



Campaigns Overview

Lisa Bainbridge
Head of Campaigns
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Introduction

- What has been our impact on helping more people to secure a diagnosis of coeliac disease?
- What can you now expect from the NHS?
- Gluten free substitutes on prescription
- Working to improve access to safe gluten free food
- Engaging the gluten free community
- What's on the horizon?

Getting diagnosed

- University of Nottingham study in 2011, published 2014:
 - 5.2/100,000 diagnosed in 1990 to 19.1/100,000 diagnosed in 2011.
 - This is a fourfold increase in diagnosis in two decades.
- Still more to do:
 - Expected prevalence of the condition is 1% but actual diagnosis is at 0.24%.
 - Diagnosis is important to relieve suffering and reduce risk of health complications associated with undiagnosed coeliac disease.

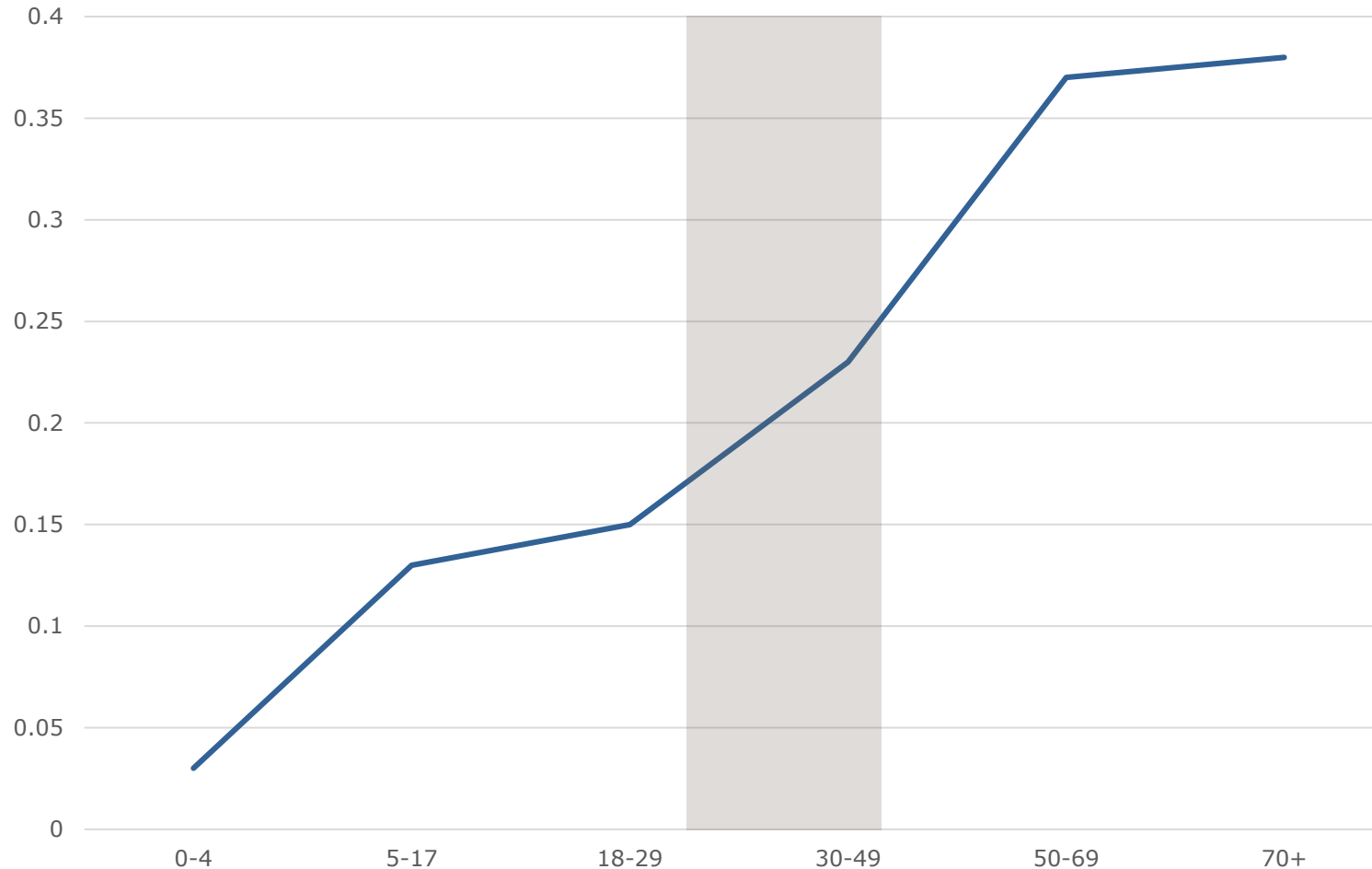
Our aim is to find the half a million people with undiagnosed coeliac disease.



