

# Proposal to prescribe gluten-free staple foods to children and adolescents under the age of 18



# Background

In the past year (June 2018 to July 2019), Cannock Chase, East Staffordshire, South East Staffordshire and Seisdon Peninsula and Stafford and Surrounds Clinical Commissioning Groups (CCGs) prescribed 16,023 prescriptions for gluten-free foods at a cost of more than a quarter of a million pounds.

The prescription of gluten-free (GF) products is not a cure for coeliac disease, nor does it treat the symptoms. Medical advice given to patients who are gluten intolerant would be to avoid food products containing gluten.

The current prescribing guidelines with south Staffordshire supports the standardisation of prescribing of gluten-free foods in primary care and applies to people with coeliac disease requiring only gluten-free foods.

As the CCGs look to control finances and make the best use of NHS resources, difficult decisions have to be made. We are seeking views about proposals to remove GF products for adults from our prescribing policy, which could potentially lead to a reduction in patients receiving gluten-free products on prescription by around 85 per cent.

The proposed policy advises GPs to prescribe gluten-free staple foods to children and adolescents under the age of 18 diagnosed with coeliac disease, other gluten-related enteropathy or dermatitis herpetiformis. The range of foods available on prescription will be restricted to bread and mixes.

A five-week public engagement period will begin on **Monday 6 January 2020** and will close at midnight on **Sunday 9 February 2020**. Findings will then be analysed before being presented to the CCGs' Governing Bodies later in the year.

If responding on behalf of an organisation, please provide one response.

CCG	Cost of GF food prescriptions (£)	Total number of prescriptions
Cannock Chase CCG	£59,214	3,132
East Staffordshire CCG	£58,421	3,434
South East Staffordshire and Seisdon Peninsula CCG	£102,885	5,658
Stafford and Surrounds CCG	£63,844	3,799
<b>Grand Total</b>	<b>£284,364</b>	<b>16,023</b>

# Why we are looking to change

In November 2018, NHS England published guidance and the Government restricted prescriptions to gluten-free foods to bread and mixes. [www.england.nhs.uk/publication/prescribing-gluten-free-foods-in-primary-care-guidance-for-ccgs](http://www.england.nhs.uk/publication/prescribing-gluten-free-foods-in-primary-care-guidance-for-ccgs)

Arrangements for provision of GF foods on the NHS were made when availability was very limited. However, with the increased awareness of coeliac disease and gluten sensitivity, as well as a general trend towards eating less gluten, GF foods are now much easier and accessible to purchase. A wide and expanding range of high-quality GF foods are now available from supermarkets, convenience stores and online.

It is acknowledged that in some supermarkets, the GF food range can be more expensive than the gluten-containing equivalents. However, the price paid by the NHS is much higher than the prices of similar products found in supermarkets. In some cases, the NHS has to pay four times more than a customer would to purchase an equivalent GF product.

The prescription of GF products is not a cure for coeliac disease, nor does it treat the symptoms. Medical advice given to patients who are gluten intolerant would be to avoid food products containing gluten. People who have gluten sensitivity can use other foods that do not contain gluten and yet are a good source of carbohydrate foods such as rice, potatoes, fruits and vegetables are healthy and naturally gluten-free options.

More than a quarter of all CCGs are now restricting or withdrawing GF products on prescription. In the longer term, withdrawal by CCGs will stimulate the market and create more patient choice as the manufacturers will seek to make their products available on the open market.

North Staffordshire CCG and Stoke-on-Trent CCG have already restricted GF food prescribing to children and adolescents under the age of 18 diagnosed with coeliac disease, other gluten-related enteropathy or dermatitis herpetiformis. The range of foods available on prescription will be restricted to bread and mixes.

It may be considered inequitable that one section of the community is able to access significant amounts of food on the NHS but other members of the public who also have other special dietary requirements do not benefit from the same level of access.

