

The future of gluten-free foods on NHS prescription in Cornwall and the Isles of Scilly

Engagement report
August 2016

Contents

Introduction	3
Background	4
Methodology.....	5
Survey results	6
Other feedback.....	13
Next steps	14
Appendices	14

Appendices

We are not able to share the appendices referenced within the report as the appendices contain potentially patient identifiable information.

Introduction

The purpose of this document is to report on the public engagement exercise that ran for seven weeks from 24 June until 12 August 2016, regarding the future of gluten-free food on prescription in Cornwall and the Isles of Scilly.

The aim of the engagement was to gather the views of patients, health professionals and the wider public to understand the potential impact of the proposal being engaged upon by NHS Kernow. The proposal was:

There is strong support from NHS Kernow to consider stop funding the supply of gluten-free foods on the NHS in Cornwall and the Isles and of Scilly; this means they will no longer be available on prescription, nor from the community pharmacy and dispensing practices scheme. No final decision will be made until NHS Kernow has considered the public's views.

The supporting rationale for this proposal was stated as:

There is an increased awareness of coeliac disease and dermatitis herpetiformis (DH) compared to when gluten-free products were initially made available on prescription more than 30 years ago. Gluten-free foods are now generally more accessible and affordable to buy from supermarkets and online. We acknowledge that gluten-free foods often remain more expensive to purchase compared to gluten-containing counterparts although direct purchase from supermarkets tends to be significantly less than the NHS prices. The NHS does not provide food on prescription for most other groups of people whose conditions are associated with, or affected by, the type of food they eat but which can be managed by eating a diet naturally free from certain ingredients.

NHS Kernow needs to balance the benefits of providing gluten-free foods on prescription with the need to share resources equitably across our whole population. In Cornwall and the Isles of Scilly, £350,000 per year is spent on supplying gluten-free foods on the NHS. NHS Kernow needs to make sure the services it commissions provide value for money and are sustainable for the future.

A total of 607 responses were received during the engagement period, comprising:

- 555 surveys submitted online;
- 41 hard copy surveys returned;
- Six letters received from:
 - Coeliac UK x two;
 - British Specialist Nutrition Association Ltd;
 - British Society of Gastroenterology;

- Cornwall and Isles of Scilly Local Pharmaceutical Society;
- A member of the public who has Coeliac disease.
- Three telephone calls from members of the public;
- Two emails from members of the public.

Not everyone who started the survey fully completed it, so the results in section three that shows the findings per question are based on the actual number of people who answered that question.

Prior to the seven week public and stakeholder engagement being launched, NHS Kernow liaised with the Health Scrutiny Committees of Cornwall Council and the Council of the Isles of Scilly. Some pre-engagement work was also undertaken with secondary care Gastroenterology consultants and dietitians at both Plymouth Hospitals Trust and Royal Cornwall Hospitals Trust. The outcome of this work can be found at Appendix 1.

The public engagement was widely advertised to stakeholders (several of whom were asked to cascade the information to their contacts) and the public, supported by information on the NHS Kernow website, media release and social media. NHS Kernow appreciated the cooperation of the Coeliac UK which directly notified its members in Cornwall and the Isles of Scilly that the engagement was taking place.

A total of 18 online survey responses were received from people who reside outside of the Cornwall and Isles of Scilly area. This probably reflects the national coverage that this subject has attracted.

Background

Coeliac disease is an autoimmune disease. It is lifelong and triggered by the immune system reacting to gluten, which is a protein found in wheat, barley and rye. Some people are also sensitive to oats. Approximately one in 100 people are affected by the disease, with symptoms ranging from mild to severe, including abdominal pain, diarrhoea or constipation, bloating, nausea, tiredness, weight loss, hair loss, headaches, mouth ulcers and anaemia.

Women are two to three times more likely to develop the disease than men, which can be diagnosed at any age. The only treatment for coeliac disease is a lifelong gluten-free diet. There is no medication to control the disease, nor can it be cured. When someone with coeliac disease eats gluten it causes damage to the lining of the small intestine where most nutrients are absorbed. People with untreated coeliac disease can develop a wide range of symptoms, nutritional deficiencies and potential long-term complications, e.g. osteoporosis, infertility and intestinal malignancy.

