

**Public Consultation On  
GLUTEN-FREE PRESCRIBING  
2 March – 22 March 2016**

## INTRODUCTION

For the past 30 years the NHS has prescribed gluten free foods to patients who have been diagnosed with coeliac disease. This service started when gluten-free foods were not as readily available as they are today.

The NHS has a limited budget and with an increasing demand for services it must evaluate every service it pays for.

In south east Essex (Castle Point, Rochford and Southend-on-Sea) prescribed gluten free foods cost the NHS more than £180,000 a year.

The two local Clinical Commissioning Groups (CCGs) — NHS Southend CCG and NHS Castle Point and Rochford CCG — are jointly reviewing their policies on gluten-free food and are proposing to stop prescribing it. We would like to hear your views, whether you live with coeliac disease or not.

The consultation is open from 2 March 2016 to 22 March 2016

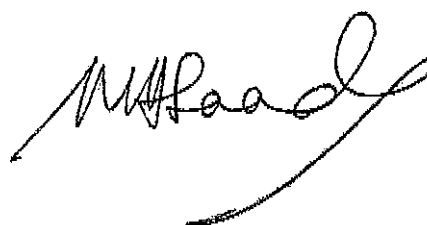
The consultation questionnaire is available at

[www.surveymonkey.co.uk/r/\\_glutenfree](http://www.surveymonkey.co.uk/r/_glutenfree)

If you need more information about this consultation or would like the consultation document in another format please contact [cpr.ccg@nhs.net](mailto:cpr.ccg@nhs.net) or call 01268 464508.



Dr José Garcia Lobera  
Chair, NHS Southend Clinical  
Commissioning Group



Dr Mike Saad  
Chair, NHS Castle Point and Rochford  
Clinical Commissioning Group

## **WHAT IS A CCG?**

A CCG is a local NHS organisation which was created by the Health and Social Care Act 2012. As more than 90% of patients' contact with the NHS is with their GP, CCGs were created to enable GPs to buy the services that their patients need.

All GP practices within a given area now work together as a Clinical Commissioning Group (CCG) to buy most of the services that they refer their patients on to such as hospital, mental health and community services. The CCG is led by a Governing Body of elected local GPs supported by other clinicians and NHS managers.

## **HOW WE COMMISSION NHS SERVICES**

The NHS is funded through taxation and this provides a fixed budget to buy and provide health services for the whole population. Commissioning health services is about understanding the health of a population group, planning what services to purchase to meet those needs and monitoring the quality of services that are delivered.

NHS Castle Point and Rochford CCG is responsible for assessing the needs of people living in the districts of Castle Point and Rochford, whilst NHS Southend CCG is responsible for the borough of Southend.

They decide which health services to purchase for their population. NHS England is responsible for direct commissioning of services outside the remit of clinical commissioning groups.

The challenge faced by organisations across the NHS is how to spend their allocated budgets in a way that benefits the health of the whole population while ensuring that services also meet the needs of individuals and delivers value for money.

With a growing population and rising demand for services, CCGs have to evaluate every service they commission to see if they offer good quality, value for money and an effective and equitable way of using our resources.

## **WHAT IS THIS DOCUMENT ABOUT?**

Like many other financially challenged organisations across the NHS, we regularly review all the services we commission to ensure that we are using NHS funds appropriately and fairly. We are constantly looking for ways to save money without impacting on patient care and this means that we have to look at how we can do things differently. As part of our regular reviews of services we commission we have identified that we would like to review our policy on the prescribing of gluten-free foods.

Castle Point and Rochford CCG and Southend CCG are proposing to stop prescribing gluten-free food. In this document, we will explain why we want to make this change and we would like to hear your views on this proposal.

## **WHAT IS GLUTEN-FREE FOOD AND WHY DO PEOPLE NEED TO FOLLOW A GLUTEN-FREE DIET?**

Gluten is a type of protein that is found in three types of cereals: wheat, barley and rye. Gluten-free foods are recommended for people who have been formally diagnosed by the NHS with coeliac disease or dermatitis herpetiformis (a skin condition linked to coeliac disease) and who want to continue to eat similar foods to the ones that contain gluten. Coeliac disease is a long-term condition that affects approximately 1 in every 100 people in the UK and is a lifelong, serious autoimmune disease caused by the immune system reacting to gluten. This damages the surface of the small bowel (intestines) disrupting the body's ability to absorb nutrients from food. The only way to reverse this damage is to remove gluten from the diet.

