

Public consultation on the proposal to stop providing NHS prescriptions for gluten-free products

The local NHS is proposing a change to the availability of gluten-free products on prescription.

Currently, we provide our patients, including those diagnosed with coeliac disease and dermatitis herpetiformis, with up to eight units of gluten-free bread or flour on prescription. This is taken up by approximately 1,300 people across Leicester, Leicestershire and Rutland.

For the reasons outlined below, we propose to stop providing gluten-free products on prescription for all adults and children. Before we make a final decision, we wish to understand what this means for people and their families.

Read on for further information about the proposals and to provide your feedback.

About coeliac disease and dermatitis herpetiformis

Gluten-free foods are sometimes prescribed to individuals who suffer from coeliac disease and/or dermatitis herpetiformis.

Coeliac disease is a long-term autoimmune condition, where the immune system mistakenly attacks healthy tissue. The immune system mistakes substances found inside gluten as a threat to the body and attacks them, which damages the surface of the small bowel, disrupting the body's ability to absorb nutrients from food. Symptoms can range from mild to severe and can include bloating, diarrhoea, nausea, weight loss, headaches, osteoporosis, tiredness, hair loss and anaemia. These symptoms do not occur in all cases. It can also cause more general symptoms which impact on health, for example tiredness and unintentional weight loss.

Dermatitis herpetiformis is a skin condition associated with coeliac disease and gluten intolerance, which occurs as an itchy skin rash that commonly appears on the elbows, knees and buttocks. This affects around one in 3,300 people.

Coeliac disease and dermatitis herpetiformis are usually treated by excluding foods that contain gluten. All sources of gluten must be given up for life from a coeliac's diet to prevent long-term damage to their health.

Why we are proposing this change

Accessibility of gluten-free foods

Historically, the availability of gluten-free foods was limited; therefore, the foods were made available from local pharmacies via prescriptions. However, with an increased awareness of coeliac disease and gluten intolerance, as well as a general trend towards eating less gluten, these foods have become more accessible in some supermarkets and online.

Food labelling

Better labelling on foods means that people are better able to see whether ordinary foods are free from gluten.

Affordability of gluten-free foods

We do appreciate that gluten-free food is still more expensive than equivalent products containing gluten. However, the price paid by the NHS for gluten-free foods on prescription is still much higher than the supermarket or online prices.

Eat well

It is possible to eat a gluten-free diet that follows the Eat Well Guide (<https://www.nhs.uk/live-well/eat-well/food-guidelines-and-food-labels/the-eatwell-guide/>) for balanced eating without the need for any specialist dietary foods. People can choose naturally gluten-free carbohydrate-containing food, such as rice and potatoes, as part of a healthy balanced diet.

Considering the options

When the NHS develops plans to change services, it appraises different options for change. This allows a few alternatives to be evaluated prior to putting together a proposal. It looks at how strong and weak each option is including accessibility and affordability. More information about the options the ICB considered and this project can be found by visiting www.bit.ly/llrgfsurvey.

The local NHS proposal for gluten-free products

We are proposing to stop providing NHS prescriptions for gluten-free products for all adults and children.

The Leicester, Leicestershire and Rutland Integrated Care Board (ICB), the organisation that plans and pays for local services and medications, wants to find out how it can support those who have a diagnosis of coeliac disease and/or dermatitis herpetiformis.

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Please complete the questionnaire to tell us how you may be affected by this proposal or to share your thoughts on the topic. The consultation closes on **Sunday 25 August 2024 at 11.59pm.**

The questionnaire takes 5 to 10 minutes to complete. Please do not share any personal information in your response (information that could be used to identify you, such as your name).

If you would prefer to complete this questionnaire online, please visit:
www.bit.ly/llrgfsurvey
or scan the QR code.