Diagnosis insights and obstacles

- People tend to be diagnosed later in life, but it takes on average 13 years once symptoms start.
- Health inequalities exist in diagnosis rates for children and adults.
- 1 in 4 are misdiagnosed with coeliac disease before getting their coeliac disease diagnosis.
- People experience different symptoms to differing degrees.
- People ignore everyday symptoms as being nothing more than a result of their busy lifestyle and treat with over the counter medicines.
- Awareness of coeliac disease and its symptoms is still low.
- People unaware they are just a few steps away from a symptom free life.

**Prevalence (%) coeliac disease and dermatitis
herpetiformis by age, 30 June 2011**



**Target audience
those aged
between 25-45**

Number of reported symptoms reported, market research July 2015, base n=828



**More than half of
participants
reported 5 or
more symptoms.**

Q. Before you had your Coeliac disease diagnosis which of the following symptoms did you have?
Base n=828 participants

The symptoms we have been highlighting through our campaign...

FREQUENT DIARRHOEA
ANAEMIA - FATIGUE
NAUSEA - VOMITING
BLOATING
CONSTIPATION
WEIGHT LOSS
MOUTH ULCERS
GAS - CRAMPING
ABDOMINAL PAIN

Empowering people to take those steps to diagnosis

- Online video plus TV commercial “Everyday Symptoms” viewed by over 11 million people
- Screen, poster, leaflet displays in NHS/GP surgeries in May 2015 and 2016
- Outreach events hosted by Coeliac UK across seven UK cities where 17% of people seen were referred on for formal diagnosis
- Volunteer national leaflet day 2016 led to over 10,000 leaflets being handed out to the public
- Traditional and social media.

Our most recent campaign materials have focused on children



Is your little one struggling to take off?

Coeliac disease is an autoimmune condition caused by an intolerance to gluten, found in food containing wheat, barley and rye.

Common symptoms of coeliac disease in children are faltering growth, frequent bouts of diarrhoea, nausea and vomiting, stomach pain and extreme tiredness. Once treated with a gluten free diet symptoms will improve and your little one will be ready for take off in no time.

For further information go to:
www.isitcoeliacdisease.org.uk

coeliacuk
live well **gluten free**

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The campaign has led to a large number of heart warming diagnosis stories being shared by people across the UK...

I was 29. I only got the test done after seeing advert on TV regarding it. Ticked so many buttons. I tricked a nurse into testing for it at the same time I was being tested for under active thyroid. Bloods came back as yes, then my doctor arranged biopsy. Only been on the diet a month. Seen huge difference already. Posted Julie Stirling.

In addition to developing our own materials we've worked with our partners to raise awareness across the NHS...

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Coeliac disease runs in the family



Coeliac disease

The importance of testing immediate family members

Coeliac UK and the RCGP are both working to support GPs in the diagnosis of coeliac disease, a common condition that affects 1 in every 100 people. These figures increase to 1 in 10 if the condition is in the family.¹

While the diagnosis of coeliac disease has improved over recent years, it remains low with only 24% of those with the condition benefiting from a diagnosis.²

Coeliac disease is a genetic condition so serological testing should be offered to first degree relatives of patients already diagnosed, in accordance with NICE recommendations.²

You can find out more about opportunities to improve the recognition of coeliac disease within your practice [here](#).


