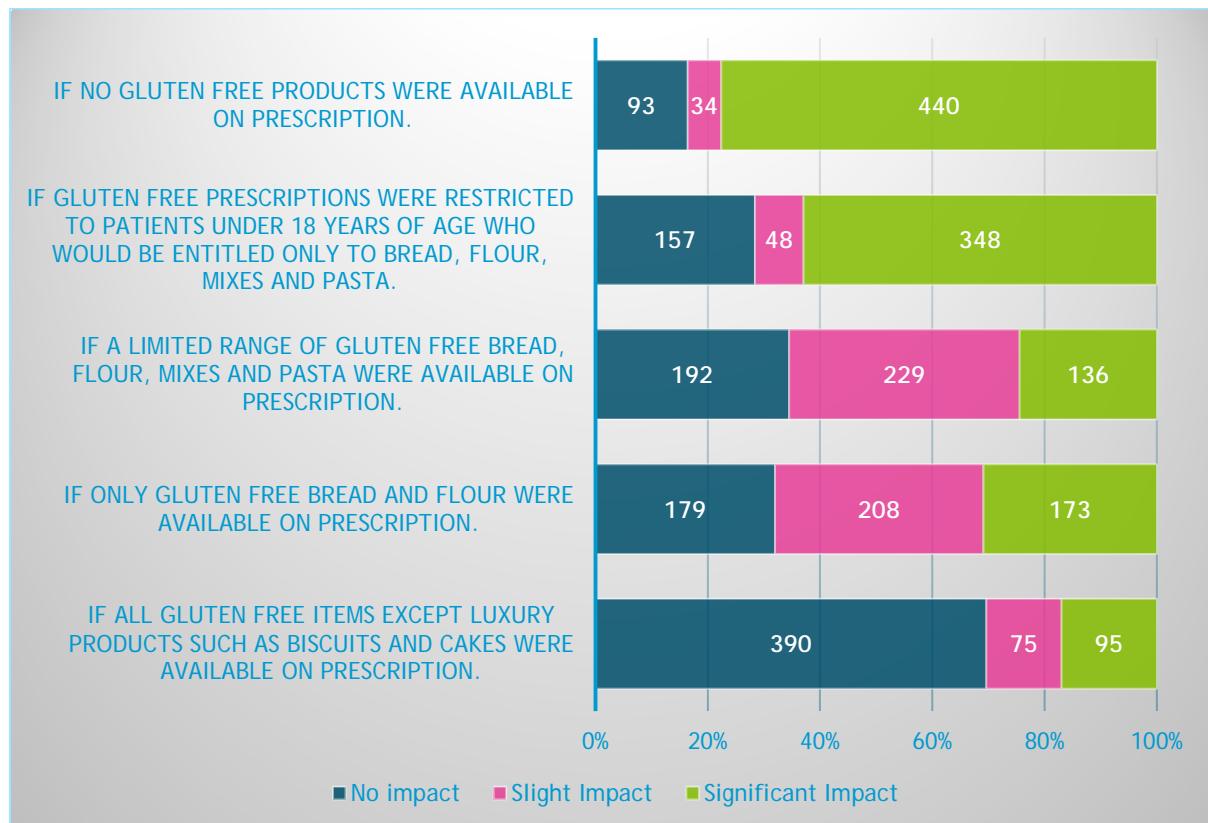


78 people provided a comment to this question, but the majority of these, 44, were to say that the question was not applicable to them as they were not coeliac, or were a healthcare professional for example.

The most common theme reinforces the graph above; people did not want to cost the NHS money, or felt there was better choice at the supermarket.