Dermatitis herpetiformis (DH) is the skin manifestation of coeliac disease, which occurs as a rash, with some people suffering both types of the disease. The treatment for DH is also a lifelong gluten-free diet.

Currently, people in Cornwall and the Isles of Scilly can be prescribed gluten-free foods if they have a confirmed medical diagnosis of coeliac disease or DH. Additionally, a scheme has been running since 2008 whereby gluten-free foods can be ordered on the NHS directly from community pharmacies. Luxury items, such as cakes and sweet biscuits, cannot be supplied. Prescriptions for gluten-free foods are not free of charge to the patient unless the patient qualifies for free prescriptions under the Help with Health Costs Scheme.

NHS Kernow, like the rest of the NHS, is facing a significant financial challenge. The cost of supplying gluten-free foods in Cornwall and the Isles of Scilly is £350 000 a year. Over recent years gluten-free foods have become much more available than when prescribing for coeliac disease was started over 30 years ago, with supermarkets and online retailers stocking increasing ranges of products. These products can be three to four times more expensive than the corresponding non-gluten-free item. However, the price paid by the NHS for gluten free foods on prescription can be higher again, as when prescribing gluten-free foods the NHS pays both for the food plus the additional cost of processing the items. Not all patients with a diagnosis of coeliac disease use the option of getting food on prescription.

Methodology

Prior to going to public engagement NHS Kernow took views on the subject of gluten-free prescribing from lead GPs, secondary care health professionals and its Patient Reference Group.

Having identified a preferred option, public engagement was undertaken. The principle route by which people were invited to comment was via a structured survey, but within the survey there was opportunity for people to give free text comments. In addition, people were able to write, phone and email if they preferred.

The survey was designed to facilitate responses from people who have coeliac disease or DH, parents/guardians of children that have coeliac disease or DH, people who are the carer of someone with coeliac disease or DH, health professionals responding to give their opinion as clinicians, and people who do not fall into any of the above categories.

Notice of the engagement was given by direct notification to a wide range of statutory and voluntary sector stakeholders, including Healthwatch (for Cornwall and the Isles of Scilly), Patient Participation Groups and both the Local Medical Committee and the local Pharmaceutical Committee. Coeliac UK was also informed, and helpfully notified their members in Cornwall.

The local media and social media were also used to raise awareness, in addition to which the engagement and its associated rationale were on the public facing part of the CCGs website.

Survey results

1. Your GP practice

At least one response was received from a patient of every GP practice in Cornwall and Isles of Scilly, plus 18 responses from outside of the area.

2. Your nearest town

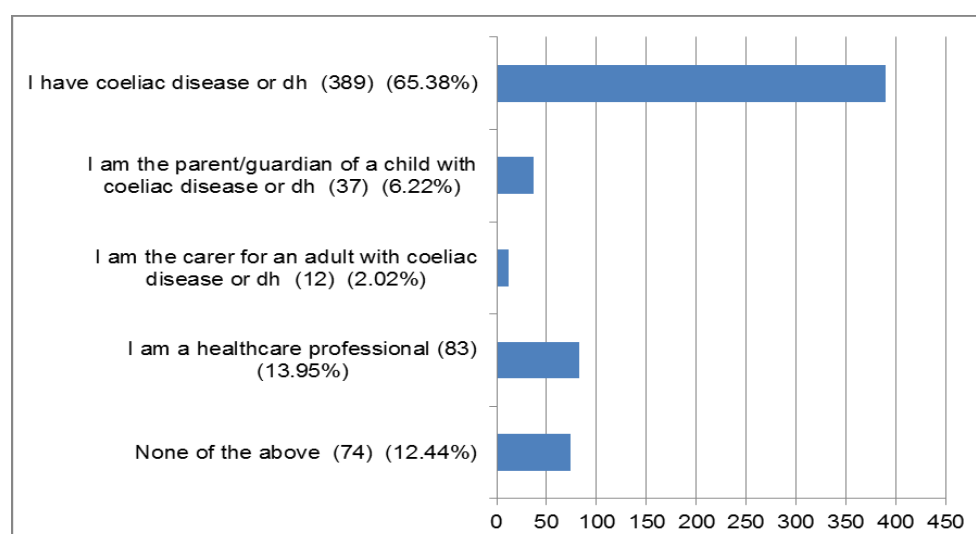
Based on how respondents identified their nearest town, 35 places were named. The top ten most frequent responses were:

Truro	95
St Austell	56
Newquay	47
Redruth	45
Camborne	32
Helston	25
Bodmin	24
Saltash	23
Penzance	22
Falmouth	21

With two responses being received from the Isles of Scilly, the results from question one and two show that countywide coverage was achieved.