RCGP Royal College of General Practitioners

Sponsored by an educational grant from Thermo Fisher Scientific

1. NHS Choices. Available from: <http://www.nhs.uk/Conditions/Coeliac-disease/Pages/introduction.aspx>; last accessed April 2016.
2. National Institute for Health and Care Excellence. Coeliac disease: recognition, assessment and management (N320). 2015. London: National Institute for Health and Care Excellence.



If only the cause was as easy to spot as the symptom



30-50% of patients with coeliac disease have anaemia at diagnosis

The importance of testing patients with unexplained iron, B12 or folate deficiency anaemia for coeliac disease

Coeliac UK and the RCGP are both working to support GPs in the diagnosis of coeliac disease, a common condition that affects one in every 100 people.¹ While the diagnosis of coeliac disease has improved over recent years, it remains low with only 24% of those with the condition benefiting from a diagnosis.²

Iron-deficiency occurs in 30-50% of patients at diagnosis with coeliac disease.³ The damage to the small intestine in patients with undiagnosed coeliac disease can cause malabsorptive signs and symptoms. As such NICE recommends that anyone with unexplained iron, B12 or folate deficiency is offered serological testing for coeliac disease.⁴

You can find out more about opportunities to improve the recognition of coeliac disease within your practice [here](#).

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1. NHS Choices. Available from: <http://www.nhs.uk/Conditions/Coeliac-disease/Pages/introduction.aspx>; last accessed April 2016.
2. West J, et al. Am J Gastroenterol. 2014; 109:757-768.
3. Ludvigsson JF, et al. Am Med Assoc 2013; 309:406-410.
4. National Institute for Health and Care Excellence. Coeliac disease: recognition, assessment and management (N320). 2015. London: National Institute for Health and Care Excellence.

Some things can be very similar and yet, very different



Coeliac disease

The importance of testing IBS patients for coeliac disease

The RCGP and Coeliac UK are both working to support GPs in the diagnosis of coeliac disease, a common condition that affects 1 in every 100 people.¹ However, in the UK, only 24% of these patients are currently diagnosed.²

As symptoms are often similar, 1 in 4 patients with coeliac disease have previously been treated for irritable bowel syndrome (IBS).³ NICE recommends that anyone being considered for a diagnosis of IBS should first be tested for coeliac disease.^{4,5}

With coeliac disease significantly underdiagnosed the RCGP and Coeliac UK recommend testing your IBS patients to identify which patients have not been investigated for coeliac disease. You can find out more about opportunities to increase the pickup rate within your practice population [here](#).