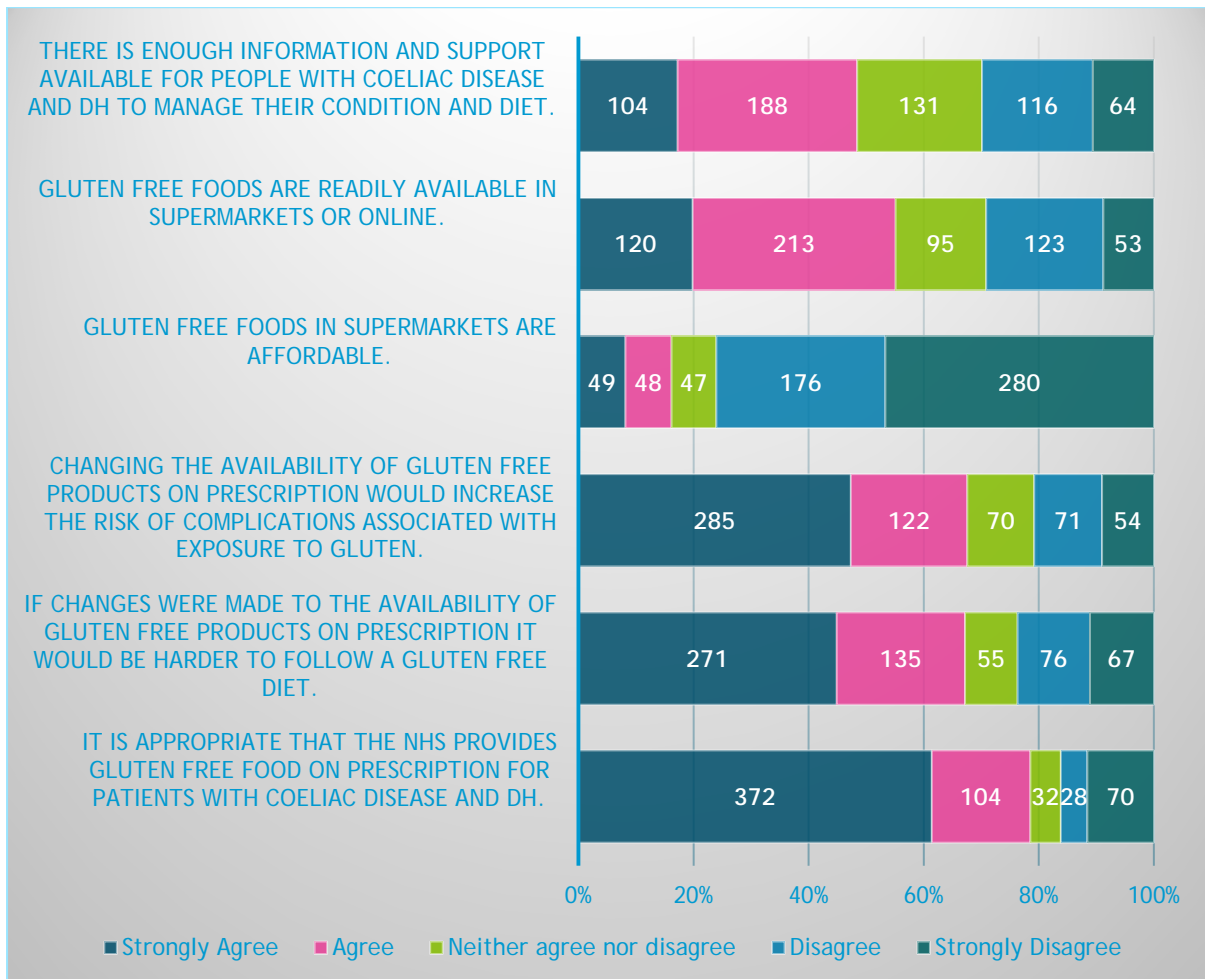
3.7 NEW Devon CCG’s current prescribing advice is based on the Coeliac UK National Prescribing Guidelines. As part of this review the CCG is considering different options for the future guidance for the provision of gluten free foods on NHS prescription. One option is to make no changes to the current advice, the other options are listed in the table below. We are interested to know how each of these possible changes might impact on your health and wellbeing.

572 people answered this question.