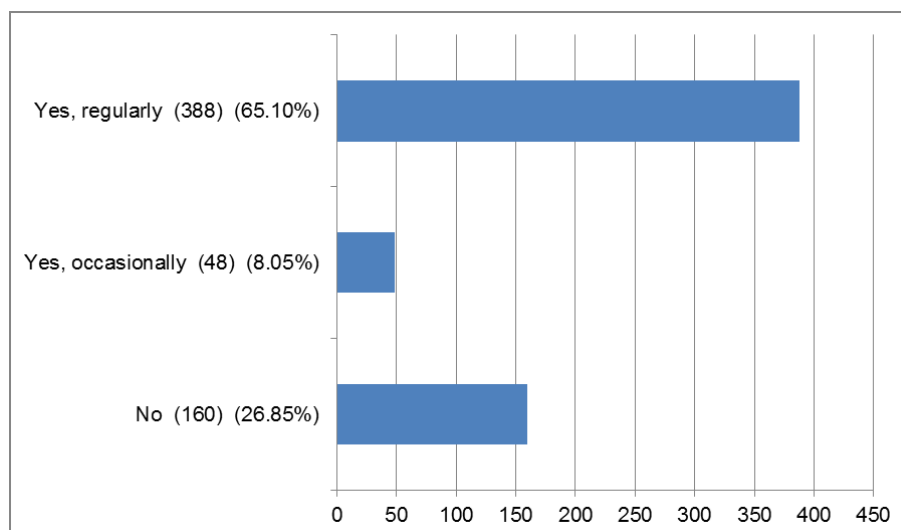
3. Which of the following applies to you?

Total responses: 595



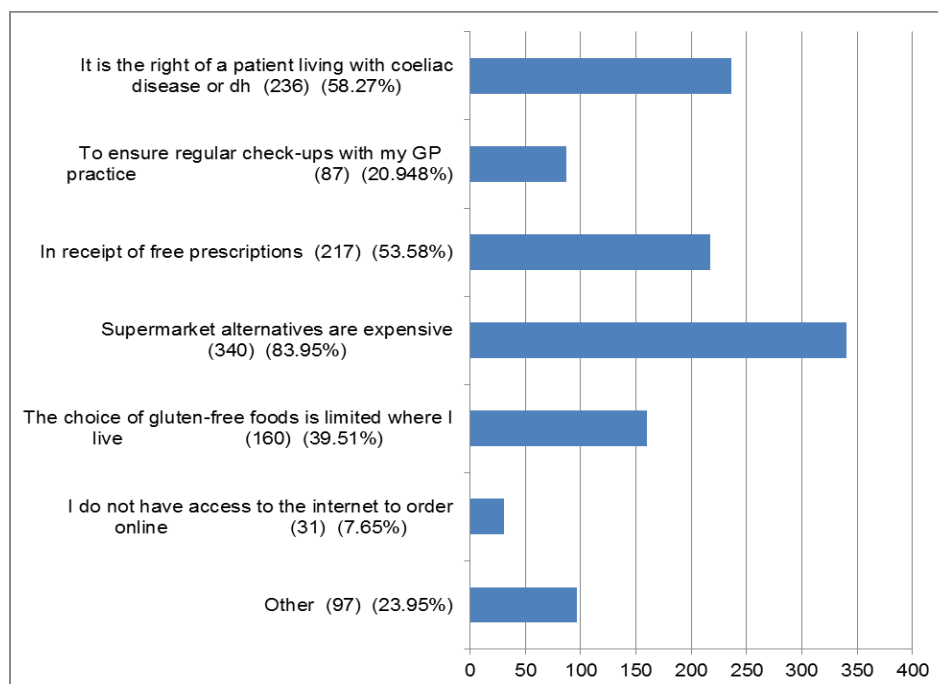
4. Do you (or someone you care for) receive gluten-free foods on prescription?