Alternative formats

If you would like some help to complete a questionnaire or to request an alternative format, please contact us:



llricb-llr.beinvolved@nhs.net



0116 295 7532



Freepost Plus RUEE-ZAUY-BXEG
LLR Gluten-Free Consultation
NHS LLR ICB
Room G30, Pen Lloyd Building
County Hall, Leicester Road
Glenfield, Leicester LE3 8TB

अगर आपको इस दस्तावेज़ में शामिल जानकारी समझने में सहायता चाहिए तो कृपया 0116 295 2110 पर फ़ोन कीजिए।

ਜੇਕਰ ਤੁਹਾਨੂੰ ਇਸ ਦਸਤਾਵੇਜ਼ ਦਾ ਵਿਸ਼ਾ ਵਸਤੂ ਸਮਝਣ ਲਈ ਮਦਦ ਦੀ ਲੋੜ ਹੈ ਤਾਂ ਕ੍ਰਿਪਾ ਕਰਕੇ ਇਸ ਨੰਬਰ ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ 0116 295 2110.

ਜੇ તમને આ દસ્તાવેજમાં આપેલ માહિતી સમજવા માટે મદદ જોઈતી હોય તો મહેરબાની કરીને 0116 295 2110 પર ફોન કરો.

এই ডকুমেন্ট'এর কোন বিষয় বুঝতে আপনার যদি সাহায্যের প্রয়োজন হয়, তাহলে অনুগ্রহ করে 0116 295 2110 নাম্বারে টেলিফোন করুন।

Hadii aad u baahantahay in lagaa caawiyo fahmida qoraalka ku qoran documintigaan fadlan nagala soo xiriir telefoonkaan 0116 295 2110.

Jeśli potrzebujesz pomocy w zrozumieniu treści tego dokumentu prosimy o telefon pod numer 0116 295 2110.

"اگر آپ کو اس دستاویز کے مضمولات کو سمجھنے میں مدد کی ضرورت ہو تو براہ کرم ہمیں 0116 295 2110 پر فون کریں۔"

Caso pretenda ajuda para compreender o conteúdo deste documento, por favor ligue para o 0116 295 2110.

如果您在理解本档的内容时需要任何帮助，请致电 0116 295 2110.

Jeï norétuméte, kad kas nors padėtų suprasti šį dokumentą, skambinkite tel. 0116 295 2110.

Ja jums nepieciešama palīdzība, lai saprastu šī dokumenta saturu, lūdzam zvanīt uz 0116 295 2110.

Data Protection Statement

The NHS Leicester, Leicestershire and Rutland Integrated Care Board (ICB) would like to understand your views on a proposal to stop providing gluten-free bread and flour on prescription.

Any information you provide will be handled in accordance with GDPR and the Data Protection Act 2018.

The questionnaire also asks respondents to provide their full postcode and demographic profiling data (age, gender, ethnicity, etc.). This information is used to ensure the responses are representative of the demographics of the local population. You do not have to provide this information to take part in the questionnaire, but it really helps the ICB to ensure that any decisions made meet the needs of a diverse community.

No person identifiable data collected will be shared with any organisations outside of the ICB. Any reports published using the insights from the questionnaire will not contain any personal identifiable information and only show feedback in an anonymous format. These anonymised results may be shared publicly, for example on NHS public facing websites or printed and distributed.

Your involvement is voluntary and you are free to stop completing the questionnaire at any time. Only submitted responses will be included in the analysis. You can also refuse to answer questions in this questionnaire, should you wish. All information collected via the questionnaire will be held for a period of five years from the date of questionnaire closure, in line with the Records Management Code of Practice for Health and Social Care 2020, which all NHS organisations work under.

Survey questions

Q1	Please tick to confirm you have read and agree with the data protection act statement on the previous page. (Please note that we cannot use any surveys that don't have this box ticked)	
Q2	How did you hear about this consultation? Please tick all the boxes that apply.	
	Text/letter/app notification from my GP practice	
	Coeliac UK charity	
	Social media (e.g. Facebook)	
	Email	
	Staff communication	
	Radio	
	Newspaper	
	Poster	
	Friend or family member	
	Other, please tell us: _____	

Q3	In what capacity are you completing this questionnaire? Please tick one box only.
	<i>This questionnaire is for individual responses. If you would like to submit a formal response on behalf of your organisation, please email llricb-llr.beinvolved@nhs.net</i>
	As a member of the public <i>(move onto Q5)</i>
	As a pharmacist
	As a GP
	As a dietician
	As somebody who works in healthcare (but not as a pharmacist, GP or dietician)
	As somebody who works for another public sector organisation (e.g. local authority)
	As a member of a patient representative organisation
As a member of a voluntary, community or social enterprise organisation	

Q4	If you are completing this questionnaire as somebody who works/volunteers for an organisation, please tell us the name of the organisation <i>(then move onto Q6)</i>.

