

# **Tell us what you think about NHS Prescriptions for gluten-free bread, rolls, and flour mix**

**Involvement findings report,**

**Final report – November 2025**

**The Communications and Involvement Team**

**Better health  
and wellbeing for all...**

## Contents

Executive summary.....	3
Background.....	3
Sample.....	3
Key findings .....	4
Plain English summary.....	6
What's the issue?.....	6
Why is this being considered? .....	6
How we listened .....	6
What people told us .....	7
1. Prescriptions are essential for many .....	7
2. Financial strain is a major concern .....	7
3. Health and wellbeing risks .....	7
4. Emotional and social impact.....	7
5. Access and availability .....	7
6. Suggestions for alternatives .....	8
What people think should happen .....	8
Conclusion .....	8
Background.....	9
Background and case for change.....	9
Why change is needed.....	9
Our legal duty to involve people .....	10
Involvement and communication methods .....	10
Sample and equality.....	10
Communication methods.....	11
Involvement methods .....	11
Survey.....	11
Focus groups and community discussions .....	12
Additional submissions.....	12
Survey findings .....	13
Overall profile of survey respondents .....	13
About our sample .....	14
Being diagnosed .....	15
Receiving prescriptions .....	16
Importance of prescriptions .....	17
Important to people: (n=913) .....	17
Not important to people (n=59).....	19
Not sure / does not apply (n=8) .....	20
Difference if prescriptions no longer available .....	21

Impact on people if prescriptions no longer available .....	22
Confidence in managing a gluten-free diet without prescriptions .....	24
Thoughts on NHS spending on gluten-free prescriptions?.....	25
Ease of finding and affording gluten-free foods .....	26
Changes to gluten-free food support .....	27
Additional support .....	30
Prioritising NHS funds .....	33
About NHS costs.....	36
Yes, for everyone (n=636) AND Yes, but only for those in greatest need (n=340).....	37
No, people should buy their own (n=181) .....	39
Not sure / no response (n=88).....	40
Final thoughts .....	41
Online focus group and community group findings.....	43
Overall profile.....	43
Online focus group respondents.....	43
Community groups .....	43
Impacts of removing gluten-free prescriptions .....	44
Burden of increased costs .....	44
Health and wellbeing risks.....	44
Impacts on vulnerable groups .....	46
Procurement costs of gluten-free prescriptions .....	48
Disproportionate costs to the NHS .....	48
Comparisons with NHS and online prices.....	49
Stimulating market competition and reducing costs .....	50
Alternatives and solutions to gluten-free prescriptions.....	50
Community-based support .....	50
Voucher/cash schemes as an acceptable alternative .....	51
Letters and email responses .....	54
Financial burden and accessibility.....	54
Health implications of non-adherence .....	54
Inequality and vulnerability .....	55
Policy and procurement critique .....	55
Discussion .....	56
Appendix 1 – Survey demographics.....	59
Appendix 2 – Survey.....	61

# Executive summary

The NHS North East and North Cumbria Integrated Care Board (NENC ICB) is thinking about stopping gluten-free food prescriptions.

Currently, the ICB only offers prescriptions for gluten-free bread, rolls and flour.

People with coeliac disease or dermatitis herpetiformis need gluten-free food to stay healthy. Some people with other conditions might also need it. Right now, they can get some gluten-free food on prescription from the pharmacy. But things have changed:

- Gluten-free food is easier to buy in shops and online.
- Food labels are clearer, so it's easier to pick the right things.
- These foods still cost more than normal food.
- The NHS has a limited budget and needs to spend money in the best way.

## Background

Gluten-free products have historically been prescribed for individuals diagnosed with coeliac disease and dermatitis herpetiformis. NENC ICB is reviewing its policy considering national guidance and changing availability of gluten-free products. Currently:

- Around 4,700 patients receive gluten-free prescriptions.
- Approximately 34,000 items are prescribed annually, costing £712,000.
- Prescriptions are delivered via FP10 (standard NHS) and a voucher scheme (North Cumbria).

The proposal seeks to:

- Align with NHS England guidance (2018).
- Reduce variation and inequity in prescribing.
- Improve resource efficiency.
- Encourage self-management, noting that 90% of patients already self-manage.
- Address cost disparities: gluten-free bread mix costs £2.27 in supermarkets vs £9.57 on prescription, plus handling fees.

## Sample

The survey gathered responses from 1,414 individuals. Most respondents were female (78%), had coeliac disease or dermatitis herpetiformis (63%), with others contributing as carers or professionals. A significant proportion identified as low income households

(27%), and 62% reported having a long-term health condition. These demographics provide essential context for understanding the varied experiences and needs of the population affected by gluten-free dietary requirements.

Additional feedback was received from 40 members of the public through focus groups and community groups discussions.

We also received 16 written responses from members of the public, an MP, Coeliac UK, and a Facebook support group.

## Key findings

The key findings from all involvement methods are summarised below, with detailed discussion and full feedback analysis included in this report.

**Diagnosis and disease management** - Most respondents (91%) had been diagnosed more than a year ago, though recent diagnoses were more common among children and young adults. This underscores the need for early support and clear guidance for newly diagnosed individuals and their families.

**Access to prescriptions** - Nearly three-quarters (72%) of survey respondents received prescriptions for gluten-free bread and flour. Access was more prevalent among older adults, South Asian respondents, and carers of children. Prescriptions were widely viewed as essential. This sentiment was echoed across both survey data and qualitative feedback, reinforcing the role of prescriptions in enabling dietary adherence.

**Economic hardship and affordability** - Affordability was a dominant theme. Gluten-free products were consistently described as expensive, with many respondents relying on prescriptions to manage costs. The cost of living crisis further exacerbated financial strain, particularly for pensioners, students, and families not eligible for benefits.

**Health necessity and dietary management** - Prescriptions were seen as medically necessary, not optional. Respondents described how they supported complex dietary needs, including autoimmune conditions and diabetes. This highlights the intersection of coeliac disease with broader health management.

**Quality, nutrition and satisfaction** - Many respondents valued the quality and nutritional benefits of prescription products, especially flour used for baking. However, others expressed dissatisfaction with limited variety and poor quality of some prescription items, preferring supermarket alternatives.

**Accessibility and availability** - Access to gluten-free products outside prescriptions was described as inconsistent and often inadequate. Respondents noted that some prescription items were unavailable in retail settings, and rural residents faced additional barriers. This theme was particularly strong among older adults and those with mobility issues.

**Psychological and social wellbeing** - The emotional impact of managing coeliac disease was significant. Respondents described anxiety, depression, and social exclusion.

Prescriptions were seen as a source of reassurance and dignity, helping individuals feel supported and included.

**Concerns about removal of prescriptions** - The potential withdrawal of prescriptions raised widespread concern. Quantitative data showed 73% believed their costs would increase, and 33% were worried about access to gluten-free products. This reflected fears of worsening health outcomes and increased inequality.

**Alternative support models and suggestions** - Respondents proposed various alternatives, with voucher schemes being the most popular (65%). The Welsh model was frequently cited as a positive example. Suggestions included:

- Pre-paid cards for supermarket use.
- Subsidies to offset cost differences.
- Tiered support based on income or health needs.
- Dietetic support: Calls for more specialised, accessible services, including online group sessions.
- Community resources: Facebook groups and peer networks were described as lifelines.
- Public education: Raising awareness about coeliac disease to prevent cross-contamination and stigma.