## **WHY DO PEOPLE HAVE GLUTEN-FREE FOOD PRESCRIBED BY THE NHS?**

There is no cure for coeliac disease and the only treatment for the condition is a strict gluten-free diet for life. The NHS has been prescribing gluten-free food for over 30 years. Back then gluten-free foods were not easily available to buy in shops. The NHS has historically prescribed gluten-free foods to patients, but we think that this practice is now outdated.

Over the past 30 years, changing diets and lifestyle choices mean there is a much wider range of food available and gluten-free alternatives are now readily available and prices have come down. It is also much more expensive for the NHS to supply gluten-free foods to patients than it is for people to buy them because this has to be done through the same prescription process that is used to deliver medicines.

## **OUR CURRENT GUIDELINES**

Patients can be prescribed gluten-free food if they have received a diagnosis of coeliac disease by a NHS professional. Access to gluten-free foods on prescription is managed through GPs and items are supplied by pharmacists. In England, prescriptions for gluten-free food are not free of charge unless you qualify for free prescriptions.

We currently allow the prescription of a limited number of gluten-free items per month for patients who have received an NHS diagnosis of coeliac disease. These standard items include: bread loaves, bread rolls, bread/flour mix, plain savoury crackers, crisp breads, pasta, unsweetened breakfast cereal and pizza bases.

Depending on age a patient can receive up to 18 items per month, with extra items allowed for breastfeeding women and women in the third trimester of pregnancy.

## **WHAT IS THE COST OF GLUTEN FREE PRODUCTS TO THE NHS?**

The NHS spends about £25 million a year on prescribing gluten-free food. Castle Point and Rochford CCG and Southend CCG could save more than £180,000 per year if they stopped prescribing gluten-free food, which could be used to fund other healthcare.

It is possible that because the NHS spends so much on prescribing, the price charged to the NHS by suppliers compared to supermarket prices may actually be holding prices artificially high. By removing this distorting factor the market for gluten-free foods should be more attractive for manufacturers to produce suitable products at competitive prices.

## **WHY WE ARE PROPOSING A CHANGE TO GLUTEN-FREE PRESCRIBING?**

We considered how we can use our prescribing budget in the most effective and equitable way to improve the health of our whole population. We have been reviewing treatments that are shown to be less clinically effective, provide insufficient health benefits and those that do not represent good value for money. We have reviewed gluten-free prescribing against these measures and have considered the following evidence:

- The NHS does not provide food on prescription for other groups of patients whose conditions are associated with, or affected by, the type of food they eat. For example we do not provide food for diabetics, people with high blood pressure or high cholesterol. These are also conditions which can be managed by eating a diet naturally free from certain ingredients. We need to balance health and wellbeing of the affected patients with the need to share our resources equitably across our whole population
- There is no strong clinical evidence that patients who receive gluten-free food on prescription are more likely to comply with a gluten-free diet or have better health outcomes than those who do not
- There are a number of naturally gluten-free carbohydrates which are widely available that can be used instead of foods like bread and pasta. These include rice, potatoes and flour alternatives such as millet and corn flour
- As a protein, gluten is not essential to diet and can be replaced by other foods.
- Many currently prescribed gluten-free foods are not essential components of a healthy, nutritious diet, for example pizza bases
- There is lots of information available to patients via their GP, dietitian or online about how to eat a healthy gluten-free diet
- Changes to the law mean food labelling has improved and it's easier to see which foods contain gluten
- We have undertaken a quality impact assessment and we don't believe that this proposed change will impact the quality of healthcare that patients currently receive. An equality impact assessment indicates that a change in prescribing policy would not discriminate against any particular protected characteristics.
- We could invest the money we spend on gluten-free prescribing (over £180,000) on other services which would benefit more patients

### **WHAT CHANGES ARE WE PROPOSING TO GLUTEN-FREE PRESCRIPTIONS?**

As a result of this review, we are considering amending the prescribing policy for gluten-free foods and stopping prescriptions. While the CCGs recognise that this proposal may not be supported by patients who are currently receiving gluten-free foods on prescription, we believe that it won't impact the quality of clinical care patients receive.