Q5	If you are completing this questionnaire as a member of the public, which GP practice are you registered with?

Q6	Which of the following best describes you? Please tick one box only.
	I have coeliac disease and/or dermatitis herpetiformis
	I am the parent/guardian/carer of a child with coeliac disease and/or dermatitis herpetiformis
	I am the carer of an adult with coeliac disease and/or dermatitis herpetiformis
	I do not have (nor care for someone who has) coeliac disease and/or dermatitis herpetiformis <i>(move onto Q9)</i>
I don't know/have not been diagnosed <i>(move onto Q9)</i>	

Q7	When were you (or the person you care for) diagnosed with coeliac disease and/or dermatitis herpetiformis? Please tick one box only.
	In the last 3 months
	3 to 6 months ago
	6 to 12 months ago
	Over 12 months ago
	I haven't received a diagnosis
Other, please tell us: _____	

Q8	Are you (or the person you care for) currently in receipt of gluten-free products on NHS prescription? Please tick one box only.	
	Yes – bread only	<input type="checkbox"/>
	Yes - flour only	<input type="checkbox"/>
	Yes – both bread and flour	<input type="checkbox"/>
	No	<input type="checkbox"/>

Q9	To what extent do you agree or disagree with the proposal to stop providing up to eight units of gluten-free bread or flour on prescription to people diagnosed with coeliac disease and/or dermatitis herpetiformis? Please tick one box only.	
	Strongly agree	<input type="checkbox"/>
	Agree	<input type="checkbox"/>
	Neither agree nor disagree	<input type="checkbox"/>
	Disagree	<input type="checkbox"/>
	Strongly disagree	<input type="checkbox"/>

Q10	Please tell us why you chose that answer.	

Q11	How does the proposal impact you, your family, or any groups? If you have concerns, please include how they could be overcome.	

Q12	<p>From the below list, what are the top 3 most important things the local NHS can do to help those who suffer from coeliac disease and/or dermatitis herpetiformis? Please tick three boxes only.</p> <table border="1"> <tr> <td data-bbox="220 241 1402 297">More training for doctors/nurses/specialists</td> <td data-bbox="1402 241 1477 297"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="220 297 1402 353">Dietary advice and support</td> <td data-bbox="1402 297 1477 353"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="220 353 1402 409">More information for patients about coeliac disease and dermatitis herpetiformis</td> <td data-bbox="1402 353 1477 409"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="220 409 1402 465">Raise awareness of coeliac disease and dermatitis herpetiformis</td> <td data-bbox="1402 409 1477 465"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="220 465 1402 555">Support for newly diagnosed patients <i>(please tell us what support would be helpful using the box below)</i></td> <td data-bbox="1402 465 1477 555"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="220 555 1402 611">Ease of getting a diagnosis</td> <td data-bbox="1402 555 1477 611"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="220 611 1402 667">More research</td> <td data-bbox="1402 611 1477 667"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="220 667 1402 723">Regular follow-ups (e.g. annual review or check-up appointment)</td> <td data-bbox="1402 667 1477 723"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="220 723 1402 779">I don't know</td> <td data-bbox="1402 723 1477 779"><input type="checkbox"/></td> </tr> <tr> <td data-bbox="220 779 1402 857">Other <i>(please tell us using the box below)</i></td> <td data-bbox="1402 779 1477 857"><input type="checkbox"/></td> </tr> <tr> <td colspan="2" data-bbox="220 857 1477 1081"> <div style="border: 1px solid black; height: 40px; width: 100%;"></div> </td> </tr> </table>	More training for doctors/nurses/specialists	<input type="checkbox"/>	Dietary advice and support	<input type="checkbox"/>	More information for patients about coeliac disease and dermatitis herpetiformis	<input type="checkbox"/>	Raise awareness of coeliac disease and dermatitis herpetiformis	<input type="checkbox"/>	Support for newly diagnosed patients <i>(please tell us what support would be helpful using the box below)</i>	<input type="checkbox"/>	Ease of getting a diagnosis	<input type="checkbox"/>	More research	<input type="checkbox"/>	Regular follow-ups (e.g. annual review or check-up appointment)	<input type="checkbox"/>	I don't know	<input type="checkbox"/>	Other <i>(please tell us using the box below)</i>	<input type="checkbox"/>	<div style="border: 1px solid black; height: 40px; width: 100%;"></div>	
More training for doctors/nurses/specialists	<input type="checkbox"/>																						
Dietary advice and support	<input type="checkbox"/>																						
More information for patients about coeliac disease and dermatitis herpetiformis	<input type="checkbox"/>																						
Raise awareness of coeliac disease and dermatitis herpetiformis	<input type="checkbox"/>																						
Support for newly diagnosed patients <i>(please tell us what support would be helpful using the box below)</i>	<input type="checkbox"/>																						
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More research	<input type="checkbox"/>																						
Regular follow-ups (e.g. annual review or check-up appointment)	<input type="checkbox"/>																						
I don't know	<input type="checkbox"/>																						
Other <i>(please tell us using the box below)</i>	<input type="checkbox"/>																						
<div style="border: 1px solid black; height: 40px; width: 100%;"></div>																							