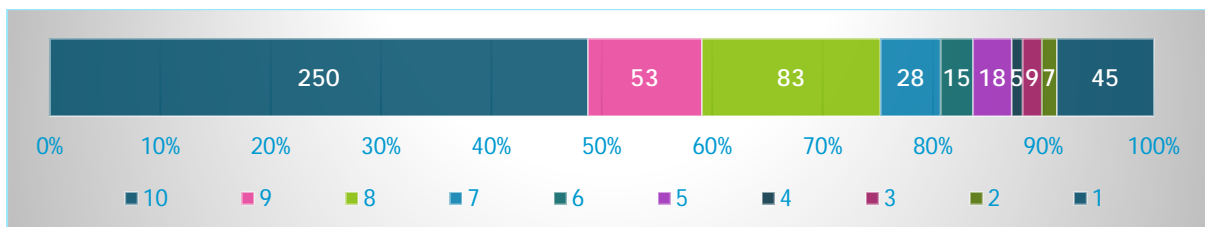
3.8 Please tell us your response to the following statements:

610 people answered this question.



3.9 On a scale of 1 to 10, where 1 is not important and 10 is very important, how important is it in the management of your condition that you have gluten free foods on prescription?

514 people answered this question.



3.10 Is there anything else we could do to support people with coeliac disease/DH to better manage the condition?

There were 318 comments in response to this question. Whilst many of these overlap, in order of frequency these were regarding:

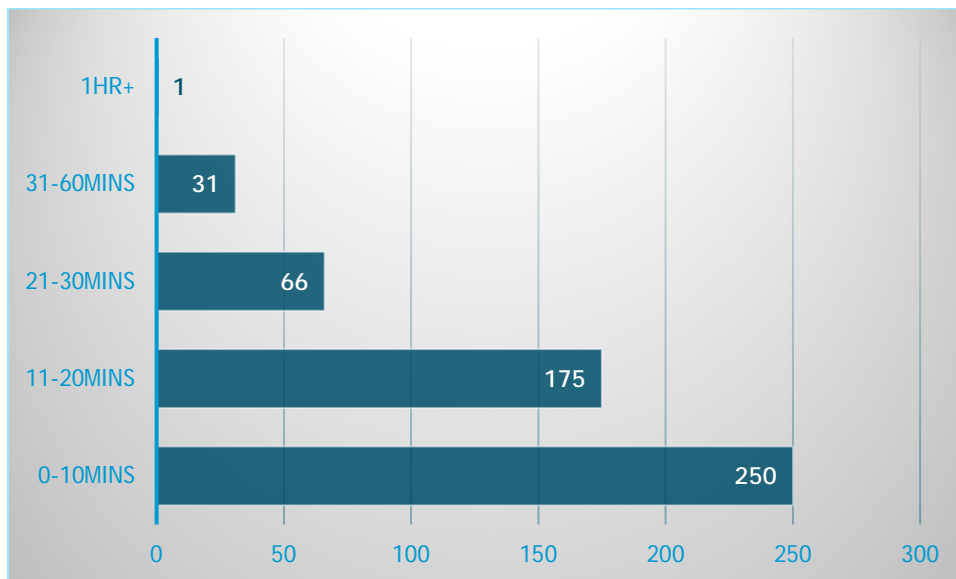
- Support and ongoing monitoring, annual check-ups, support groups etc.
- Reduce the cost; put pressure on manufacturers and/or supermarkets
- Increase awareness, including: health professionals, food retailers and the general public
- Maintain the current prescribing system
- Develop an alternative 'prescribing' mechanism, i.e. a voucher system, means testing, annual limit or prescriptions only for the first year after diagnosis
- Improve availability and quality of supermarket gluten free products to include those currently only available on prescription and improve labelling.

3.11 Is there anything else you would like us to consider, that hasn't been included in this questionnaire?

There were 287 comments in response to this question. Comments in this section were often either of a personal or general perceptions about what impact changes to prescribing might have. The majority of the points have already been highlighted within the report:

- The lack of availability of gluten-free products in supermarkets and the difficulties of getting to the supermarket in a large rural county, especially if dependent upon public transport.
- The poor quality of gluten free food from supermarkets compared with what is available on prescription. In addition the poor and unreliable labelling.
- Gluten free food is expensive compared to its gluten containing alternatives.
- Reinforcing that coeliac disease and DH are medical conditions not lifestyle choices.
- Further support for alternative 'prescribing' mechanisms such as a voucher scheme, paying a subsidised amount etc.
- Additional comments who do not think it appropriate to prescribe gluten free products.