**Procurement costs and NHS efficiency** - Participants expressed frustration with NHS procurement practices, noting that gluten-free products cost significantly more when purchased through prescriptions. There was strong support for improving procurement efficiency rather than removing support altogether.

**Impacts on vulnerable groups** - Focus group discussions and letters highlighted the disproportionate impact on vulnerable populations, which underscore the need for inclusive, equitable support systems:

- Children and young people: Concerns about school meals and long-term financial burden.
- Disabled individuals: Barriers to shopping and reliance on delivery services.
- Low income households: Risk of food insecurity and poor dietary adherence.
- Rural communities: Limited access to gluten-free products locally.
- Older adults: Challenges with digital systems and comorbidities.

# Plain English summary

## What's the issue?

The NHS in the North East and North Cumbria is thinking about stopping prescriptions for gluten-free bread, rolls, and flour. These are currently offered to people with coeliac disease or dermatitis herpetiformis, who need to follow a strict gluten-free diet to stay healthy.

## Why is this being considered?

- Gluten-free food is now easier to find in shops and online.
- Food labels are clearer, making it easier to choose safe products.
- The NHS pays much more for gluten-free items than shoppers do (e.g. £9.57 vs £2.27 for bread mix).
- The NHS has a limited budget and wants to spend money fairly and effectively.

## How we listened

To understand how this change might affect people, the ICB ran a public engagement process that included:

- A public survey with 1,414 valid responses.
- Four focus groups with people with coeliac disease, parents of children with the condition, and professionals speaking with 17 people
- Two community group discussions speaking with 23 people.
- 16 written responses from members of the public, an MP, Coeliac UK, and a Facebook support group.

The ICB also made sure to hear from groups who might be more affected, including:

- People on low incomes.
- People with children in their household and older adults.
- Rural residents.
- Pregnant women and new mothers.
- South Asian communities.

## What people told us

### 1. Prescriptions are essential for many

- 84% of people said prescriptions were very important.
- They help people afford gluten-free food, which is often much more expensive than regular food.
- Prescriptions support strict dietary adherence, which is vital to avoid serious health problems.

*It's not an option. Gluten free food is expensive to start with.*

### 2. Financial strain is a major concern

- Many people said they couldn't afford gluten-free food without prescriptions.
- This was especially true for pensioners, students, and families not eligible for benefits.
- Some said they would have to skip meals or eat unsafe food if prescriptions stopped.

*It would make my food budget impossible.*

### 3. Health and wellbeing risks

People worried that without prescriptions, they might not stick to their diet, leading to:

- Nutritional deficiencies.
- Long-term complications like osteoporosis or cancer.
- Increased NHS costs in the future.

*This is not a lifestyle choice but the required treatment for a medical condition.*

### 4. Emotional and social impact

- Many described feeling anxious, isolated, or depressed about managing their diet.
- Prescriptions gave them confidence and dignity, especially in social settings.

*Everyone else can live a normal life & go out & enjoy food*

### 5. Access and availability

- Some gluten-free products are only available on prescription.



- People in rural areas or with limited mobility said they struggled to find suitable products in shops.

*The flour mix we get on prescription... is not possible to buy.*

## 6. Suggestions for alternatives

People offered constructive ideas if prescriptions were to stop:

- Voucher schemes (like in Wales) to help buy gluten-free food in shops.
- Pre-paid cards or subsidies to cover the cost difference.
- Tiered support based on income or health needs.
- Better dietitian support and online advice.
- Public education to raise awareness and reduce stigma.

*Give people vouchers for supermarkets for the free from section*

## What people think should happen

- 77% disagreed with stopping prescriptions.
- 73% said their costs would increase if prescriptions ended.
- 33% said it would be harder to find gluten-free food.

Most people want the NHS to:

- Continue prescriptions, especially for those in greatest need.
- Fix procurement issues so the NHS doesn't overpay.
- Avoid a postcode lottery and ensure fair access for all.

## Conclusion

People with coeliac disease and their families made it clear: gluten-free prescriptions are not a luxury, they are essential. The ICB heard a wide range of voices and concerns, and this feedback will help shape future decisions to ensure fairness, health, and dignity for all affected.

# Background

## Background and case for change

Gluten-free products have historically been prescribed for people diagnosed with coeliac disease and dermatitis herpetiformis. As gluten-free food has become widely available and more affordable in supermarkets and online, NHS England guidance (2018) allows local areas to restrict or stop prescribing.

Currently, gluten-free products such as bread and flour mixes are prescribed in primary care across the ICB area, though prescribing patterns vary by geography and socioeconomic status. Nationally, many ICBs have already stopped prescribing. The NENC ICB now proposes to end routine gluten-free prescribing to align with national trends, reduce costs, and encourage self-management.

- Around 4,700 patients currently receive gluten-free products on prescription across the region.
- Approximately 34,000 items are prescribed each year, costing around £712,000.
- There are 2,877 patients with a confirmed diagnosis of coeliac disease.

Two systems are used:

- FP10 prescriptions – the standard NHS process used across most of the region.
- Voucher scheme (North Cumbria only) – patients register with community pharmacies and access products without prescriber involvement.

Most prescriptions are exempt from charges. Common products include Juvela and Glutafin bread mixes, and Warburtons gluten-free rolls. Prescribing levels vary significantly, with higher rates in North and South Tyneside compared to County Durham.

## Why change is needed

- To align with NHS England guidance.
- To reduce variation and inequity in prescribing.
- To use NHS resources more effectively.
- Gluten-free products are now widely available at competitive prices.
- Cost comparison: gluten-free bread mix costs an average of £2.27 in supermarkets versus £9.57 on prescription, plus £1.48–£2.00 handling charges.

## Our legal duty to involve people

The ICB must involve people under the Health and Care Act 2022. This can be through communication, engagement, or consultation. The duty is also set out in the NHS Act 2006, the NHS Constitution, and the Gunning Principles.

**NHS Act 2006:** ICBs must involve patients, carers, and the public in:

- Planning commissioning arrangements.
- Developing and considering proposals that affect how services are delivered or what services are available.
- Decisions that affect how commissioning arrangements operate.

**NHS Constitution:** The NHS Constitution sets out rights, commitments, and responsibilities for patients, the public, and staff. NHS bodies and providers must take it into account in all decisions.

**The Gunning Principles:** Consultations must be:

- Run when proposals are still open to change.
- Provide enough information for people to respond.
- Allow adequate time for responses.
- Responses must be considered before decisions are final.

These apply formally to consultations but are good practice for all involvement. The quality of the process, not the outcome, shows if obligations were met.

**Equality Duties:** Under the Equality Act 2010, we must:

- Eliminate discrimination.
- Advance equality of opportunity.
- Foster good community relations.

**Health Inequalities:** ICBs also have a duty to reduce inequalities in access to and outcomes from health services. Understanding people's needs helps remove barriers and improve services.