Total responses: 596



5. If you answered yes, please can you tell us why you choose to obtain gluten free foods on prescription? (Please tick all that apply)

Total responses: 405



Note: The above responses have been filtered to include only people who have coeliac disease/dh, or who are a parent/guardian or carer of someone who does

Additional comments raised under ‘other’

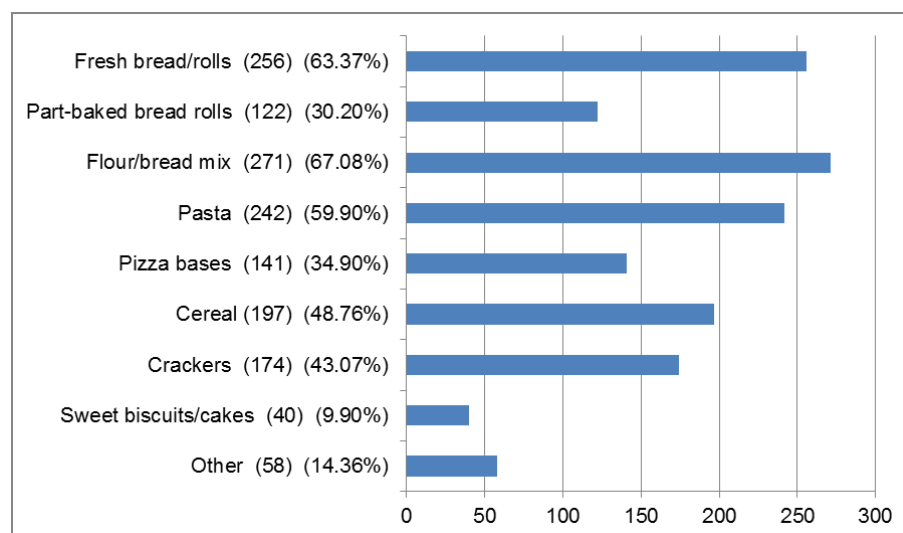
Recurring additional comments included references to:

- The high retail price of gluten-free products
- Better quality of prescribed gluten-free products
- The problems for people on a low income
- The lack of local availability of gluten-free products
- Glutafin and Juvela bread are only available on prescription

The full list of responses can be found at Appendix 2.

6. If you answered yes, please can you tell us which gluten-free foods you choose to get on prescription? (Please tick all that apply)

Total responses: 404



Note: The above responses have been filtered to include only people who have coeliac disease/dh, or who are a parent/guardian or carer of someone who does

Additional comments raised under ‘other’

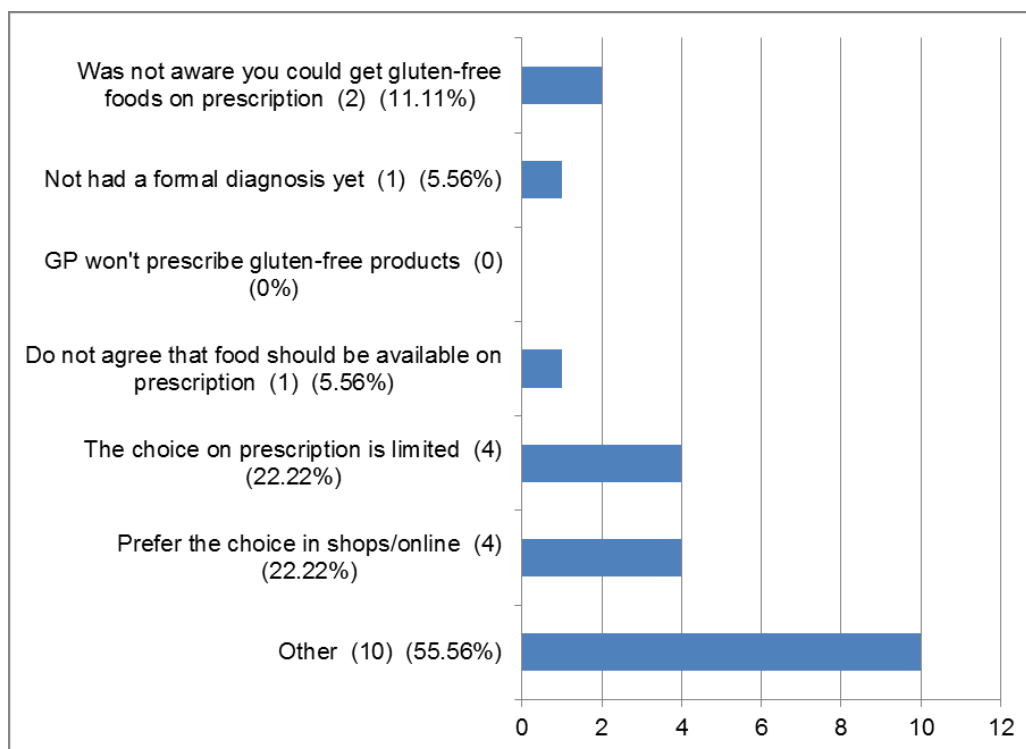
Recurring additional comments included references to:

- (Gluten-free) Oats/porridge oats
- Xanthan gum
- Long-life bread

The full list of responses can be found at Appendix 3.

7. If you answered no, please can you tell us why you choose not to obtain gluten free food on prescription? (Please tick all that apply)

Total responses: 18



Note: The above responses have been filtered to include only people who have coeliac disease/dh, or who are a parent/guardian or carer of someone who does

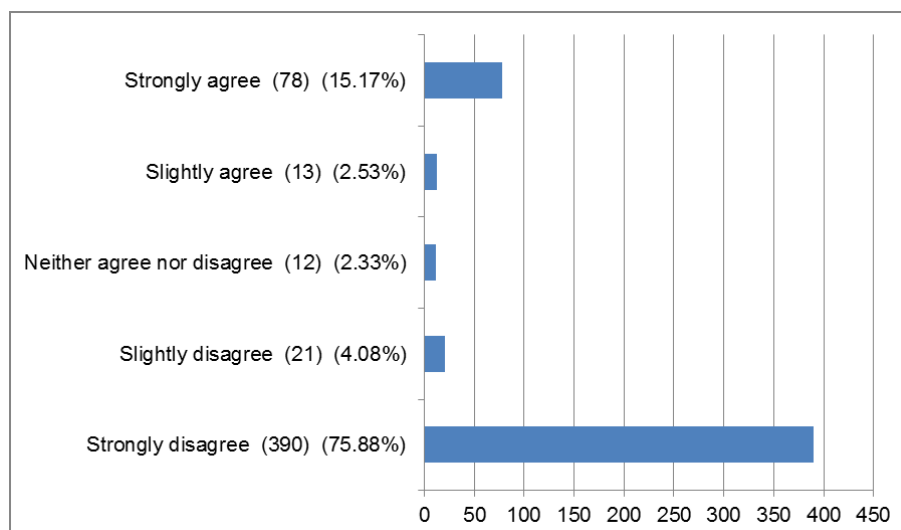
Additional comments raised under 'Other'

Too few responses were given to identify any recurring comments.

The full list of responses can be found at Appendix 4.

8. Please tell us whether or not you agree with the CCGs proposal to stop all prescribing/NHS supply of gluten-free products.

Total responses: 514



Responses by respondent group:

	I have coeliac disease or dh	I am the parent/guardian of a child with cd or dh	I am the carer of an adult with cd or dh	I am a health professional	None of the above	Total
Strongly agree	7	1	0	33	37	78
Slightly agree	6	0	0	6	1	13
Neither agree nor disagree	8	1	0	0	3	12
Slightly disagree	11	0	0	8	2	21
Strongly disagree	324	35	12	12	7	390
Total	356	37	12	59	50	514

9. Please tell us your response to the following questions:

	Strongly agree	Slightly agree	Neither agree nor disagree	Slightly disagree	Strongly disagree	Total
Do you believe that it's appropriate that the NHS provides gluten-free food on prescription for patients with coeliac disease and dermatitis herpetiformis?	75.92% 391	5.83% 30	0.97% 5	2.91% 15	14.37% 74	515
Do you think not prescribing gluten free foods will make it harder to follow a gluten free diet?	63.18% 326	12.60% 65	5.04% 26	5.04% 26	14.15% 73	516
Do you think not prescribing gluten free foods will increase the risk of complications associated with exposure to gluten?	62.72% 323	12.43% 64	6.60% 34	6.02% 31	12.23% 63	515
Do you think that gluten free foods in supermarkets or online are affordable?	10.39% 53	7.25% 37	6.67% 34	13.53% 69	62.16% 317	510
Do you think that gluten free foods are readily available in supermarkets or online?	20.08% 103	29.24% 150	14.81% 76	23.39% 120	12.48% 64	513
Do you think that there is enough information and support available for people with coeliac disease or dermatitis herpetiformis in Cornwall and the IOS to manage their condition and diet?	14.96% 76	17.91% 91	22.83% 116	21.26% 108	23.03% 117	508