3.12 How long does it take you to travel to your nearest shop or supermarket that sells gluten free food?

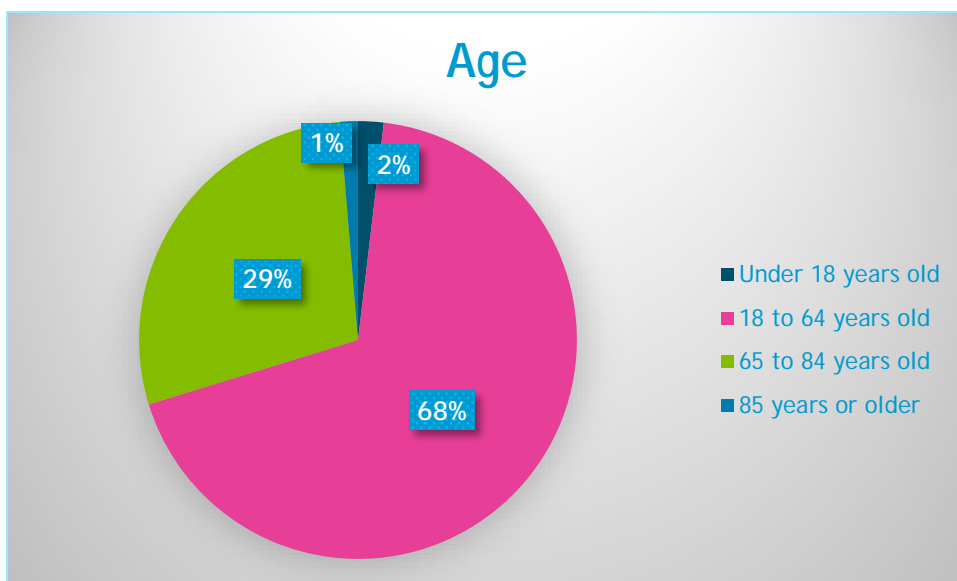
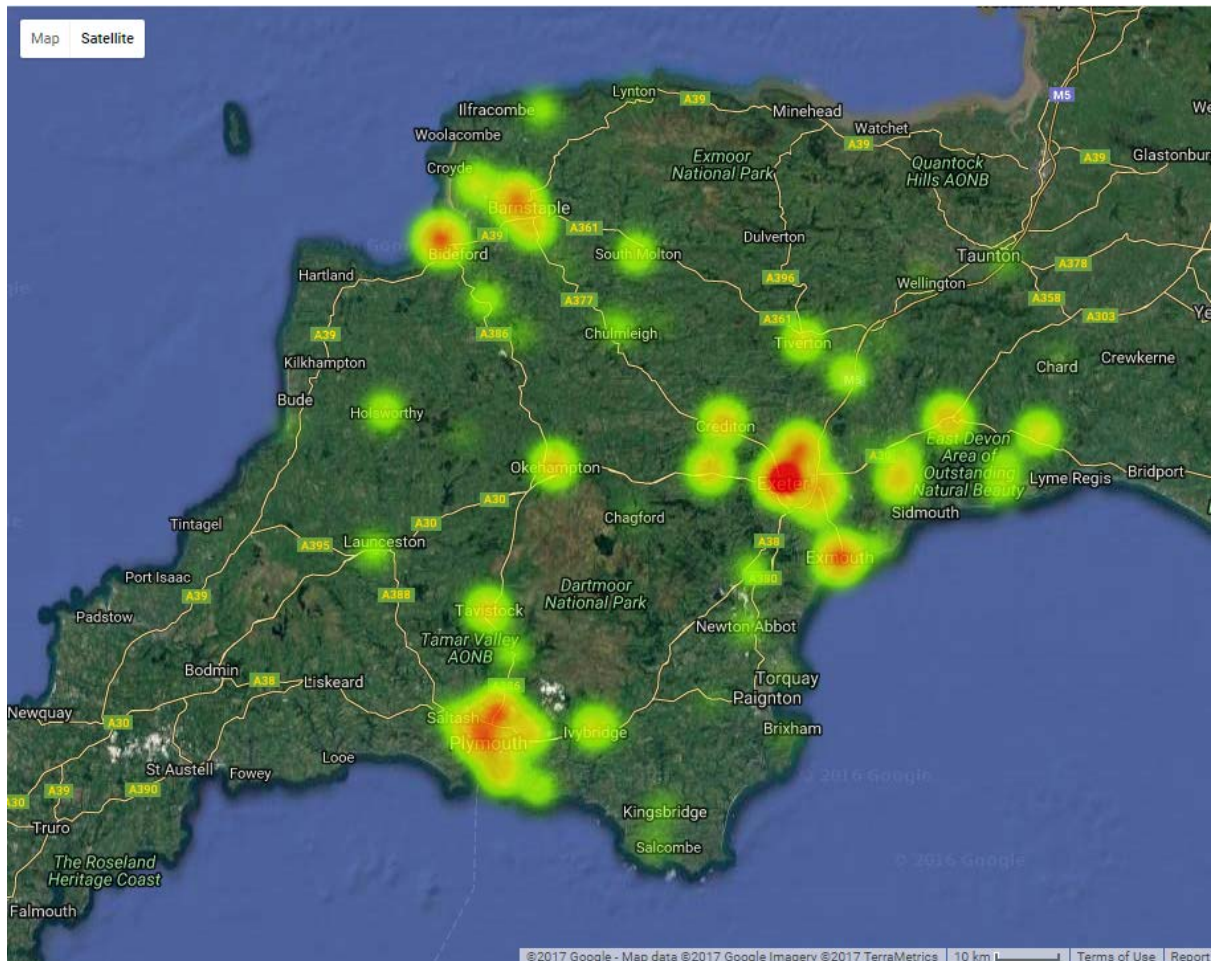