## Involvement and communication methods

### Sample and equality

The Equality and Quality Impact Assessment (EQIA) identified several groups who may be disproportionately affected by the stopping of gluten-free prescriptions. These groups include:

- South Asian individuals.
- Persons under 16 years of age.
- Persons over 60.
- Residents of rural areas.
- Individuals from low income backgrounds.
- Pregnant women, and new mothers.
- Females.

The involvement and communication mechanisms tracked responses from these cohorts to ensure their views were represented.

## Communication methods

- A communications toolkit was developed and shared widely across a range of stakeholders, including GP practices and pharmacies. This supported stakeholders to share information about the engagement activities.
- Information was shared with Healthwatch, the voluntary and community sector, and Coeliac UK, letting them know about the engagement, sharing the toolkit, and inviting them to share the information wider.
- Briefings were shared with key stakeholders, including MPs, joint overview and scrutiny committees and health and wellbeing boards.
- A dedicated webpage was created for the gluten-free prescription engagement, letting people know how they could share their thoughts.

## Involvement methods

### Survey

A public survey was launched to gather views on the potential discontinuation of gluten-free prescriptions. Currently, the ICB only offers prescriptions for gluten-free bread, rolls and flour.

The survey explored accessibility, affordability, and the impact on individuals managing gluten-free diets. The survey was open for six weeks, between 15 July to 25 August 2025 and received responses from 1,608 participants.

This report excludes responses from individuals who did not provide a postcode (168) and those with a postcode outside the NENC ICB area or its borders (26).

As a result, the final sample consists of **1,414** respondents.

A total of 1,372 respondents provided a postcode from the North East and North Cumbria, 25 listed a postcode bordering or included in ICB strategic planning, and 17 gave partial postcodes indicating possible residence in or near the region.

## **Focus groups and community discussions**

Survey respondents were given the opportunity to volunteer to take part in a focus group to further explore the issue. Volunteers were monitored closely to ensure participation from groups identified in the EQIA (see below). Four focus groups were carried out with the following groups:

- Two focus groups for people with a coeliac diagnosis.
- One focus group for parents of under 16s with a coeliac diagnosis.
- One focus group with professionals with a stakeholder interest.

We gathered feedback from 17 people through the four focus groups, and a further 23 people took part in two community group conversations. Demographic information is available from focus group participants but not from community group members.

## **Additional submissions**

In addition to the survey responses and focus groups, an additional 15 responses were received by letter and email. Including from:

- Coeliac UK.
- An MP.
- A representative from a Facebook support group.
- Members of the public.

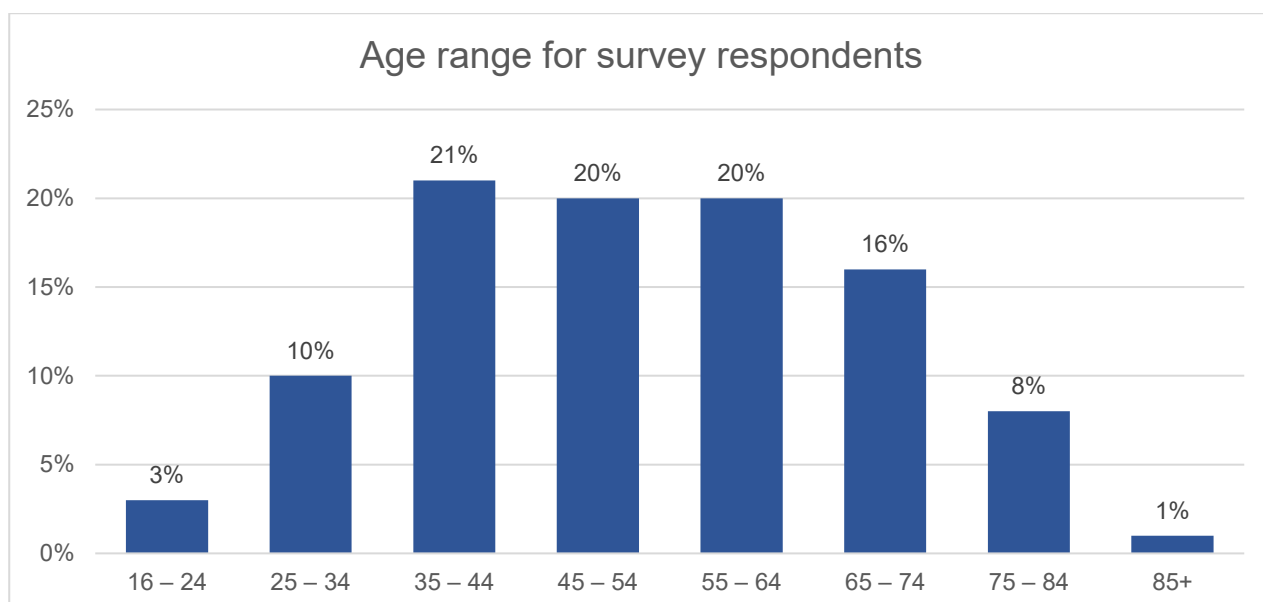
# Survey findings

## Overall profile of survey respondents

In total, we collected feedback from 1,414 people through the survey.

A detailed breakdown of the demographic information is included in Appendix 1, and a summary is included below.

- Most responses to the survey came from people living in the northern part of the North East (Newcastle, Gateshead, Northumberland, North Tyneside) (43%).
- The survey received more responses from females (78%).
- Three responses were received from people who identified themselves as non-binary.
- Five respondents indicated their gender now is different to what was given at birth.
- Over a quarter of respondents (27%) identified themselves as a low income household. Either through describing their home as such (8%), being in receipt of universal credit (13%), or living with someone who gets a benefit (5%).
- Six out of ten respondents said they had a long-term health problem or disability (62%). Of these, 44% said it impacted them a little, and 44% said it impacted them a lot.
- Two percent of respondents told us they were currently pregnant or had been pregnant in the past six months.
- Five percent of respondents identified themselves as gay or lesbian, bi or bisexual, or another sexuality.
- Three percent of respondents identified themselves as an ethnic group other than white. This includes: Asian or Asian British; black, black British, Caribbean, or African; mixed or multiple ethnic groups; or another ethnic background.
- Most respondents identified themselves as Christian (53%), with 44% identifying no religion or belief.
- People from a range of age groups responded to the survey, with most responses being from between 35 – 74 years of age.



## About our sample

The first four questions were used to explore how people were responding to the survey. Including through personal experience, parental or caring responsibilities, or through a professional role. These have all been combined and summarised in table 1.

- **Coeliac** - Most respondents to the survey had coeliac disease or dermatitis herpetiformis (63%).
- **Parental or carer role / relative** - 19% of respondents reported having a parental or carer role of someone coeliac disease or dermatitis herpetiformis or were a relative or of someone who is unable to eat gluten (as suggested through the 'other' comments).
- **Professional role** – 13% of respondents did so in a professional role, whether as a clinician, volunteer, through a local authority or educational role.
- **Not coeliac** – 6% of respondents reported they do not have coeliac and do not care for someone who does.