Q13	<p>Please use the space below to share any other comments on the proposal to stop providing gluten-free products (bread and flour) on prescription or suggest any alternative proposals that you think we should consider.</p> <div style="border: 1px solid black; height: 400px; width: 100%;"></div>
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Equality monitoring questions

Please complete as many of the following questions as you feel comfortable with, as this will help us understand who is taking part in the consultation. The information you provide will be kept in accordance with the terms of the Data Protection Acts 1998 and 2000 and will be used for monitoring purposes and questionnaire analysis.

Your answers help us to ensure that everyone receiving services has the opportunity to get involved in shaping their care. They also help us make services better. For example, if we find that a certain group of people have had a worse experience, we can work with them to make improvements.

These questions are optional, but the information provided will be anonymous and play an important role in improving care.

If you are completing this survey on behalf of someone else, please complete the equality monitoring form about them.

Q14	What is your sex? Please tick one box only.	
	Male	<input type="checkbox"/>
	Female	<input type="checkbox"/>
	Intersex	<input type="checkbox"/>
	Prefer not to say	<input type="checkbox"/>
Q15	Do you identify as the gender you were assigned at birth? Please tick one box only.	
	Yes	<input type="checkbox"/>
	No, please tell us your gender identity: _____	<input type="checkbox"/>
	Prefer not to say	<input type="checkbox"/>
Q16	What is your age? Please tick one box only.	
	16 – 19 years	<input type="checkbox"/>
	20 – 24 years	<input type="checkbox"/>
	25 – 34 years	<input type="checkbox"/>
	35 – 49 years	<input type="checkbox"/>
	50 – 64 years	<input type="checkbox"/>
	65 – 74 years	<input type="checkbox"/>
	75 – 84 years	<input type="checkbox"/>
	85+ years	<input type="checkbox"/>
	Prefer not to say	<input type="checkbox"/>
Q17	What is your religion or belief? Please tick one box only.	
	No religion	<input type="checkbox"/>
	Bahá'í	<input type="checkbox"/>
	Buddhist	<input type="checkbox"/>
	Christian	<input type="checkbox"/>
	Hindu	<input type="checkbox"/>

Q17 cont..	Jain	
	Jewish	
	Muslim	
	Sikh	
	Prefer not to say	
	Other, please tell us: _____	