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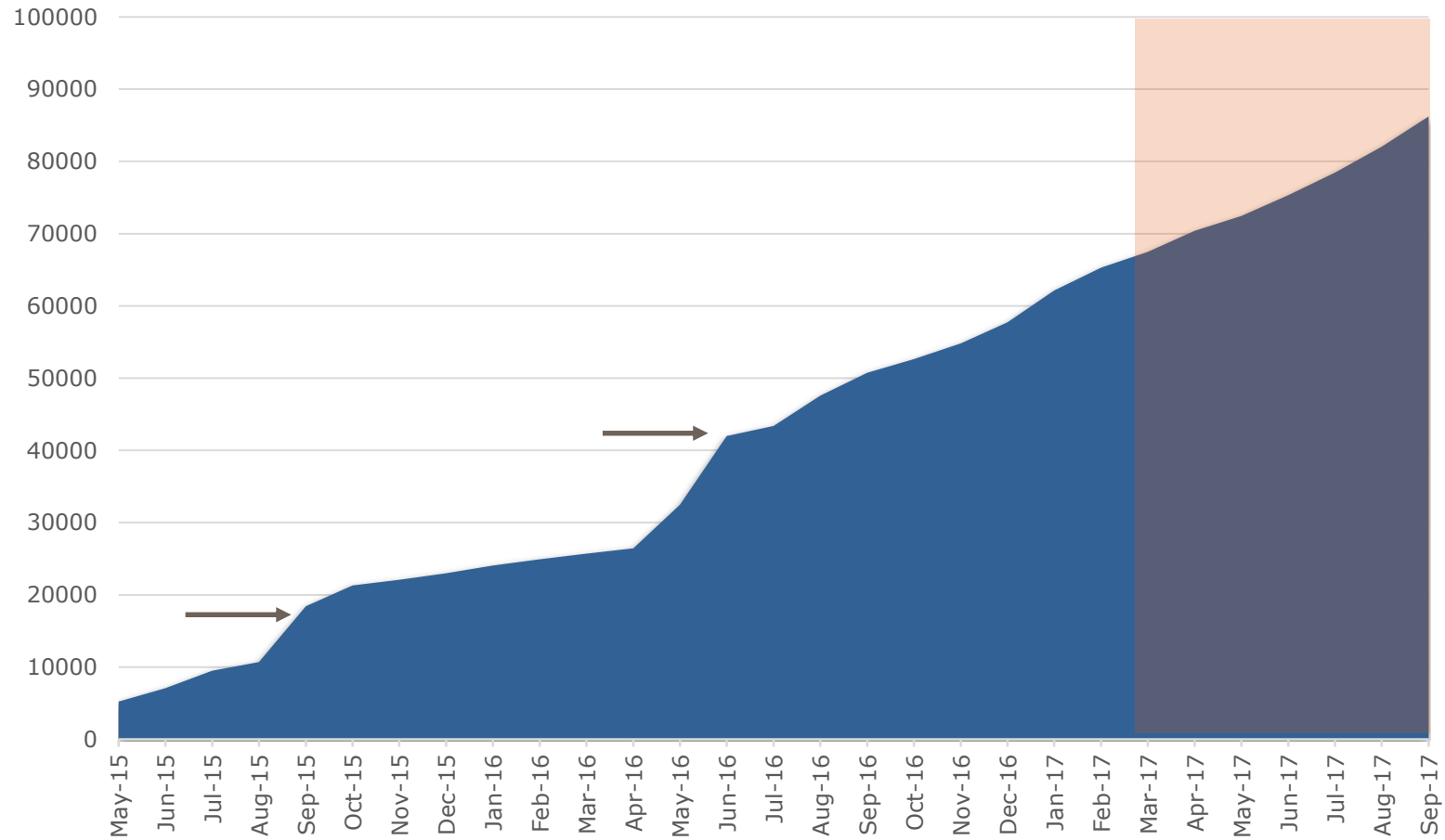
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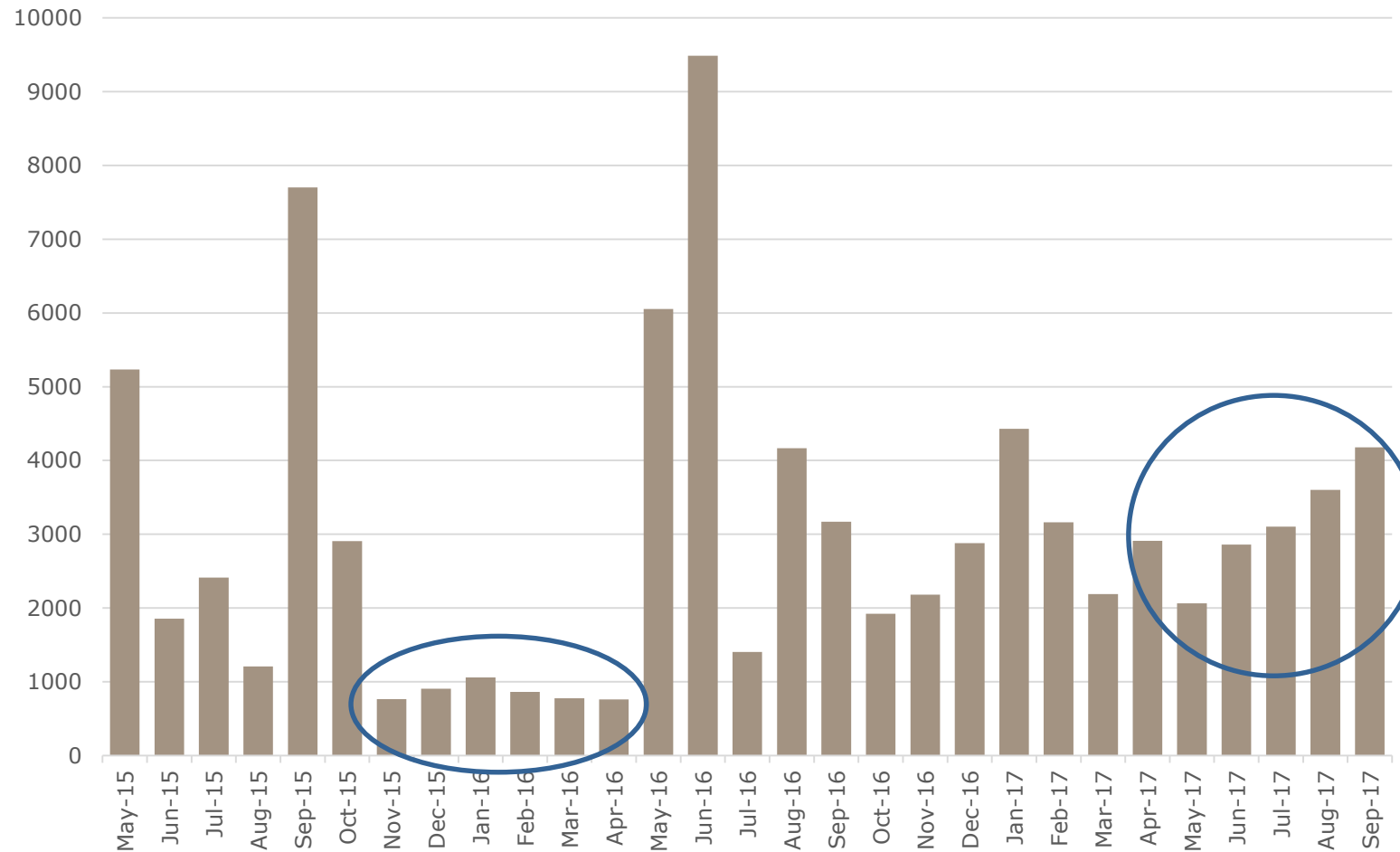
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2. West J et al. Am J Gastroenterol. 2014; 109:757-768; doi:10.1038/ajg.2014.55.
3. Card TR et al. Scand J Gastroenterol. 2013; Early Online, 1-7. doi:10.3109/00365521.2013.786130.
4. National Institute for Health and Care Excellence. Coeliac disease: recognition, assessment and management (N320). 2015. London: National Institute for Health and Care Excellence.
5. National Institute for Health and Care Excellence. Irritable bowel syndrome in adults: diagnosis and management (CG61). 2006. London: National Institute for Health and Care Excellence.