Personal and professional experience	N	%
<b>Personal</b>	1,019	72%
I have coeliac disease or dermatitis herpetiformis	885	63%
I do not have coeliac disease or dermatitis herpetiformis and do not care for someone who does	91	6%
I'm not sure or haven't been diagnosed Can't eat gluten / sensitive to / gluten intolerant / food allergies (suggested in 'other')	43	3%
<b>Parent, relative, or friend</b>	270	19%
I am the parent, guardian, or carer of a child under 16 with coeliac disease or dermatitis herpetiformis	152	11%
I care for someone aged 16 or over who has coeliac disease or dermatitis herpetiformis	47	3%
Parent of a child with coeliac / gluten intolerance – no age provided (suggested in 'other')	14	1%
Spouse / relative / friend / grandchild / carer of disabled person (suggested in 'other')	66	5%
<b>Professional</b>	179	13%
I am a pharmacist / GP / dietitian / health worker	94	7%
I work for another public organisation (e.g. Council, NHS, education)	70	5%
I work or volunteer for a public service or community group	8	1%
Other employment / former healthcare worker	8	1%
	1,414	

Table 1: People could identify themselves in more than one category through the 'other' option. E.g. as a parent of a child with coeliac, and as someone with coeliac. Therefore, numbers will exceed 1414

## Being diagnosed

Respondents who confirmed, through the first question, that they have or are the parent or guardian of a child with coeliac disease or dermatitis herpetiformis, were invited to answer some questions about their experience. In total, 1,015 people were invited to complete these questions.

Most respondents (91%) reported that their diagnosis was made more than 12 months ago. Those diagnosed within the past year (last 12 months) make up 8% of the total.



Diagnosed	N	%
Less than 12 months ago *	86	8%
Over 12 months ago	925	91%
I haven't been diagnosed / Not applicable	4	0.4%
	1,015	

\*(In the last 3 months, 3 – 6 months, 6 – 12 months)

The following observations were made from the demographic information:

- 24% of parents, guardians, or carers of children under 16 with coeliac disease or dermatitis herpetiformis indicated that the diagnosis occurred within the past 12 months (n=36).
- 14% of people aged between 16 - 24 years indicated that the diagnosis occurred within the past 12 months (n=5).

## Receiving prescriptions

Almost three-quarters (72%) of respondents reported receiving a prescription for gluten-free bread and / or flour.

Receiving gluten-free prescriptions	N	%
Yes – bread and / or rolls only	390	38%
Yes – flour mix only	106	10%
Yes – both bread, rolls and flour mix	231	23%
No – I used to, but i now buy my own	147	14%
No – I never had them on prescription	137	13%
Not sure	4	0.4%
	1,015	

The following cohorts of people were more likely to identify receiving a prescription for gluten-free bread and / or flour:

- Respondents aged 65 years and over (84%, n=259), with 90% of respondents aged 75 years and over (n=99).
- South-Asian respondents (86%, n=12).
- Male respondents (81%, n=198).

- Parents, guardians, or carers of children under 16 with coeliac disease or dermatitis herpetiformis (78%, n=119).
- Respondents aged between 16 – 24 (78%, n=29).

## Importance of prescriptions

When asked how important these prescriptions are to individuals with coeliac disease or dermatitis herpetiformis, 84% of respondents said very important.

Importance of prescriptions	N	%
Very important	850	84%
Important	95	9%
Not very important	25	2%
Not important at all	36	4%
Not sure / does not apply	9	1%
	1,015	

These prescriptions were viewed as very important by:

- Respondents from non-white ethnic groups (90%, n=19) particularly South Asian respondents (100%, n=14).
- Respondents currently in receipt of prescriptions (91%, n=661).
- Respondents from low income backgrounds (91%, n=248).

People were asked to tell us why these prescriptions were important or not important to them. In total, 980 people provided a response.

### Important to people: (n=913)

#### Economic hardship and affordability

A significant number of respondents expressed concern about the high cost of gluten-free products, which are often priced above regular alternatives and create difficulties for those who must follow a strict gluten-free diet.

*It's not an option. Gluten free food is expensive to start with.*

Many respondents with limited financial resources struggle to allocate enough money for gluten-free items, placing strain on their overall budget. Prescriptions were often described as essential to make diets affordable.

*It's really quite expensive to buy and couldn't afford it without having my prescription.*

## **Health necessity and dietary management**

Respondents with additional health conditions often rely on prescriptions to manage complex dietary needs, such as combining gluten-free requirements with low-GI or high-fibre diets.

*I have other autoimmune diseases and require low GI and high fibre diet in addition to gluten free.. my one box per month is my lifeline for bread and pastry.*

Families with gluten-free members described the difficulty of balancing costs while ensuring nutritious meals for everyone. Prescriptions were said to help reduce expense and provide acceptable alternatives for children.

*We buy everything else our daughter needs but she struggles with the breads available... the bread mixes we receive on prescription are important for her.*

Respondents also emphasised that prescriptions support strict dietary adherence, which is vital to prevent long-term complications and serious health decline.

*I would have to eat a percentage of normal bread rather than gluten free completely and this would likely impact on my health and life expectancy.*

## **Quality, nutrition, and satisfaction with prescription flour**

Being able to bake with prescription flour gave people control over quality and taste, with many saying homemade bread was more palatable than shop-bought alternatives.

*I am 90 years old and make my own bread buns... they are more palatable than the buns available in the shops.*

Respondents also valued the ability to use prescription flour in a range of nutritious meals, which supported both variety and dietary management for coeliac disease and other conditions.

*I'm also type one diabetic so need an accessible reliable form of carbohydrates to manage my condition as well as meet my nutritional needs.*

## **Accessibility and availability**

Many described difficulties accessing reliable, affordable gluten-free flour outside prescriptions, noting that high-quality products were rarely available in shops.

*The flour mix we get on prescription... is not possible to buy, it is only available on prescription.*

For many, prescriptions were the only way to access gluten-free products without risking financial hardship or health decline.

*The cost in the shops is extortionate and... on my state pension it would be too costly for me to manage any gluten free products.*

### **Psychological and social wellbeing**

Managing strict dietary restrictions often caused stress and anxiety. Respondents explained that access to prescriptions helped reduce this burden and provided peace of mind.

*Everyone else can live a normal life & go out & enjoy food but us coeliacs cannot & it is very depressing & causes a lot of anxiety.*

Prescriptions also supported participation in social situations, reducing the risk of exclusion or cross-contamination when eating outside the home.

*Shops and restaurants do not understand, there is a lack of understanding.*

### **Not important to people (n=59)**

#### **Availability and variety in supermarkets**

Some respondents highlighted the wide availability and variety of gluten-free products in supermarkets as a key reason why they did not find prescriptions important.

*The bread and rolls I used to get on prescription weren't a patch on other brands from the supermarket*

#### **Cost and affordability**

Others felt that gluten-free products were now reasonably priced and easily accessible in supermarkets, making prescriptions unnecessary.

*Waste of NHS money, easily bought at most supermarkets at the same cost of the gluten containing version,*

#### **Quality and preference**

A few respondents expressed dissatisfaction with the quality of gluten-free products provided through prescriptions, preferring supermarket alternatives.

*Quality of bread etc on prescription was poor. I can identify good quality available elsewhere, and bake some myself,*

#### **Convenience**

The convenience of buying directly from supermarkets, rather than going through the prescription process, was valued by some.