Q18	What is your ethnicity? Please tick one box only.	
	Asian or Asian British:	
	Bangladeshi	
	Chinese	
	Indian	
	Pakistani	
	Any other Asian background, please tell us: _____	
	Black or Black British:	
	African background, please tell us: _____	
	Caribbean	
	Any other Black background, please tell us: _____	
	Mixed:	
	Asian and White	
	Black African and White	
	Black Caribbean and White	
	Any other Mixed or multiple background, please tell us: _____	
	White:	
	British, English, Northern Irish, Scottish, Welsh	
	Irish	
	Gypsy/Irish Traveller	
	Roma	
	Any other White background, please tell us: _____	
	Other:	
	Arab	
	Polish	
	Somali	
	Any other ethnicity, please tell us: _____	
Prefer not to say		

Q19	Are you pregnant or have you given birth in the last 26 weeks? Please tick one box only. <i>The Equality Act 2010 protects women who are pregnant or have given birth within a 26-week period.</i>	
	Yes	
	No	
	Prefer not to say	

Q20	Do you consider yourself to have a disability or suffer from poor health? Please tick all boxes that apply. <i>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.</i>	
	Yes, I have a disability	
	Yes, I am in poor health	
	No <i>(go to Q22)</i>	
	Prefer not to say <i>(go to Q22)</i>	

Q21	If you selected 'yes', which condition(s) do you have? Please tick all the boxes that apply.	
	Physical	
	Partial or total loss of vision	
	Learning disability/difficulty	
	Partial or total loss of hearing	
	Mental health condition	
	Speech impediment or impairment	
	Long standing illness or condition	
	Other medical condition or impairment, please tell us: _____	
	Prefer not to say	

Q22	Do you provide care for someone? Please tick all the boxes that apply.	
	Yes - Care for young persons(s) aged 24 years or younger	
	Yes - Care for adults(s) aged 25 to 49 years	
	Yes – Care for older person(s) aged 50 years or over	
	No	
	Prefer not to say	

Q23	What is your relationship status? Please tick one box only.	
	Single	<input type="checkbox"/>
	Married/civil partnership	<input type="checkbox"/>
	Separated or divorced	<input type="checkbox"/>
	Partnered/living with a partner	<input type="checkbox"/>
	Widowed/surviving civil partner	<input type="checkbox"/>
	Prefer not to say	<input type="checkbox"/>

Q24	What is your sexual orientation (preference)? Please tick one box only.	
	Bisexual (relationship with any gender/s)	<input type="checkbox"/>
	Gay or lesbian (same sex relationship)	<input type="checkbox"/>
	Heterosexual/straight (male to female relationship)	<input type="checkbox"/>
	Other, please tell us: _____	<input type="checkbox"/>
	Prefer not to say	<input type="checkbox"/>

Q25	Which of the following applies to you? Please tick all the boxes that apply.	
	I am serving personnel in the Armed Services	<input type="checkbox"/>
	I have previously served in the Armed Services	<input type="checkbox"/>
	I am a family member of someone serving in the Armed Services	<input type="checkbox"/>
	I am a reserve in the Armed Services	<input type="checkbox"/>
	I am a civilian or have another role in the Armed Services	<input type="checkbox"/>
	None of the above	<input type="checkbox"/>
	Prefer not to say	<input type="checkbox"/>

Q26	What is your full postcode?	
	<input type="text"/>	

Please ensure that you have ticked the consent box at the beginning of the survey.

(Please note that we cannot use any surveys that don't have this box ticked)

Thank you for your time in completing this questionnaire. Your feedback is valuable.

Please return this questionnaire to arrive by **Sunday 25 August 2024** to:

**Freepost Plus RUEE-ZAUY-BXEG
LLR GF Consultation
NHS LLR ICB
Room G30, Pen Lloyd Building
County Hall, Glenfield
Leicester LE3 8TB**

**To find out about other NHS surveys and involvement opportunities, please visit the Be Involved page on our website:
www.leicesterleicestershireandrutland.icb.nhs.uk/be-involved**

What happens next?

All the feedback we receive from the public consultation will be analysed and evaluated. A final report of the public consultation findings will be received by the Integrated Care Board in a public meeting and the feedback will be considered in any decisions they make.

We will promote the Board Meeting to enable people to attend and hear the discussions. All decisions will be made public after the Board Meeting. This work will include communicating the decision via local newspapers, social and broadcast media.

Follow our social channels:



@NHS Leicester, Leicestershire and Rutland



@NHS_LLRL

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