**Number of people who have completed and online
assessment for coeliac disease
May 2015 – Sept 2016**



People completing assessments each month May 2015 - Sept 2017



From funding to support the creation of our campaign materials to samples being handed out at diagnosis events, we've not been working alone...



ThermoFisher
S C I E N T I F I C

M&S

EST. 1884

Sample foods provided by:

Kent and Fraser

Dr Schaer

Peace of Cake

Walker Shortbread

Doves Farm

Co Fresh

Nature's Path

Gluten-free Goodies

Wholebake

Genius

No.G

Delicious Alchemy

Eat Natural

Byron Bay Cookie Co.

Darling Spuds

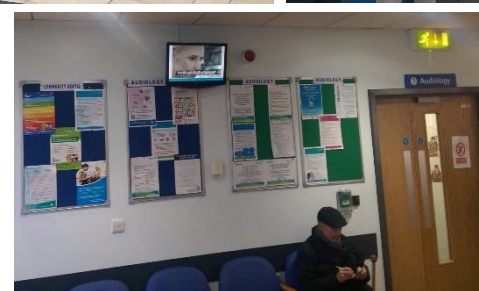
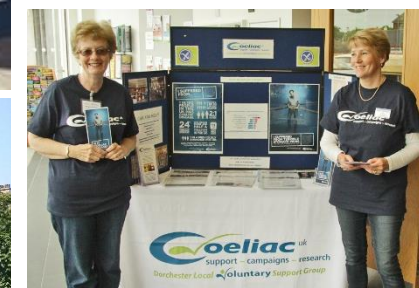
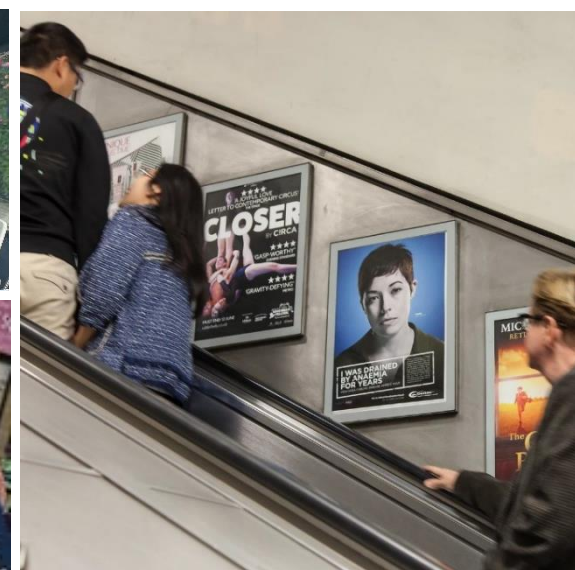
Orgran

Big Bear Confectionery

Gluten Free Foods Ltd

...and of course we've been supported by our campaigners and members...





Key messages to take to your area

- 1 in 100 people has coeliac disease, but less than a quarter are diagnosed.
- It takes on average 13 years to secure a diagnosis for coeliac disease
- 1 in 4 of those diagnosed with coeliac disease have been previously diagnosed with IBS.
- Coeliac disease has a range of symptoms that can affect different people in different ways.

Key messages to take to your area

- Women are twice as likely to have coeliac disease than men.
- You must be on a gluten containing diet before having the test.
- There are fewer coeliac disease patients in GP practices in deprived areas than those in affluent areas.
- Diagnosis of coeliac disease in children is 80% higher in the least-deprived areas than in the most-deprived.

Our goal is to confirm a diagnosis for 250,000 more people by 2020, so they are freed from not knowing what is causing their discomfort, pain and suffering.

Join the campaign

- Share your personal experiences to inspire and encourage others to get tested
- Promote the online assessment www.isitcoeliacdisease.com
- Speak to other organisations and charities
- Contact campaigns@coeliac.org.uk to get hold of materials to distribute in your area!

Next steps in High Wycombe

- We are finalising our campaign evaluation report
- Key learnings will be integrated into our support services.