Please refer to National Institute for Health and Care Excellence (NICE) NG20 on coeliac disease for further information or Coeliac UK [www.coeliac.org.uk](http://www.coeliac.org.uk)

# Gluten Free Survey

**For your feedback to be included you must tick to confirm you have read and agree with the following data protection act statement.**

Between June 2018 and July 2019, Cannock Chase, East Staffordshire, South East Staffordshire & Seisdon Peninsula and Stafford & Surrounds Clinical Commissioning Groups (CCGs) prescribed 16,023 prescriptions for gluten-free foods at a cost of more than a quarter of a million pounds.

As the CCGs look to control finances and make the best use of NHS resources, difficult decisions have to be made. As a result, we are seeking your views about proposals to remove gluten-free products for adults from our prescribing policy, which could potentially lead to a reduction in patients receiving gluten-free products on prescription by around 85 per cent.

The proposed policy advises GPs to prescribe gluten-free staple foods to children and adolescents under the age of 18 diagnosed with coeliac disease, other gluten-related enteropathy or dermatitis herpetiformis. The range of foods available on prescription will be restricted to bread and mixes.

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## Data Protection statement

NHS Midlands and Lancashire Commissioning Support Unit (MLCSU) have been commissioned to collect, handle, process and report on the responses gathered in the engagement. MLCSU uses a survey tool called Snap which is owned by Snap Surveys Ltd, a private company who specialise in surveys.

Any information you provide will be inputted into Snap for analysis and handled in accordance with UK data protection legislation.

The survey asks respondents to provide their demographic profiling data (age, gender, ethnicity etc.). This information is used to understand the representativeness of survey respondents compared to the local population. The raw data will be available in its entirety to MLCSU and to the NHS organisations listed above. You do not have to provide this information to take part in the survey.

Any reports published using the data collected will not contain any personally identifiable information and only show anonymous, aggregated feedback. Reports could also be placed within the public domain for example on NHS public facing websites or printed and distributed.

Your involvement is voluntary, and you are free to exit the survey at any time. You can also refuse to answer questions in the survey, should you wish. All information collected via the survey will be held for a period of five years from the date of survey closure, in line with the NHS records management retention schedule.

Any queries about your involvement with this survey can be emailed to:

**[mlcsu.researchservices@nhs.net](mailto:mlcsu.researchservices@nhs.net)**

or call **0333 150 2155**.

- Please tick here to confirm you have read and accept the terms outlined within the data protection statement on the previous page.

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## Section A: Your experience of Gluten-Free Prescribing

### Q1. Which of the following applies to you?

- I have been diagnosed by my doctor as having coeliac disease
- I am the parent/guardian of a child with coeliac disease
- I am the carer of an adult with coeliac disease
- I am responding on behalf of someone who has coeliac disease
- I am a clinician, e.g. GP, nurse, consultant etc. (please state which below)
- I am responding on behalf of a group or organisation (please state which below)
- I do not have coeliac disease
- Other (please state below)

### Q2. Do you, or the person you care for, receive gluten-free foods on prescription?

- Yes                                       No                                       Prefer not to say

### Q3. Do you agree to change the policy to be in line with North Staffordshire and Stoke-on-Trent CCGs, to only prescribe gluten-free bread and mixes for children and adolescents under the age of 18 diagnosed with coeliac disease, other gluten-related enteropathy or dermatitis herpetiformis?

- Yes (Go to Q5)                                       No (Go to Q4)

### Q4. Why do you feel this way?

## Section B: About you

We would like to know a little more about you. The following questions will help us understand more about who has responded to this survey. This will help us to ensure we have listened to as many different people as possible. You can leave this section blank if you wish.