### **HOW ARE WE ENGAGING ON THIS PROPOSAL?**

We have already discussed a proposal to stop gluten-free prescribing with our Drugs and Therapeutics Committee, with local GPs, CCG clinical executives and have closely following conversations elsewhere in Essex.

We are now inviting local patients, stakeholders and local clinicians to tell us their views on our proposal to stop prescribing gluten-free foods by completing the following questionnaire.

Your responses will be used to produce a report which will help to inform your CCG's final decision.

Please return this questionnaire to:

**FREEPOST NHS Castle Point and Rochford CCG**

You do not need a stamp.

Or you can complete the same survey online at

[www.surveymonkey.co.uk/r/\\_glutenfree](http://www.surveymonkey.co.uk/r/_glutenfree)

## QUESTIONS

We would like to hear your views on our proposal to stop the prescribing of gluten-free foods. We would particularly like to hear from those affected by the proposals, but everyone's views are welcome as this consultation affects the way the local NHS spends public money on healthcare.

1. Which of the following applies to you? (Multiple choice)	
<input type="checkbox"/>	I have coeliac disease
<input type="checkbox"/>	I am the parent/guardian of a child with coeliac disease
<input type="checkbox"/>	I am a carer of an adult with coeliac disease
<input type="checkbox"/>	I am responding on behalf of someone who has coeliac disease
<input type="checkbox"/>	I am a clinician, for example a GP/nurse or consultant (please state below)
<input type="checkbox"/>	I am responding on behalf of a group or organisation (please state below)
<input type="checkbox"/>	I do not have coeliac disease
<input type="checkbox"/>	Other (please specify below):

2. Where do you live? (Please select one)	
<input type="checkbox"/>	Castle Point
<input type="checkbox"/>	Rochford
<input type="checkbox"/>	Southend-on-Sea
<input type="checkbox"/>	I do not live in Castle Point, Rochford or Southend



**3. Which GP Practice are you registered with?**

Name of Practice	
Address	

**4. Do you (or the person you care for) receive gluten-free foods on prescription? If no, please go straight to question 6.**

Yes
No

**5. If you receive gluten-free food on prescription, please tell us why? (tick all that apply)**

<input type="checkbox"/>	I am on a low income
<input type="checkbox"/>	The food available on the High Street/in supermarkets is too expensive
<input type="checkbox"/>	The choice is limited where I live
<input type="checkbox"/>	It helps ensure I have regular GP check-ups
<input type="checkbox"/>	I am eligible for free prescriptions
<input type="checkbox"/>	I have coeliac disease and believe the NHS should provide gluten-free food for me
<input type="checkbox"/>	Other – please state below

**6. Please select the one option below you most agree with.**

	Gluten-free food should continue to be available on prescription as it currently is, with no change.
	No gluten-free food should be available on prescription.
	Some gluten-free food should be available on prescription but only for those who currently receive free prescriptions.
	Some gluten-free food should be available on prescription but this should be restricted to only bread and flour.

**7. I understand the reason my CCG is reviewing whether or not to continue offering gluten-free food on prescription.**

	Strongly Agree
	Agree
	Not Sure
	Disagree
	Strongly Disagree

**8. It is appropriate that the NHS provides gluten-free food on prescription for those who need it.**

	Strongly Agree
	Agree
	Not Sure
	Disagree
	Strongly Disagree

**9. People who need gluten-free food should buy it themselves.**

	Strongly Agree
	Agree
	Not Sure
	Disagree
	Strongly Disagree

<b>10. It is difficult to find gluten-free food in my locality.</b>	
	Strongly Agree
	Agree
	Not Sure
	Disagree
	Strongly Disagree

<b>11. We would like to obtain views through this survey from all parts of our community. To help with this, we would be grateful if you could answer a few questions. Any information you provide will remain anonymous.</b>	
Your year of birth	
Your gender	
Your ethnic origin	
Your sexual orientation	
Your religion or belief	
Do you consider yourself to have a disability? (please state)	

<b>12. If you would like us to provide you with an update on this proposal, please give us your name and email address so we can contact you:</b>	
Name	
Email	
Postal Address (incl. postcode)	