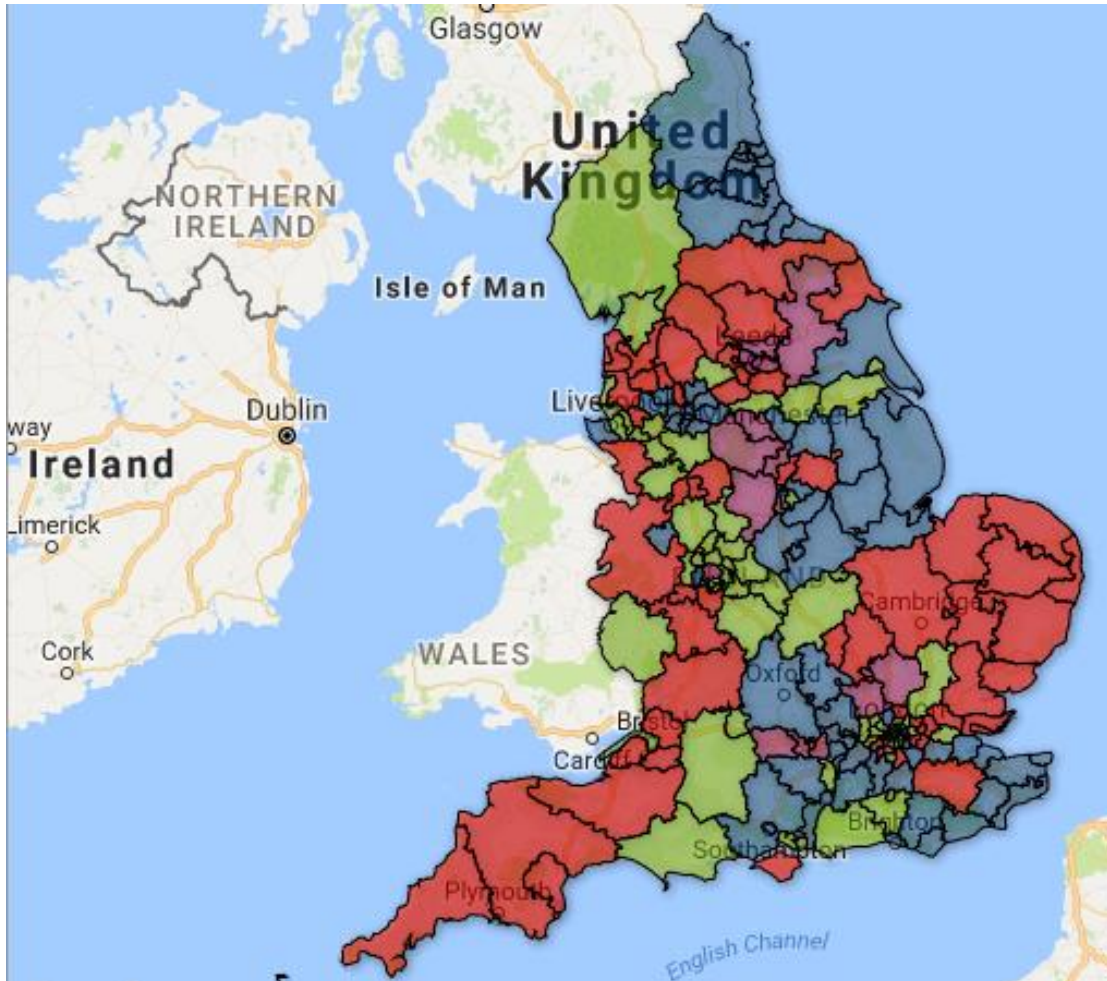
What you can expect from the NHS: managing your condition

- In 2015 the new NICE Guideline NG20 (2015) (replacing CG86) came out. It:
 - Covers recognition, assessment and management of the condition
 - Suggests an annual review with a GP, highlighting such is particularly important for recently diagnosed, after changed service.
 - Provides details of management information and support for patients, including information on complications, advice from HCP with specialist knowledge, and information on and the role of local groups.





What to expect from the NHS: diagnosing coeliac disease

- NICE Quality Standard QS134: Coeliac disease
- Looks at:
 - improved outcomes for diagnosis of coeliac disease
 - growth of diagnosis amongst children/young people
 - health-related quality of life
 - picking up incidence of osteoporosis, intestinal lymphoma, and vitamin D and iron deficiency.
- Includes:
 - Five quality statements on testing for coeliac disease (underdiagnosed)
 - referral to a specialist for endoscopy
 - Referral to a specialist for advice on the gluten free diet
 - Recommendation of an annual review.

Prescriptions



Map key

-  Following National Prescribing Guidelines
-  Restricting products and/or units
-  Policy on gluten-free prescribing under review
-  Partial or complete withdrawal of prescriptions

- Coeliac UK has written to all CCGs
- Supported a debate on gluten free prescribing in the House of Commons
- Contributed to the national consultation on prescriptions
- Waiting to hear back on the consultation
- Continuing to look at and promote alternative options to access gluten free foods

Access to safe gluten free food.