### Q5. Which town is your GP surgery located?

- |  |   |   |
|--|---|---|
| <input type="checkbox"/> Abbots Bromley        | <input type="checkbox"/> Essington      | <input type="checkbox"/> Rugeley                      |
| <input type="checkbox"/> Alrewas               | <input type="checkbox"/> Featherstone   | <input type="checkbox"/> Stafford                     |
| <input type="checkbox"/> Barton Under Needwood | <input type="checkbox"/> Glasgote Heath | <input type="checkbox"/> Stapenhill                   |
| <input type="checkbox"/> Bilbrook              | <input type="checkbox"/> Great Haywood  | <input type="checkbox"/> Stone                        |
| <input type="checkbox"/> Branston              | <input type="checkbox"/> Great Wyrley   | <input type="checkbox"/> Tamworth                     |
| <input type="checkbox"/> Burntwood             | <input type="checkbox"/> Hednesford     | <input type="checkbox"/> Tutbury                      |
| <input type="checkbox"/> Burton-upon-Trent     | <input type="checkbox"/> Kinver         | <input type="checkbox"/> Uttoxeter                    |
| <input type="checkbox"/> Calverley             | <input type="checkbox"/> Lichfield      | <input type="checkbox"/> Winshill                     |
| <input type="checkbox"/> Cannock               | <input type="checkbox"/> Norton Canes   | <input type="checkbox"/> Wombourne                    |
| <input type="checkbox"/> Cheslyn Hey           | <input type="checkbox"/> Penkridge      | <input type="checkbox"/> Yoxall                       |
| <input type="checkbox"/> Codsall               | <input type="checkbox"/> Perton         | <input type="checkbox"/> Other (please specify below) |
| <input type="checkbox"/> Eccleshall            | <input type="checkbox"/> Rocester       |   |

### Q6. What is your ethnic group? (Choose one option that best describes your ethnic group or background)

- |  |   |
|--|---|
| <input type="checkbox"/> White: English/Welsh/Scottish/Northern Irish/<br>British  | <input type="checkbox"/> Asian/Asian British: Indian  |
| <input type="checkbox"/> White: Irish  | <input type="checkbox"/> Asian/Asian British: Pakistani   |
| <input type="checkbox"/> White: Gypsy or Irish Traveller   | <input type="checkbox"/> Asian/Asian British: Bangladeshi   |
| <input type="checkbox"/> White: Any other White background<br>(please specify below)   | <input type="checkbox"/> Asian/Asian British: Chinese   |
| <input type="checkbox"/> Mixed/Multiple ethnic groups:<br>White and Black Caribbean  | <input type="checkbox"/> Asian/Asian British: Any other Asian<br>background (please specify below)  |
| <input type="checkbox"/> Mixed/Multiple ethnic groups:<br>White and Black African  | <input type="checkbox"/> Black/African/Caribbean/Black British: African   |
| <input type="checkbox"/> Mixed/Multiple ethnic groups:<br>White and Asian  | <input type="checkbox"/> Black/African/Caribbean/Black British:<br>Caribbean  |
| <input type="checkbox"/> Mixed/Multiple ethnic groups:<br>Any other Mixed/Multiple ethnic background<br>(please specify below) | <input type="checkbox"/> Black/African/Caribbean/Black British:<br>Any other Black/African/Caribbean<br>background (please specify below) |
|  | <input type="checkbox"/> Other ethnic group: Arab   |
|  | <input type="checkbox"/> Any other ethnic group (please specify below)  |

**Q7. What is your age category?**

- |                                  |                                  |  |
|----------------------------------|----------------------------------|--|
| <input type="checkbox"/> 16 - 19 | <input type="checkbox"/> 40 - 44 | <input type="checkbox"/> 65 - 69           |
| <input type="checkbox"/> 20 - 24 | <input type="checkbox"/> 45 - 49 | <input type="checkbox"/> 70 - 74           |
| <input type="checkbox"/> 25 - 29 | <input type="checkbox"/> 50 - 54 | <input type="checkbox"/> 75 - 79           |
| <input type="checkbox"/> 30 - 34 | <input type="checkbox"/> 55 - 59 | <input type="checkbox"/> 80 and over       |
| <input type="checkbox"/> 35 - 39 | <input type="checkbox"/> 60 - 64 | <input type="checkbox"/> Prefer not to say |

