

Questions and answers – Gluten-Free Public Consultation

Q1. Why are you proposing to stop gluten-free prescribing

Answer

There are a range of reasons we are proposing to stop gluten-free prescribing which currently offers up to eight units of bread or flour on prescription to people diagnosed with coeliac disease and/or dermatitis herpetiformis.

Historically, the availability of gluten-free foods was limited; therefore, obtaining these products from community pharmacies via prescriptions improved access to them. With the increased awareness of coeliac disease and gluten sensitivity as well as a general trend towards eating less gluten, these products are now much more widely available than before.

Most major supermarkets and many other retailers now stock gluten-free foods as well as other special diet alternatives both online and in-store. Furthermore, improved food labelling now means people are better able to see whether ordinary food products are free from gluten.

The price paid by the NHS for gluten-free foods on prescription is much higher than the supermarket prices available to the public. It is complex to put together an average difference in cost between supermarkets and prescription costs, however some examples of the variations are shown in question 2.

Stopping prescribing gluten-free food would make savings in the region of £250,000 per year. This is based on the current rate of gluten-free prescribing.

More areas across the East Midlands are moving towards or have already removed gluten-free food provision from prescriptions. In addition, 40% of NHS Integrated Care Boards have stopped or restricted prescribing of gluten-free products on prescription.

Q2. What is the cost difference between NHS gluten-free foods on prescription versus supermarket costs?

Answer

It is complex to put together an average difference in cost between supermarkets and prescription costs, however, below are some examples of the variations:

Costs at end of June 2024

From Tesco - Warburtons white bread sliced (800g) = £1.40 (17.5p/100g)

From Tesco - Warburtons Gluten free white bread sliced (300g) = £2.20 (73p/100g)

Available on prescription - Warburtons Gluten free white bread sliced (400g) = £3.34 (83.5p /100g)

Costs at end of June 2024

From Tesco – Juvela gluten free fresh fibre loaf sliced (400g) = £2.95 (74p/100g)

Available on prescription - Juvela gluten free fresh fibre loaf sliced (400g) = £3.80

(95p/100g)

There are also hidden costs that the NHS has to pay, which supermarkets don't, such as costs associated with the time it takes a GP practice to generate a prescription and sign it. Also the cost of the pharmacy ordering the stock and processing the prescriptions and then the pharmacist checking it. All these activities are funded either directly or indirectly by the NHS.

Q3. How many people are prescribed bread and/or flour in prescription in Leicester, Leicestershire and Rutland.

Answer

Currently circa 1,300 people across Leicester, Leicestershire and Rutland diagnosed with coeliac disease and dermatitis herpetiformis receive up to eight units of gluten-free bread or flour on prescription. These figures are broken down below and show data at 26 June 2024.

Place	BNF Paragraph plus Code (from ePACT2 accessed 26/06/2024)	Financial Year (from ePACT2 accessed 26/06/2024)	Prescriber Level Identified Patient Count	Patient identified using Eclipse (accessed 28/06/2024) having read code J690. - Coeliac disease (no date specified for read code)
East Leicestershire and Rutland (includes Rutland Health PCN)	Food - Gluten free (091327)	2023/2024	472	1,947
Leicester City	Food - Gluten free (091327)	2023/2024	338	1,344
West Leicestershire	Food - Gluten free (091327)	2023/2024	2,191	2,191
RUTLAND HEALTH PCN	Food - Gluten free (091327)	2023/2024	49	220

Q4. What are you going to do with the savings made from stopping prescribing of gluten-free foods?

Answer

The public consultation aims to understand the impact of the proposal to stop prescribing gluten-free foods. A Report of Findings will be published showing what people told us about the proposals. The Report of Findings will be considered by the Leicester, Leicestershire and Rutland Integrated Care Board (LLR ICB) and will influence their decision. The decision made will then influence how we spend NHS finances in the future and where investment should be made, which will be based on need.

Q5. If the ICB decides to stop prescribing bread and flour where can I buy them in the future?

Answer

Most major supermarkets and many other retailers now stock gluten-free foods as well as other special diet alternatives both online and in-store. In addition, improved food labelling now means people are better able to see whether ordinary food products are free from gluten. Further information on labelling can be found at: <https://www.gov.uk/guidance/food-labelling-giving-food-information-to-consumers>

Q6. What support will I be offered if I can't afford to buy gluten-free products?

Answer

It is possible to eat a gluten-free diet that follows the Eatwell Guide (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, simply by choosing naturally gluten-free carbohydrate containing foods (e.g. rice and potatoes) as part of a healthy balanced diet.

Other advice and guidance including cost of living support available online:

Coeliac UK - www.coeliac.org.uk

NHS - www.nhs.uk/conditions/coeliac-disease/

The Association of UK Dietitians - www.bda.uk.com/resource/coeliac-disease-and-gluten-free-diet.html

[Cost of Living Support, Leicestershire County Council](#)

[Household Support Fund, Leicester City Council](#)

[Cost of Living Support, Rutland County Council](#)

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Q7. If you decide to stop prescribing gluten-free products, then why do you need our views?