- Encouraging all stores, regardless of location or size, to commit to a standard selection of gluten free staples

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GfG basket for large stores

1. Gluten free fresh bread (brown or seeded)
2. Gluten free fresh bread (white)
3. Gluten free bread rolls
4. Gluten free crackers (savoury)
5. Gluten free cereal bars
6. Gluten free breakfast cereal
7. Gluten free pasta
8. Gluten free flour

GfG basket for small stores

1. Gluten free sandwich, wrap or ready to eat meal on to the go
2. Gluten free fresh bread (of any type)
3. Gluten free breakfast cereal
4. Gluten free pasta



OPEN
up to 1.3 million
new customers

**GIVE YOUR CUSTOMERS A
GLUTEN FREE GUARANTEE.**

Coeliac UK is asking retailers to commit to providing gluten free staples in every store, providing the choice and access that 1.3 million gluten free consumers need.

To find out more about how you can give a Gluten Free Guarantee, contact us at campaigns@coeliac.org.uk or call 0800 333 2038.

For more information go to www.coeliac.org.uk/gfgr

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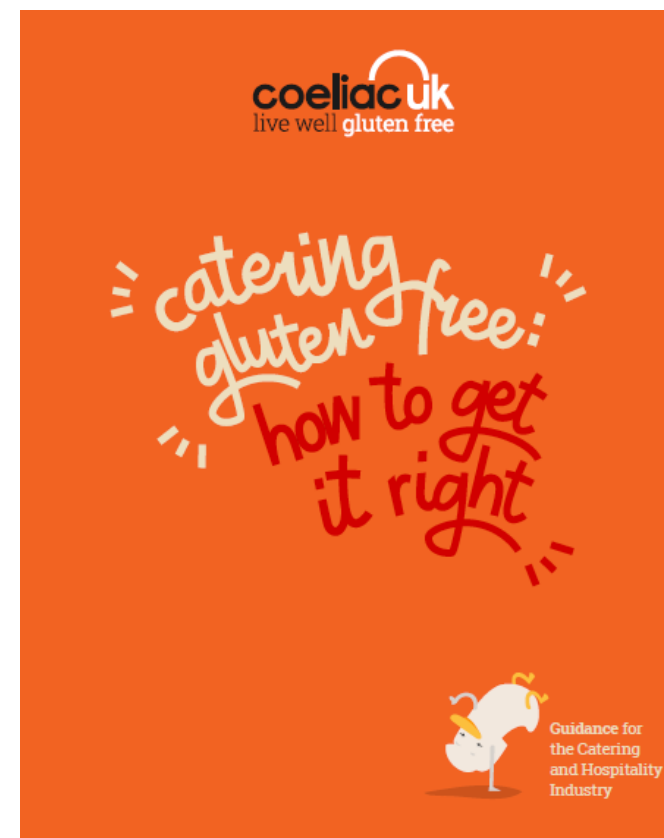
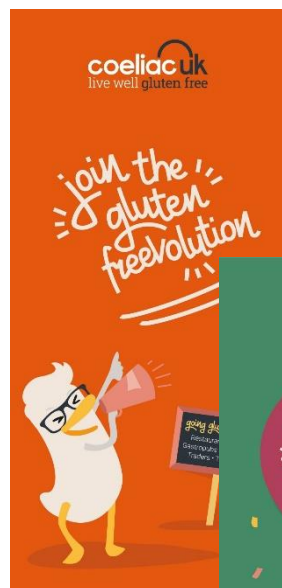
Improving access to safe gluten free food

What you can do

- Highlight the growing need and demand for gluten free meals, including to the public service sector
- Increase listings on the Coeliac UK venue guide
- Rate venues listed on the venue guide
- Promote gluten free catering accreditation
- Use Coeliac UK materials to educate businesses on the benefits of gluten free and how to address food safety issues in a simple way
- Encourage venues to develop a gluten free menu option
- Open discussions with local services and organisations
- Feedback directly to stores and venues
- Use your voice on social media.

Access to safe gluten free food

We have a range of materials you can use...



What's on the horizon? Campaigning in 2018

- Incorporating our learnings from the diagnosis campaign into our work
- Identifying opportunities to improve aftercare support
- Monitoring the impact of change on the cost of gluten free foods
- Pressing retailers to do more
- Continuing the discussion with retailers and venues
- Supporting our research goals
- Celebrating our successes.



Campaigners

campaigns@coeliac.org.uk

0333 332 2033