*It is more convenient to choose the type of bread I want to eat, more options are now available in supermarkets,*

### **NHS resource allocation**

Some felt NHS funding should be prioritised elsewhere, arguing that prescriptions for gluten-free foods were not the best use of limited resources.

*Funding is tight across NHS and funding could be better used elsewhere now that the price of a gluten free loaf has reduced to more acceptable levels,*

### **Personal dietary habits**

Finally, a minority noted that they did not eat much gluten-free bread or relied on naturally gluten-free foods, making prescriptions less relevant.

*Plenty of natural foods out there for people to eat instead of processed foods like bread,*

### **Not sure / does not apply (n=8)**

#### **Access to prescriptions**

Some people feel that coeliac disease should be treated like other lifelong conditions, with the same access to free prescriptions. Some were unaware that gluten-free items could be prescribed at all, showing a lack of clear communication or support from healthcare providers. A few also mentioned that their GP practices have not offered or supported access to gluten-free prescriptions.

*We should get free prescriptions like all other life long conditions*

#### **Affordability and financial impact**

Gluten-free products are described as expensive, especially everyday staples such as bread, pasta, and cereal. While some people can manage the cost themselves, others rely heavily on prescriptions or struggle financially, particularly students or families with limited income.

*When I was a student I had barely any money at all and the prescriptions were a lifeline, I still lost a lot of weight and found thing difficult, but it would have been a lot worse without those prescriptions*

#### **Quality and availability of products**

The range of gluten-free products available through prescription is described as narrow and often unappealing, especially for children. Because of this, some people prefer to buy supermarket alternatives, which offer better taste and variety, even though this often means higher costs.

*The current offer available to my child on prescription is very limited and the products that are available he has tried and does not like in comparison to alternatives available at the supermarket, therefore we no longer get any of his food on prescription and source them elsewhere.*

### **Family and new diagnoses**

One parent shared the challenges of navigating the early stages of their child's recent coeliac diagnosis, pointing to the need for clearer guidance and stronger support at the beginning of the journey.

*I didn't even know this was a thing. No one has told me about this... My daughter was diagnosed a month ago and we're navigating this.*

## **Difference if prescriptions no longer available**

People were asked to tell us what difference it would make if gluten-free bread, rolls and flour mix were no longer available on NHS prescription, if any. In total, 976 people shared their thoughts which have been summarised into the themes below:

### **Accessibility and availability**

Respondents expressed frustration over the limited availability of gluten-free products in supermarkets, warning this would worsen if prescriptions were removed.

*The availability to get items within supermarket settings can be limited, this would be especially exasperated with removing the prescription and making families fight it out to get these items.*

### **Economic hardship and affordability**

The high cost of gluten-free products was a common concern, with many warning this would make managing budgets impossible.

*It would make my food budget impossible. I'm nearly in a position where, in this cost of living crisis, I'm going to have to choose if I can afford to heat my house in the coming winter*

### **Health necessity and dietary management**

Participants highlighted the risks to health if they were unable to adhere to a strict gluten-free diet. Prescriptions were described as critical in preventing illness and long-term complications.

*It would cost us more money, I wouldn't buy normal food as we would be very ill. This isn't a choice, it's an auto immune disease with long term health issues like f a strict gf diet is not followed*

## Perceptions of gluten-free diet as a choice

Some respondents voiced frustration at perceptions that a gluten-free diet is simply a lifestyle choice rather than a medical necessity.

*A huge difference and patient's will miss out, we do not choose to be gluten free we HAVE TO because it is an autoimmune disease*

## Lack of awareness

Others stressed that removing prescriptions would hit deprived areas hardest, showing a lack of awareness of the realities faced by low income families.

*Obviously in a deprived area this resource is vital for low income people. By removing the prescription you are forcing people to eat gluten as they could not afford gluten-free.*

## Impact on people if prescriptions no longer available

73% of respondents said stopping prescriptions would increase their costs, and a third (33%) said it would be harder to find gluten-free bread, rolls and flour mix.

Effect if prescriptions were stopped	N	%
It would cost me more	737	73%
It would be harder to find gluten-free bread, rolls and flour mix	335	33%
No change - i already buy my own gluten-free bread, rolls and flour mix	156	15%
I wouldn't know what food is safe	116	11%
No change - I never had prescriptions	94	9%
Other	90	9%
	1,014	

These groups of people were more concerned that the removal of prescriptions would cost them more:

- People who currently receive prescriptions (92%, n=672).
- People over the age of 65 years (83%, n=254) and over the age of 75 years (82%, n=90).
- People who are the parent, guardian, or carer of a child under 16 with coeliac disease or dermatitis herpetiformis (82%, n=124).

These groups of people were more concerned it would be harder to find gluten-free bread, rolls and flour:

- People who currently receive prescriptions (43%, n=315).
- People from non-white ethnicities (48%, n=10), including South-Asian respondents (50%, n=7).

Interestingly, people from rural areas were not more likely to be more concerned it would be harder to find gluten-free bread, rolls and flour (36%, n=113).

84 people identified other effects from not having gluten-free prescriptions, which have been summarised in the themes below:

### **Economic hardship and affordability**

Respondents highlighted the potential financial burden of losing prescriptions, with supermarket prices described as unsustainable for many households.

*We would struggle with additional costs.*

Some were already concerned about how long they could cope financially.

*Currently I can afford to buy my gf products, but I am unsure of what the economic future holds for me.*

### **Health necessity and dietary management**

Parents and carers in particular worried that families would struggle to afford gluten-free staples, risking poor adherence and worsening long-term outcomes.

*As a parent, I worry that removing prescriptions will make it harder for families like mine to consistently afford the gluten-free staples needed to manage coeliac disease. This could lead to reduced dietary adherence, especially in lower-income households, and increase the risk of long-term health complications.*

Others stressed the mental health impact of losing prescriptions, with rising anxiety about affordability and diet management.

*[I would] STOP FOLLOWING DIET - INCREASED MENTAL HEALTH - INCREASE IN MEDICAL COMPLICATIONS*

### **Accessibility and availability**

Some noted the inconsistency of gluten-free products in shops, and the difficulty of sourcing specific items outside the prescription system.

*The stress of not having that affordable supply of gluten free bread.*

Others emphasised that some staple products were only available on prescription.



*I would not be able to eat bread or rolls again as the only brand of bread i like is prescription only.*

## Psychological and social wellbeing

The removal of prescriptions was seen as undermining recognition of coeliac disease as a serious medical condition, leaving people feeling unsupported.

*I would feel that this autoimmune disease was not taken seriously.*

## Confidence in managing a gluten-free diet without prescriptions

Overall, six out of ten (59%) respondents were somewhat or very confident in managing a gluten-free diet without support from a prescription.

Confidence with managing diet without a prescription	N	%
Very confident	290	29%
Somewhat confident	303	30%
Not very confident	191	19%
Not at all confident	185	18%
Not sure / does not apply	43	4%
	1,012	

The following cohorts of people were more likely to report they were not very or not at all confident in managing a gluten-free diet without prescriptions:

- People from non-white ethnicities (52%, 11) specifically South-Asian respondents (71%, n=10).
- Respondents aged 75 years and over (52%, n=57).
- Respondents from low income backgrounds (50%, n= 137).