Answer

We have a statutory duty – and a moral duty – to publicly consult on changes to services to understand views from our communities. We genuinely want to hear people's views on this proposal and its impact on patients, their family and loved ones.

The feedback from people helps to inform the final decision on gluten-free prescribing.

Q8. How have you developed the proposal to stop NHS prescriptions for gluten-free food?

Answer

When the NHS develops plans to change services, it appraises the options for change. This allows a few different alternatives to be evaluated. It looks at how strong and weak each option is including accessibility and affordability. More information about the

options and this project can be found by visiting bit.ly/llrgfsurvey. The consultation then provides more information to shape our thinking.

Q9. What have we learnt from other ICB's who have stopped gluten-free prescribing?

Answer

In a National Library of Medicine paper (February 2024) based on a survey they conducted concluded that the majority of participants affected by the withdrawal of prescriptions were able to adapt to cope with these changes. However, participants with mobility issues, who are permanently sick or disabled and/or on lower incomes were struggling to afford and obtain gluten-free substitute foods from elsewhere. The withdrawal of prescriptions may further widen health inequalities.

This public consultation will provide us with local insights to gain a better understanding of the views of our local population.

Q10. Has cost, quality and access improved when purchasing gluten-free products?

Answer

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 people eating less gluten, these foods have become more accessible in some supermarkets and online. Of course, for many communities bread is not a staple part of their diet.

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.

Being able to buy good quality gluten-free products has become more important and supermarkets are responding. While it was once difficult to find gluten-free breads that weren't unpleasantly dry, crumbly or sweet, an increasing number of retailers are now making higher quality free-from-gluten breads. Often, matching the taste and texture of regular versions.

Q11. How can I find out the results of the public consultation and keep updated on the proposal to stop NHS prescriptions for gluten-free food?

Answer

A final report of findings from the consultation will be considered by the ICB. The report along with a recommendation will be discussed by the ICB Board in a public meeting and the feedback from the public consultation will be considered and considered in any

decisions they make.

All decisions will be made public after the governing board meeting including on the ICB website.

Q12. How can I have my say?

Answer

There are lots of ways to participate in the public consultation:

Complete a questionnaire online, visit: bit.ly/llrgfsurvey

Email your views: llricb-llr.beinvolved@nhs.net

Telephone: 0116 295 7532 and request a hard copy survey

Write to us at:

Freepost Plus RUEE–ZAUY–BXEG, Gluten-Free Consultation, Leicestershire and Rutland Integrated Care Board, Room G30, Pen Lloyd Building, Leicestershire County Council, Leicester Road, Glenfield, Leicester LE3 8TB

Pick up a questionnaire from your local GP or Pharmacy

Follow our social channels:

[@NHS Leicester, Leicestershire and Rutland](#)

[@NHS_LLRL](#)

Q13. What happens after the public consultation ends?

Answer

We will analyse all the information we receive and put together a Report of Findings, which we will publish in the Autumn.

We will use the information to make a final decision about the provision of gluten-free products on prescription. We will communicate the decision to people and include information on our website.

Q14. How do you know you are reaching all communities through public consultation?

Answer

All the feedback we receive from the public consultation will be analysed and evaluated. The survey asks a number of equality monitoring questions which although optional to answer, we hope that people complete as they help to ensure that everyone receiving services has the opportunity of getting involved in shaping their care. The anonymised data helps us to identify if there any communities, including those with

protected characteristics, who haven't participated in the public consultation. At a review half-way through the consultation, if certain communities haven't been reached, we adjust our communications and engagement plan.

Q15. If you decide to stop gluten-free prescribing, when will the change happen?

Answer

All the feedback we receive from the public consultation will be analysed and evaluated. Responses are then considered by the ICB. The timescale for implementing any change is difficult to predict, until we know what the outcome of the public consultation is.

Q16. What are the dates for the public consultation to discuss gluten-free prescribing?

Answer

The public consultation will commence on Monday 15 July and end on Sunday 25 August 2024.

Depending on the number of responses we receive it can take 6 – 8 weeks to produce a report of findings. This is then considered by the LLR Integrated Care Board (ICB) (the organisation that plans and pays for local health services) and a decision made by the ICB Board at a meeting in public. Further information on the timetable will be published at the end of the public consultation.

Q17. What if I qualify for free prescriptions or can afford Gluten Free foods?

Answer

We do appreciate that gluten-free food is still more expensive than equivalent products containing gluten. It is possible for people to eat a gluten-free diet without the need for any specialist dietary foods. People can choose natural gluten-free carbohydrate-containing food, such as rice and potatoes, as part of a healthy balanced diet. People can get more guidance online through the NHS Eat Well Guide www.nhs.uk/live-well/eat-well.

Advice and support to support people struggling with the higher costs of living is available from local authorities: -

[Cost of Living Support, Leicestershire County Council](#)

[Household Support Fund, Leicester City Council](#)

[Cost of Living Support, Rutland County Council](#)