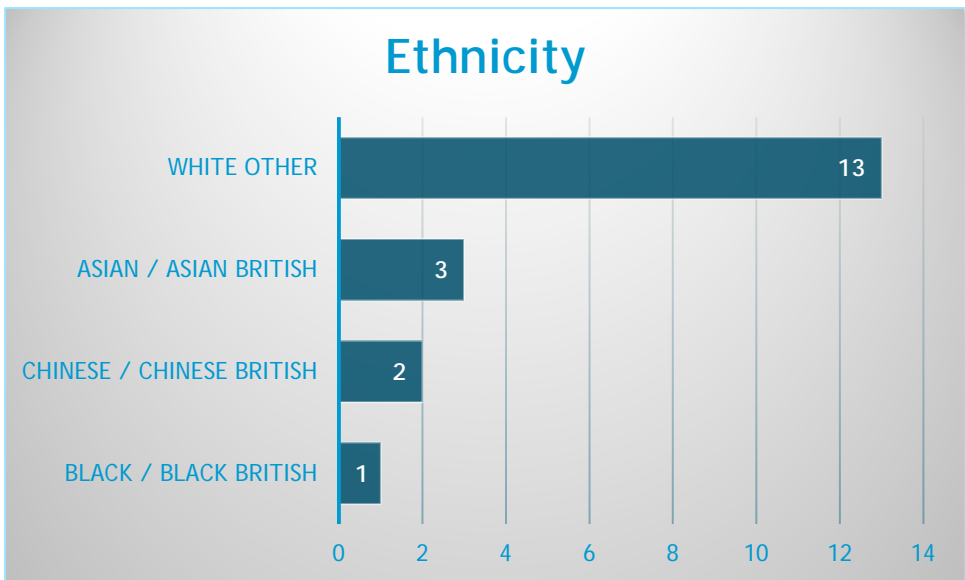
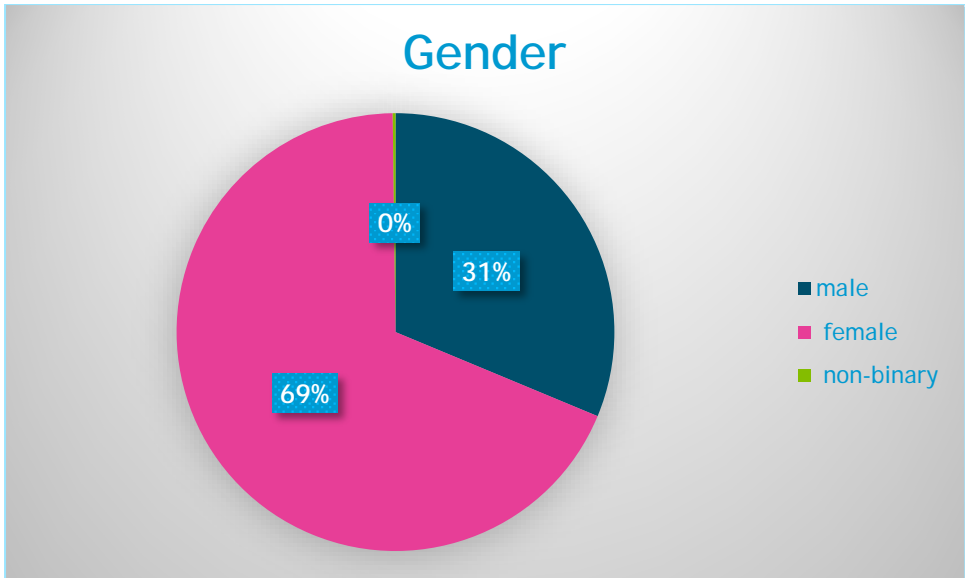
3.13 If you are a healthcare professional or are responding on behalf of an organisation, it may be helpful for us to contact you for further information. If you are happy to be contacted please enter your contact details below.