People who currently receive a prescription were more likely to say they were not very or not at all confident to manage their diet without a prescription, compared to people with coeliac / parent of a child with coeliac who is not in receipt of a prescription.

Confidence with managing diet without a prescription	No prescription	Prescription
Somewhat / very confident	81%	50%
Not very / not at all confident	11%	47%
	288	727

## Thoughts on NHS spending on gluten-free prescriptions?

All survey respondents were invited to answer the remaining questions in the survey.

People were told how the NHS is thinking about stopping gluten-free bread, rolls and flour mix on prescription for people with coeliac disease or dermatitis herpetiformis. They were asked to tell us how much they agreed or disagreed with this idea.

Most respondents disagreed or strongly disagreed with this (77%), with only a fifth (20%) agreeing or strongly agreeing.

Thoughts if NHS stopped prescriptions	N	%
Strongly agree	197	14%
Agree	87	6%
Disagree	168	12%
Strongly disagree	913	65%
Not sure	48	3%
	1,413	

The following cohorts were more likely to strongly disagree with this idea:

- Pregnant women / new mothers (80%, n=17).
- Respondents currently in receipt of a prescription (80%, n=581).
- Parents, guardians, or carers of a child under 16 with coeliac disease or dermatitis herpetiformis (79%, n=120).

The following cohorts were more likely to agree or strongly agree with this:

- People who do not have coeliac disease or dermatitis herpetiformis and do not care for someone who does (54%, n=49).
- Professionals (53%, n=94).

## Ease of finding and affording gluten-free foods

Respondents were asked to tell us how easy or hard it was to find and afford gluten-free food.

Over half (52%) of respondents felt it was quite or very easy to find gluten-free food. Whereas just under half of respondents (47%) reported it was quite or very hard to find.

Ease of finding gluten-free food	N	%
Very easy	267	19%
Quite easy	471	33%
Quite hard	377	27%
Very hard	280	20%
Not sure	18	1%
	1,414	

The following groups of people were more likely to say it was quite or very hard to find gluten-free food near them:

- Respondents currently in receipt of a prescription (60%, n=433).
- Respondents aged between 16 – 24 (60%, n=25).
- Respondents aged over 75 years (59%, n=73).
- Parent, guardians, or carers of a child under 16 with coeliac disease or dermatitis herpetiformis (58%, n=88).
- Pregnant women or new mothers (57%, n=12).

The following groups of people were more likely to say it was quite or very easy to find gluten-free food near them:

- Professionals (79%, n=179).
- People without coeliac (75%, n=91).
- Respondents from non-white ethnic backgrounds (68%, n=28), including people who identify as South-Asian (68%, n=19).

When asked about the ease of finding affordable gluten-free food, 14% reported it was quite or very easy. The majority (82%) indicated that affording gluten-free food was hard, and over half (54%) stated it was very hard to afford.

Ease of affording gluten-free food	N	%
Very easy	63	4%
Quite easy	144	10%
Quite hard	400	28%
Very hard	762	54%
Not sure	45	3%
	1,415	

The following groups of people were more likely to say it was quite or very hard to afford gluten-free food near them:

- Respondents currently in receipt of a prescription (94%, n=681). With 63% saying they find this very hard (n=455).
- Parents, guardians, or carers of a child under 16 with coeliac disease or dermatitis herpetiformis (91%, n=138). With 67% saying they find this very hard (n=102).
- Respondents aged between 16 – 24 years (90%, n=38). With 74% saying they find this very hard (n=31).
- Respondents with coeliac (90%, n=789). With 59% saying they find this very hard (n=516).

The following groups of people were more likely to say it was quite or very easy to afford gluten-free food near them:

- Professionals (44%, n=78).
- People without coeliac (36%, n=33).
- Respondents from non-white ethnic backgrounds (32%, n=13), including people who identify as South-Asian (36%, n=10).

## Changes to gluten-free food support

Most survey respondents suggested providing vouchers to help people buy gluten-free products (65%), with 40% suggesting limits to the amount of monthly products.

Support if prescriptions were changed	N	%
Give vouchers to help buy gluten-free products	916	65%
Limit the amount each month of gluten-free bread, rolls and flour mix	570	40%
Only for people on low income or in greatest need	444	31%
No prescriptions at all	113	8%
Other	110	8%
I don't know	24	2%
	1,410	

The following differences were noted in the different demographic groups:

Respondents who were more likely to suggest **'Give vouchers to help buy gluten-free products'** include:

- Parents, guardians, or carers of a child under 16 with coeliac disease or dermatitis herpetiformis (82%, n=124).
- Respondents aged between 16 – 24 (81%, n=34).
- Respondents with coeliac / parent of a child with coeliac who is not in receipt of a prescription (77%, n=222).
- Pregnant women or new mothers (76%, n=16).

Respondents who were more likely to suggest **'Limit the amount each month of gluten-free bread, rolls and flour mix'** include:

- Respondents currently in receipt of a prescription (55%, n=400).
- Respondents aged 65 years and over (53%, n=182), with 54% of respondents aged 75 years and over (n=67).

Respondents who were more likely to suggest **'Only for people on low income or in greatest need'** include:

- Professionals (50%, n=89).
- Respondents from non-white ethnic backgrounds (49%, n=20), including people who identify as South-Asian (54%, n=15).
- People without coeliac (46%, n=42).

- Respondents with coeliac / parent of a child with coeliac who is not in receipt of a prescription (43%, n=125).

Respondents who were more likely to suggest **'No prescriptions at all'** include:

- Professionals (30%, n=53).
- People without coeliac (26%, n=24).
- Respondents from non-white ethnic backgrounds (20%, n=8), including people who identify as South-Asian (21%, n=6).

In total, 109 people provided an additional comment for this question, which have been summarised in the below themes.

### **Adequacy and limitations of prescriptions**

Many participants raised concerns about the limited amount of gluten-free food available on prescription. The current allowance, often four boxes of flour or eight units per month, was described as insufficient, particularly for families or individuals with higher needs. Bread and flour were seen as staples, essential for maintaining health, and respondents argued that further reductions would make it harder to manage their condition.

*They've already been dramatically reduced to four boxes of flour per month. That's just about enough for four loaves. I need more than that. I already have to buy bread by mail order, pasta and other suitable safe foods*

There was also frustration about the lack of variety. Several participants called for the reintroduction of items such as pasta, biscuits, and porridge, pointing out that these are basic foods that help make diets more manageable. Some compared provision in Scotland and Wales, describing those systems as more supportive.

*Gluten free prescriptions were previously reduced from 32 units to 8 units and included pasta, biscuits, porridge, etc*

Overall, the tone was one of frustration and advocacy. Many stressed that coeliac disease is not a choice, and reducing support would be unfair and potentially harmful.

*I don't support a change these illnesses are not a choice.*

### **Financial impact and affordability**

The high cost of gluten-free food was another dominant concern. Respondents repeatedly said that supermarket products are far more expensive than standard alternatives, placing strain on budgets, especially for pensioners, single parents, and working people not entitled to benefits but still struggling with rising living costs.

*Gluten free products are very expensive and limited in availability in the UK compared to other countries.*

Suggestions to ease this burden included vouchers, pre-paid cards, subsidies, or discounts to bring gluten-free prices in line with regular foods. Some pointed to Wales as an example of good practice.