Responses to question nine by client group are given in Appendix 5.

10. Is there anything else we could do to support people with coeliac disease/ dermatitis herpetiformis to better manage their condition?

Recurring comments made by patients, parents and guardians and carers included references to:

- The potential adverse financial effect on some patients/families of stopping food on prescription, particularly
 - People on a low or fixed income
 - Households with more than one person with coeliac disease or dh
 - The high retail price of gluten-free products
- Lack of access to supermarkets or online shopping for some people
- The impact of non-compliance with a gluten-free diet will cost the NHS more over time, due to people becoming ill
- Retain access to a list of basic, staple gluten-free foods on prescription
- People want more and better information about the disease
- People want more and better access to dedicated services such as
 - Dietician appointments
 - Regular blood tests
- Can anything be done to reduce retail prices of gluten-free food?
- Keep the current system in place
- There is a need for a local support group(s)

The full range of responses from patients, parents and guardians and carers is shown in Appendix 6.

Recurring comments made by health professionals included references to:

- Providing better patient information
- Providing better patient education

The full range of responses from health professionals is shown in Appendix 7.

Recurring comments made by people who are not patients, parents/guardians, carers or health professionals included references to:

- Providing good information about what foods are naturally gluten-free

The full range of responses made by people who are not patients, parents/guardians, carers or health professionals is shown in Appendix 8.

11. Is there anything else you would like to tell us?

Recurring comments made by patients, parents and guardians and carers included references to:

- The potential adverse financial effect on some patients/families of stopping food on prescription, particularly
 - People on a low or fixed income
 - Households with more than one person with coeliac disease or dh
 - The high retail price of gluten-free products
- Coeliac disease/dh is not the result of lifestyle choices, unlike some other diseases that are, yet which receive free treatment

- The impact of non-compliance with a gluten-free diet will cost the NHS more over time, due to people becoming ill
- Retain access to a list of basic, staple gluten-free foods on prescription
- Adjust the points system to help to reduce cost
- Gluten-free food is the equivalent of medical treatment to people with disease
- Lack of access to supermarkets or online shopping for some people
- Retain food on prescription for the most vulnerable people

The full range of responses from patients, parents and guardians and carers is shown in Appendix 9.

Recurring comments made by health professionals included references to:

- The potential adverse financial effect on some patients/families of stopping food on prescription
- Gluten-free food is now more widely available

The full range of responses from health professionals is shown in Appendix 10.

Recurring comments made by people who are not patients, parents/guardians, carers or health professionals included references to:

- Other patient groups with limited diets do not get food provided by the NHS
- People who must follow a gluten-free diet face higher costs
- Gluten-free food is now more widely available

The full range of responses made by people who are not patients, parents/guardians, carers or health professionals is shown in Appendix 11.

Other feedback

Feedback received outside of the survey was:

- Correspondence from Coeliac UK (Appendix 12)
- Correspondence from the British Specialist Nutrition Association Ltd (Appendix 13)
- Correspondence from the Local Pharmaceutical Society (Appendix 14)
- Letter from the British Society of Gastroenterology (Appendix 15)
- Correspondence from a member of the public who has coeliac disease (Appendix 16)
- Three telephone calls from people who have coeliac disease (Appendix 17)
- Two emails from members of the public who have coeliac disease (Appendix 18)

Next steps

This engagement report will form part of the consideration of the CCG when making a decision about the future of prescribing for gluten-free foods. The findings will be submitted to the CPG on 1 September 2016 with a recommendation, and then to the Governing Body on 6 October 2016 for a decision.

Appendices

We are not able to share the appendices referenced within the report as the appendices contain potentially patient identifiable information.