



THE BIG  
HEALTH  
DEBATE

# Greater Nottingham Consultation Document

## Should gluten free products be available on prescription?

### How to have your say:

- Fill in this survey and return to the freepost address
- Complete online at: [www.surveymonkey.com/r/GN-gluten-free](http://www.surveymonkey.com/r/GN-gluten-free)
- Call: **0115 883 9594** (City patients) or **0115 883 1709** (County patients) for a printed copy or to complete over the phone
- Join us at an event: [www.nottinghamnortheastccg.nhs.uk/nhs/gluten](http://www.nottinghamnortheastccg.nhs.uk/nhs/gluten)

This consultation will run for six weeks from Thursday 14 June to Thursday 26 July 2018

# Formal consultation: have your say on the future of gluten free foods on NHS prescription

We want to hear your views about gluten free foods and if they should continue to be prescribed on the local NHS for adults and children with coeliac disease.

Across Greater Nottingham, the NHS spent £176,488 last year on gluten free foods such as bread, flour, pasta and cereal.

The NHS does not provide food on prescription for any other patients, such as diabetics or those with allergies. Over the past few years, gluten free foods have become widely available in supermarkets at more competitive prices as compared to 30 years ago when choice was limited.

To make sure that we are making the best use of NHS money, we are reviewing some of the services we provide. This means sometimes we need to make difficult decisions about what services can be funded.

We understand that our decisions can have an impact on different people in different ways. We want to work with patients, carers and local people to make sure that we consider people's views when making decisions about the services that are most needed.

If we are thinking about a big change to a service, we will always engage with the people affected and the wider public about it.

**The Big Health Debate** is our patient engagement campaign designed to start the conversation with patients about the challenges the NHS faces. We will be using it this summer to talk to people about a number of potential service changes. The review of this gluten free proposal forms part of this wider picture.

## Who are we?

The Greater Nottingham Clinical Commissioning Partnership (CCP) is made up of four Clinical Commissioning Groups - NHS Nottingham City, NHS Nottingham North and East, NHS Nottingham West and NHS Rushcliffe.

The Greater Nottingham CCP covers Nottingham City, Rushcliffe, Broxtowe, Gedling and Hucknall.

Clinical Commissioning Groups are responsible for planning and commissioning health care services for a particular local area.

## Current gluten free prescribing

Across Greater Nottingham and Mid-Nottinghamshire, there are currently differences in how much gluten free food is prescribed to people living with coeliac disease - see below.

- **Nottingham City**

Nottingham City follow the prescribing guidelines in the table below.

Age and gender	Number of units
Child (1-3 years)	10
Child (4-6 years)	11
Child (7-10 years)	13
Child (11-14 years)	15
Child (15-18 years)	18
Male 19-59 years	18
Male 60-74 years	16
Male 75+ years	14
Female 19-74 years	14
Female 75+ years	12
Breastfeeding	Add 4
3rd trimester pregnancy	Add 1

One unit is the same as: 400g loaf of bread or 250g of pasta or two pizza bases.

- **South Nottinghamshire (Nottingham North and East, Nottingham West and Rushcliffe)**

Four units in total of long life bread and/or flour each month on prescription for patients with a diagnosed condition of coeliac disease or dermatitis herpetiformis.

- **Mid Notts (Mansfield and Ashfield and Newark and Sherwood)**

No prescribing of gluten free foods.

## National and local consultation

The Government recently undertook a national consultation about whether gluten free foods should be available on prescription for people with coeliac disease.

Following the national consultation, they recommended that gluten free prescribing should be restricted to bread and mixes only. However, there has been no decision taken about limiting quantities.

Government advice is that Commissioners carry out their own consultation with local people and make their own decisions about what, if anything, to prescribe.

The South Nottinghamshire Commissioners have already conducted a consultation around gluten free food on prescription in 2015, which is when the amount and range was restricted to four units. You can find more about this on the Rushcliffe, Nottingham North and East or Nottingham West CCG websites.

## Why do people use gluten free foods?

Gluten is a type of protein that is found in three types of cereals - wheat, barley and rye. Gluten free foods are currently prescribed for people who have been formally diagnosed with

coeliac disease or dermatitis herpetiformis.

### What Is Coeliac Disease?

It is a common digestive condition, triggered by the protein gluten which is found in wheat, barley and rye. Symptoms can be mild or very severe and can include abdominal pain, diarrhoea, nausea and weight loss.