*As has been started in Wales, a pre-paid card which can be used at Supermarkets, including Aldi, Lidl.*

There was also criticism of proposals to restrict support only to low income households. Many warned this would exclude a hidden group of people in financial difficulty but without benefit entitlement.

*None. Changing it is discrimination against a lifelong serious disability. and limiting prescriptions to people on a low income unfairly exclude those who are not eligible for benefits but are still pushed into financial hardship because they have to cover all costs themselves.*

### **Accessibility and inclusivity**

Many participants emphasised the importance of making prescriptions accessible to all, with particular concern for children, pensioners, newly diagnosed patients, and people with additional health conditions such as autism. Respondents living in rural or remote areas also described greater difficulty accessing suitable gluten-free products locally.

*I also think it's important to consider those with co-existing conditions such as autism, which can affect food choices and diet.*

Some suggested targeted support, such as free prescriptions for children and older people, or a tiered system based on income or health needs, while others argued that universal provision would be the fairest approach. There were also calls for greater flexibility in product choice, as dietary needs and preferences vary widely.

*I support a fair and consistent approach that protects access for those who need it most, especially children and people on low incomes. Any change should be designed to maintain adherence to the gluten-free diet and avoid increasing health inequalities.*

There was a strong concern with fairness and dignity. Respondents urged policymakers to design a system that is both medically effective and socially just, ensuring that no one is excluded because of age, location, or financial circumstances.

*This is for life not just a choice, we need to have more support for those with Gluten Intolerance no matter what their circumstances are.*

### **Additional support**

Over half of respondents requested information about cheap gluten-free food (56%), or financial advice or support (50%) if NHS prescriptions were no longer available. A further 40% suggested help from a dietitian or nutritionist.

Support to help people manage a gluten-free diet?	N	%
Information about cheap gluten-free food	790	56%
Financial advice or support	712	50%
Help from a dietitian or nutritionist	567	40%
Online tools for meal planning or meal planning tools	407	29%
Cooking classes or support groups	392	28%
Support from a GP or health worker	340	24%
Other	172	12%
I don't know	100	7%
None needed	58	4%
	1,410	

Respondents who are currently in receipt of a prescription for gluten-free products were less likely to select any of these options, compared to respondents who have coeliac / parental responsibilities of a coeliac child and do not have a prescription.

Respondents who answered as a professional were more likely to suggest the following alternatives to help people manage a gluten-free diet:

- Information about cheap gluten-free food (73%, n=131).
- Online tools for meal planning or meal planning tools (60%, n=107).
- Help from a dietitian or nutritionist (57%, n=102).
- Cooking classes or support groups (49%, n=87).

170 people took up the opportunity to write additional suggestions or comments. These have been summarised in the themes below:

### **Prescription continuity and medical necessity**

People mentioned the critical importance of maintaining gluten-free prescriptions as a medical necessity. Participants repeatedly emphasised that coeliac disease is a lifelong autoimmune condition, not a lifestyle choice, and therefore requires consistent access to gluten-free staples such as bread, flour, and pasta. Many expressed concern over the potential withdrawal or reduction of prescriptions, arguing that such changes would severely impact their ability to manage their health and maintain a balanced diet.

*This is an autoimmune condition there should be given on prescription.  
This is not a personal choice*



There was widespread rejection of alternative support options such as cooking classes, dietary advice, or digital tools, with respondents stating that these do not address the core issue: access to affordable, safe food. One participant noted:

*The only support people need are the prescriptions for bread that they already receive, don't try and fix anything that is not broke.*

Others highlighted that prescriptions are already limited and that further cuts would be detrimental, especially for those with additional health conditions or limited mobility.

*Status Quo. I already am limited to 8 loaves per month.*

A broader concern about equity and dignity was also expressed, with many respondents feeling that removing prescriptions would be discriminatory and undermine their ability to live healthily. The consensus was clear: gluten-free prescriptions are not optional extras but essential medical support that must be preserved.

*This is not a lifestyle choice but the required treatment for a medical condition. Anything less would leave patients absorbing the extra cost themselves. Has an Equality Impact Assessment been conducted on this proposal? If not, it should be, as the removal of this service risks disproportionately affecting people with a lifelong disability.*

## **Financial burden and support mechanisms**

Participants described gluten-free products as significantly more expensive than their standard counterparts, with some citing prices up to five times higher. This cost disparity was especially challenging for families, pensioners, and individuals with additional dietary needs or health conditions.

*Reducing the cost of gluten free items - it's insane that something that is medically essentially for day to day life is so significantly more expensive than the gluten containing version*

Many respondents proposed financial support mechanisms to alleviate this burden, including vouchers, pre-paid cards, tax relief, and direct subsidies. The ideas shared reflected a strong desire for practical, targeted assistance that directly addressed the cost barrier.

*Give people vouchers for supermarkets for the free from section.*

*Using the NHS app provide a QR code to use at the till which gives a 50% discount on gluten free food.*

There was also criticism of support options that did not include financial aid, with several respondents stating that advice or education was insufficient when the core issue was affordability. This theme highlighted a need for inclusive support, not limited to low income groups, as many working individuals also struggled with the high cost of gluten-free food.

*Your financial advice won't help me. My husband already cooks. I know about cheaper gf products but they are not cheap! We already meal plan. This facility can't be removed. Stop doing this to us!*

Overall, this theme underscored the urgent need for economic solutions to ensure all individuals with coeliac disease can access the food they need without financial hardship.

*financial support (not advice) to afford the increased cost of gluten free food*

## Prioritising NHS funds

People were told how the NHS has a limited budget and must make difficult choices about how to spend it. We wanted to know where people thought the NHS should prioritise spending. Respondents were asked to limit their choices to three from the below list.

Overall, most respondents felt the NHS should prioritise spending on GP services (43%) and food supplements on prescription, including gluten-free products (43%).

Prioritising NHS funds	N	%
GP services	604	43%
Food or supplements on prescription (e.g., gluten-free, vitamins)	595	43%
Cancer care and screening	563	40%
Mental health support	542	39%
A&E and ambulances	539	39%
Help for long-term health problems	422	30%
Children and young people's health	387	28%
Care for older people	339	24%
Other	188	13%
	1,394	

The following respondents were more likely to think the NHS should spend money on **GP services**:

- Respondents from non-white ethnic backgrounds (59%, n=24), including people who identify as South-Asian (61%, n=17).
- People who do not have coeliac disease or dermatitis herpetiformis and do not care for someone who does (54%, n=49).

- Professionals (51%, n=92).

The following respondents were more likely to think the NHS should spend money on **food or supplements on prescription**:

- Respondents aged between 16 – 24 years (64%, n=27).
- Respondents who are currently in receipt of a prescription (57%, n=414).
- Respondents aged 75 years and over (54%, n=66).
- Parents, guardians, or carers of a child under 16 with coeliac disease or dermatitis herpetiformis (53%, n=81).

The following respondents were **less** likely to think the NHS should spend money on food or supplements on prescription:

- Professionals (9%, n=17).
- People who do not have coeliac disease or dermatitis herpetiformis and do not care for someone who does (18%, n=16).