The contact details provided have been passed on to the commissioners.

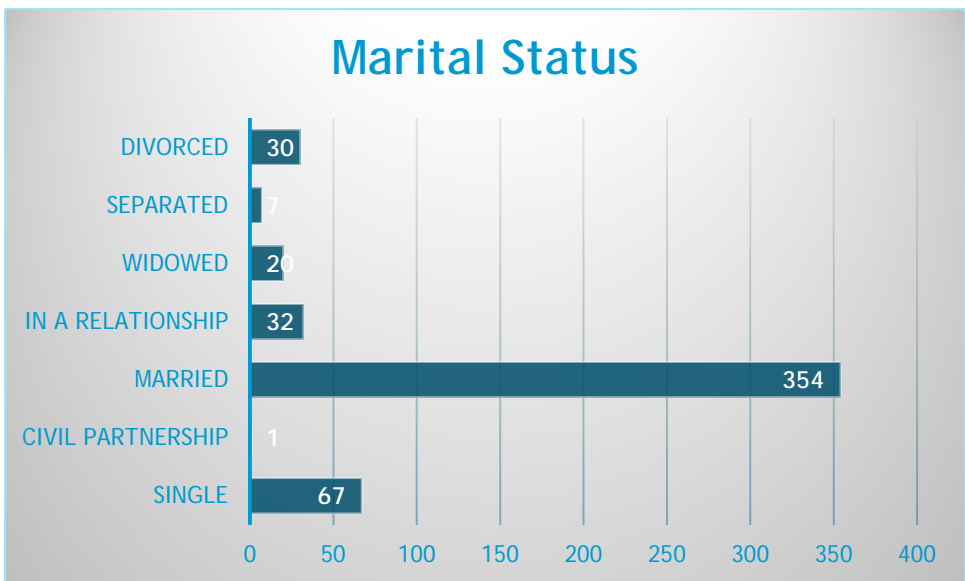
4. Demographic Information

Respondents provided the first part of their postcode. These have been plotted below on a 'heat map':

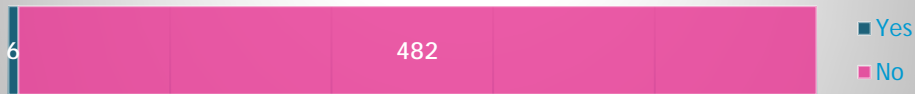




In addition, 497 identified as 'White British'.