There is no cure for coeliac disease, but switching to a gluten free diet helps to control the symptoms and prevent long-term consequences of the disease.

### What is Dermatitis herpetiformis

Dermatitis herpetiformis is a type of skin rash (linked to coeliac disease) which should clear up after switching to a gluten free diet.

## Why are we considering a change?

The Clinical Commissioning Groups have now aligned as the Greater Nottingham Clinical Commissioning Partnership. Together, we have been reviewing the services provided based on clinical effectiveness, if they provide sufficient benefits and if they offer value for money.

Local doctors have reviewed gluten free prescribing against these measures and concluded that:

- Gluten is not essential to a healthy diet and can be replaced by other foods. There is a lot of information available about how to eat a healthy gluten free diet.
- Lots of foods are naturally gluten free such as fresh fruit and vegetables, meat, chicken, fish, eggs and lentils, including widely available naturally gluten free carbohydrates that can be used such as rice and potatoes.
- Recently, there has been a large increase in the availability of gluten free foods in supermarkets, making it easier to eat a healthy and varied gluten free diet.

- The NHS does not provide food on prescription for other groups of patients whose conditions are affected by the type of food they eat, for example diabetics.
- We need to balance the health and well-being of our patients with the need to share our resources fairly.

## What are we consulting with you about?

### The options

There are three options we are currently considering. They are:

- **Limit prescribing for all patients in Greater Nottingham to four units of long life bread and flour per month.** This will mean that the same prescribing model is in place across the south of the county, including the city. It is the closest model to the national guidance and provides savings for the CCG while still enabling gluten free food to be available on prescription.
- **All Greater Nottingham CCGs to stop all gluten free prescribing, with the exception of children, who will be able to receive up to four units of long life bread and flour per month.** This provides a more significant saving for the CCGs while still allowing gluten free prescribing for children.
- **All Greater Nottingham CCGs to stop all gluten free prescribing.** This means the

same restrictions will be in place across Nottinghamshire (except Bassetlaw). It provides the greatest financial saving for the CCGs.

## How are we engaging on these options?

We'd like to hear the views of people living with coeliac disease and dermatitis herpetiformis and also those of the wider public. This is because the decisions we must make about how best to spend budgets will have implications for all Greater Nottingham residents.

We are inviting local patients, partners, organisations and local clinicians to tell us their views on the options by completing the questionnaire in this document or online. We will be promoting the consultation via social media, media and via community groups. We have provided GP Practices and other local organisations with surveys and consultation information.

We will also be at events over the next six weeks and available to talk to people. You can find out more about these events at:

[www.nottinghamnortheastccg.nhs.uk/nhs/gluten](http://www.nottinghamnortheastccg.nhs.uk/nhs/gluten)

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“ Gluten is not essential to people's diets and many basic foods such as vegetables, potatoes, meat and rice are naturally free from gluten. Many gluten free alternatives are also now widely available to buy in supermarkets and health food shops.

“ Given the ever-growing pressures on NHS services and budget, we must ensure we get the best value for taxpayers' money. We do understand the proposals to limit, or withdraw, gluten free foods on prescription may have an impact on some patients with coeliac disease. That's why we are keen to hear as many views as possible to help inform our decision. ”

If you would like to complete this survey online, go to:  
[www.surveymonkey.com/r/GN-gluten-free](http://www.surveymonkey.com/r/GN-gluten-free)

We can provide this document in other languages and formats, such as Braille and large print, on request. Please ask someone who speaks English to ring 0115 912 3384.

1. **This survey is anonymous. Please provide the first part and first number on the second part of your postcode (e.g. NG5 6)**

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2. **Do you think that gluten free products should be available on prescription?**

- Yes  No  Don't know

3. **Which of the following best describes the reason why you are completing this survey?**

- I am diagnosed with coeliac disease
- I am diagnosed with dermatitis herpetiformis
- I am the parent/guardian of a child with coeliac disease/dermatitis herpetiformis
- I am a carer of an adult with coeliac disease/dermatitis herpetiformis
- I am responding on behalf of someone who has coeliac disease/dermatitis herpetiformis
- I am a clinician with an interest in this area for example a GP/nurse or consultant
- I am responding on behalf of a group or organisation (please state which group/organisation below)

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- I receive gluten free items on prescription but don't have one of the above diagnosis
- I am interested in how, and on what, the NHS spends its budget
- Other reason (please state below)

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4. **Do you (or the person you care for) receive gluten free foods on NHS prescription?**

- Yes
- No but I am diagnosed with coeliac disease/dermatitis herpetiformis (go to question 9)
- No I don't have coeliac disease/dermatitis herpetiformis (go to question 10)

5. **Has your gluten free prescription been reduced following previous consultations?**

- Yes (Please go to question 6)  Not applicable
- No (Please go to question 7)

**6. What impact has this reduction in units had on your diet (if any)?**

- No impact/change
- Impacted on my diet because:
  - Increase in food bill/unable to manage my diet as well
  - Inconvenience as previously delivered via pharmacy and now I have to go and purchase
- Other (please state below).