**Q8. What is your religion?**

- |  |  |
|--|--|
| <input type="checkbox"/> No religion   | <input type="checkbox"/> Jewish                                    |
| <input type="checkbox"/> Christian (including Church of England, Catholic, Protestant and all other Christian denominations) | <input type="checkbox"/> Muslim                                    |
| <input type="checkbox"/> Buddhist  | <input type="checkbox"/> Sikh                                      |
| <input type="checkbox"/> Hindu   | <input type="checkbox"/> Any other religion (please specify below) |
|  | <input type="checkbox"/> Prefer not to say                         |

**Q9. What is your sex?**

- |                                   |   |
|-----------------------------------|---|
| <input type="checkbox"/> Male     | <input type="checkbox"/> Prefer not to say            |
| <input type="checkbox"/> Female   | <input type="checkbox"/> Other (please specify below) |
| <input type="checkbox"/> Intersex |   |

**Q10. What is your gender identity?**

Gender Reassignment: Have you gone through any part of a process or do you intend to (including thoughts and actions) to bring your physical sex appearance and/or your gender role more in line with your gender identity? (This could include changing your name, your appearance and the way you dress, taking hormones or having gender confirming surgery).

- |                              |                             |  |
|------------------------------|-----------------------------|--|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Prefer not to say |
|------------------------------|-----------------------------|--|

**Q11. How do you identify yourself? (e.g. non-binary, gender fluid, etc.?)**

**Q12. What is your sexual orientation?**

- Heterosexual (people of the opposite sex)
- Lesbian (both female)
- Gay (both male)
- Bisexual (people of either sex)
- Other (please specify below)
- Prefer not to say

**Q13. What is your relationship status?**

- Married
- Civil partnership
- Single
- Divorced
- Lives with partner
- Separated
- Widowed
- Other (please specify below)
- Prefer not to say

**The Equality Act 2010 protects women who are pregnant or have given birth within a 26 week period.**

**Q14. Are you pregnant at this time?**

- Yes
- No
- Prefer not to say

**Q15. Have you recently given birth? (within the last 26 week period)**

- Yes
- No
- Prefer not to say

**Q16. Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months?**

- Yes, limited a lot
- Yes, limited a little
- No
- Prefer not to say

**Q17. Do you consider yourself to have a disability?** (The Equality Act 2010 states a person has a disability if they have a physical or mental impairment which has a long-term (12 month period or longer) or substantial adverse effects on their ability to carry out day-to-day activities).

- Physical disability (Go to Q17a)
- Sensory disability e.g. deaf, hard of hearing, blind, visually impaired (Go to Q17b)
- Mental health need (Go to Q18)
- Learning disability or difficulty (Go to Q18)
- Long-term illness (Go to Q17c)
- Other (please describe below) (Go to Q17d)
- Prefer not to say (Go to Q18)

**Q17a. Please describe your physical disability**

**Q17b. Please describe your sensory disability**

**Q17c. Please describe your long-term illness**

**Q17d. Please describe your other disabilities/illnesses**

**Q18. Do you care for someone? (Tick as many as appropriate)**

- Yes - Care for young person(s) aged under 24 years       No  
 Yes - Care for adult(s) aged 25 to 49 years       Prefer not to say  
 Yes - Care for older person(s) aged over 50 years

**Q19. Have you ever served in the armed services?**

- Yes       No       Prefer not to say

**Thank you for taking the time to complete this survey.**

**Please post your completed response to:**

**Claire Dearden  
Medicines Optimisation Delivery Manager  
Stafford and Surrounds Clinical Commissioning Group,  
Number 2, Staffordshire Place,  
Stafford  
ST16 2LP**