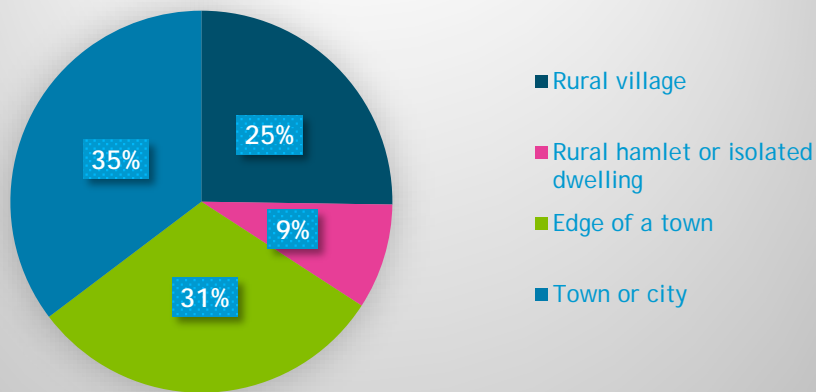
Are you pregnant?



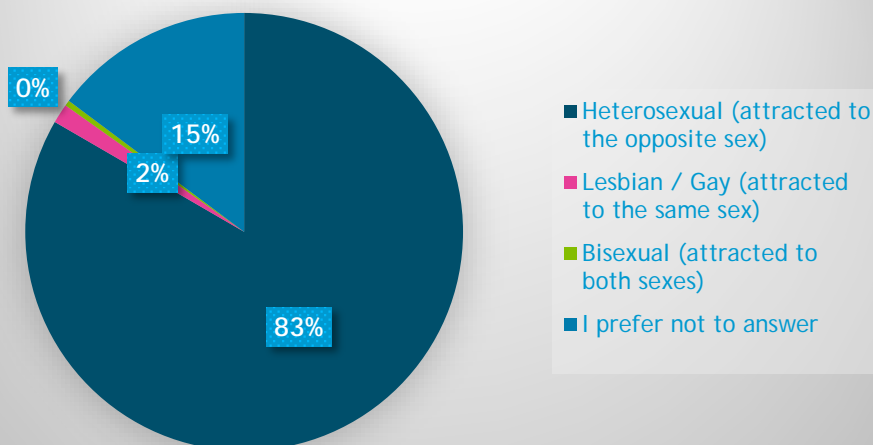
Are you disabled?



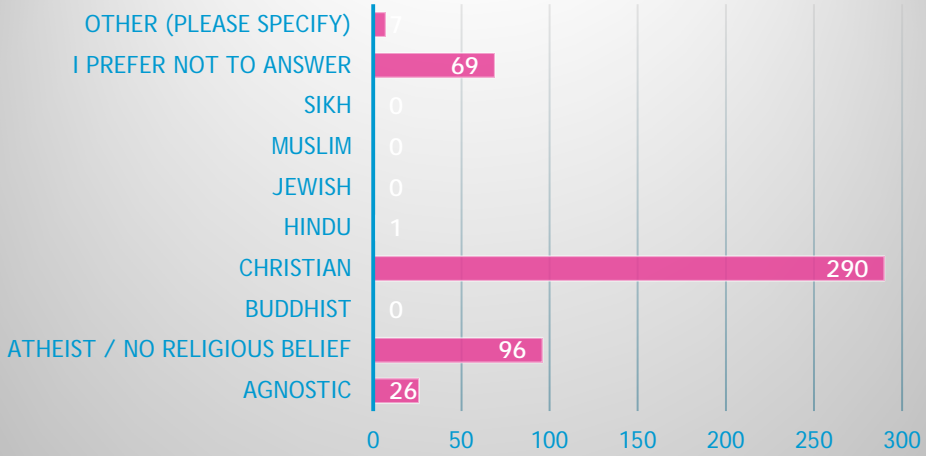
Do you live in an urban or rural setting?



Sexual Orientation



Religion/Belief:



Do you belong to any of the following groups?