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**7. Which gluten free products do you receive on prescription?**

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**8. If you, or the person you care for, receive gluten free food on prescription, please tell us why below (tick all that apply).**

- I have coeliac disease/dermatitis herpetiformis and believe the NHS should provide gluten free food for me because of my condition
- I am eligible for free prescriptions
- I receive benefits that enable me to receive free prescriptions
- Gluten free food is too expensive on the high street/in supermarkets
- The choice of shops that sell gluten free food is limited where I live
- It helps ensure that I have regular GP check-ups
- Not applicable
- Other (please specify below)

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**9. If you, or the person you care for, have coeliac disease or dermatitis herpetiformis but don't receive gluten free foods on prescription, please tell us why not below (tick all that apply)**

- I don't like the food available on prescription
- I don't agree with food being available on prescription
- I prefer to shop for my own gluten free food
- Not applicable
- Other (please specify below)

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**10. Please select which proposal you agree with for the future prescribing of gluten free foods**

- Limit prescribing for all patients in Greater Nottingham to 4 units of long life bread and flour per month (aligning with the South Nottinghamshire CCGs)
- All Greater Nottingham CCGs to stop all gluten free prescribing, with the exception of children, who will be able to receive up to 4 units of long life bread and flour per month
- All Greater Nottingham CCGs to stop all gluten free prescribing
- Other (please state below)

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**11. Would you like to make any further comments in relation to the prescribing of gluten free foods?**

- No
- Yes (please provide comments below)

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**Please tell us about you...**

We are committed to commissioning local health services that are available to all, regardless of age, disability, gender reassignment, marriage or civil partnership, pregnancy and maternity, race, religion or belief, sex or sexual orientation. We also aim to promote equality through the services we commission, paying particular attention to groups or sections of Greater Nottingham’s population where improvements in health and life expectancy are not keeping pace with the rest of the population. To do this and to help ensure that everyone has equal access to local health services, we need to collect information about people who use or may use those services. This is why we are asking you the questions below.

**Answering the questions is voluntary. Any information you do provide will be held in confidence and will not be used to identify you.**

**What is your Gender?** Male  Female  Do not wish to disclose

**Is your gender the same as the gender you were originally assigned at birth?**

Yes  No  Prefer not to say

**What is your Ethnic Origin?**

White: British  Irish  Any other White background (including Traveller)

Please specify \_\_\_\_\_

Mixed: White & Black Caribbean  White & Black African  White & Asian

Other Mixed

Please specify \_\_\_\_\_

Asian/Asian British: Indian  Pakistani  Bangladeshi

Other Asian

Please specify \_\_\_\_\_

Black or Black British: Africa  Caribbean  Other Black

Please specify \_\_\_\_\_

Other ethnic group: Chinese  Other ethnic group

Please specify \_\_\_\_\_

**What is your Age?** 0 – 17  18 -30  31 -65  65 and over

**Disability: Do you consider yourself to have a disability or long term condition?**

Yes  No  Prefer not to say

If yes, please specify \_\_\_\_\_

**What is your sexual orientation?**

Heterosexual  Gay  Lesbian

Bisexual  Prefer not to say

**What is your Religion or Belief?**

No religion  Bahai  Christian

Jainism  Jewish  Hindu

Muslim  Sikh  Prefer not to say

Other (please state) \_\_\_\_\_

**What is your Marital/Civil Partnership Status?**

Single  Married  Civil Partnership

Divorced  Separated  Widowed

Prefer not to say

**Pregnancy and Maternity**

Are you currently pregnant?

Yes  No  Prefer not to say

**This consultation will run from Thursday 14 June to Thursday 26 July 2018. Please return your application freepost (no stamp required) to:**

**Freepost RTHU-JLJL-LGLT,  
Patient Experience Team,  
Civic Centre, Arnot Hill Park,  
Arnold, NOTTINGHAM  
NG5 6LU**