The following respondents were more likely to think the NHS should spend money on **mental health support**:

- Professionals (59%, n=105).
- People who do not have coeliac disease or dermatitis herpetiformis and do not care for someone who does (53%, n=48).
- Pregnant woman or new mothers (48%, n=10).
- Respondents with coeliac / parent of a child with coeliac who is not in receipt of a prescription (47%, n=135).

In total, 186 people took the opportunity to share other thoughts or comments. These have been summarised in the below themes.

### **Reflections on survey question**

Several respondents raised concerns about the survey question that asked them to select only three NHS funding priorities. They felt it was restrictive and made it difficult to reflect the full range of important healthcare services. Some noted that this approach might not capture the true priorities of patients and the public and suggested allowing respondents to select all relevant options or provide open-ended feedback.

### **Importance of all healthcare services**

Many respondents emphasised that all NHS services are important and deserve adequate funding.

*You have forced me to tick 3 boxes. The nhs should spend money on all of these areas.*

They noted that limiting support in one area could place additional pressure on other parts of the system and potentially affect health outcomes. Preventative measures, such as gluten-free prescriptions, were recognised for their role in helping avoid future complications.

*All areas are important - but gluten free food is the only way of staying healthy, there is no other medicine so it should be viewed as that - a medicine which is just as important as any other for any other illness or disease especially as it is life long.*

Respondents also suggested broader improvements, such as reducing bureaucracy, improving efficiency, and ensuring fair access to care. The overall message was a desire for a healthcare system that supports all services and treats patients equitably, rather than prioritising one area over another.

*The government needs to give the NHS more funding to spend in all of these areas. Why should you have to pick and choose.*

Some respondents identified other areas where NHS funding could be prioritised. These have been summarised in the following three tables.

Health conditions and early diagnosis	Prevention and public health
<ul style="list-style-type: none"><li>• Pain management.</li><li>• Early screening for heart conditions to prevent undiagnosed deaths in young people.</li><li>• Improving access to diagnosis and treatment for ADHD, bipolar, autism, PTSD.</li><li>• Reducing autism and ADHD assessment wait lists.</li><li>• Early and accurate diagnosis using AI to reduce long-term costs.</li><li>• Autoimmune disease dietary requirements.</li><li>• Epilepsy care and support.</li><li>• Women's health.</li><li>• Trans healthcare.</li></ul>	<ul style="list-style-type: none"><li>• Obesity prevention.</li><li>• Preventative measures including support for gluten-free diets.</li><li>• Non-clinical interventions that support prevention through VCSEs.</li><li>• Motivating people into work for their own wellbeing.</li><li>• Early diagnosis and prevention to maintain good health.</li><li>• Education to avoid misuse of NHS services.</li><li>• Self-care support and education.</li></ul>

Access and integration	System infrastructure and workforce
<ul style="list-style-type: none"> <li>Improving GP access (e.g. reducing 16-week wait times).</li> <li>Better integrated care to avoid siloed services.</li> <li>Combined care across services and sectors.</li> <li>Continued access to medically necessary prescriptions (e.g. B12 injections, iron infusions).</li> </ul>	<ul style="list-style-type: none"> <li>Staff wages and retention.</li> <li>Research and innovation.</li> <li>Dentistry services.</li> <li>Optical services.</li> <li>Pharmacy services.</li> <li>Community-based services and support through VCSOs.</li> </ul>

Equity and inclusion	Operational improvements
<ul style="list-style-type: none"> <li>Tackling health inequalities.</li> <li>Ensuring older people are not overlooked in care planning.</li> <li>More understanding of mental health across the NHS.</li> <li>Adjusting services for people with Special Educational Needs (SEN).</li> </ul>	<ul style="list-style-type: none"> <li>Avoiding department closures for lunch breaks (e.g. elderly care and ultrasound).</li> <li>Avoiding batch prescriptions to reduce waste.</li> <li>Ensuring GPs issue correct gluten-free prescriptions first time.</li> </ul>

## About NHS costs

People were told how a gluten-free bread mix costs about £2.27 in a shop. But the NHS pays around £9.57, plus up to £2.00 for delivery. That means the NHS might pay five times more than if someone bought it themselves.

With this background information, we asked people if they think the NHS should pay for gluten-free bread, rolls and flour mix on prescription.

Half of survey respondents (50%) thought the NHS should fund this for everyone with coeliac disease or dermatitis herpetiformis. A further 29% thought the NHS should fund prescriptions for those in greatest need.

Should NHS pay for prescriptions	N	%
Yes, for everyone with coeliac disease or dermatitis herpetiformis	706	50%
Yes, but only for those in greatest need (e.g., low income, rural areas)	407	29%
No, people should buy their own	205	15%
Not sure	92	7%
	1,410	

The following groups of people were more likely to think the NHS should pay for these prescriptions for everyone with coeliac disease or dermatitis herpetiformis:

- Pregnant women and new mothers (71%, n=15).
- People currently in receipt of a prescription (70%, n=509).
- Respondents aged between 16 – 24 years (67%, n=28).
- Respondents aged over 65 years (61%, n=211), with 59% of respondents aged over 75 years (n=72).

Respondents with coeliac / parent of a child with coeliac who is not in receipt of a prescription were more likely to think prescriptions should be provided for people in greatest need (47%, n=136).

The following respondents were more likely to think people should pay for their own prescriptions:

- People who do not have coeliac disease or dermatitis herpetiformis and do not care for someone who does (49%, n=45).
- Professionals (47%, n=85).
- Respondents from non-white ethnic backgrounds (32%, n=13), including people who identify as South-Asian (36%, n=10).

### **Yes, for everyone (n=636) AND Yes, but only for those in greatest need (n=340)**

Themes among participants who thought the NHS should pay for people in greatest need were largely similar to those who supported prescriptions for everyone. Both groups emphasised the medical necessity of gluten-free products, the importance of equity, concern over high costs, and support for alternative approaches to prescription provision. Participants who supported prioritising those in greatest need were more likely to

reference vulnerable groups in their responses, such as low income families, children, pensioners, and people in rural areas, highlighting the need to protect those most at risk.

### **Medical necessity and equity**

Across both groups, coeliac disease was consistently described as a lifelong autoimmune condition requiring strict dietary management. Gluten-free foods were widely regarded as essential for health, comparable to medications for other chronic conditions. Equity of access was a common concern, highlighting the disproportionate impact on low income families, pensioners, and those just above benefit thresholds.

*Bread/rolls/flour mix is an essential part of a celiacs diet, similar to insulin for diabetics, both being an Autoimmune disease with no cure. (Prescriptions for all)*

*Working as a dietitian in gastroenterology, I see first-hand the impact of food costs on diet and health management. Removing access to gluten-free bread, rolls and mix for those who need it most (low income, rural areas), means these patients do not have the resources to manage their health condition, and increases the health disparity. (Prescriptions for greatest need)*

### **Financial burden and NHS procurement**

Both groups expressed frustration with the high cost of gluten-free products and inefficiencies in NHS procurement, questioning why the NHS pays significantly more than retail prices and calling for better contracts, bulk purchasing, and supplier negotiations.

*The cost of gluten free products is at least four times more expensive. (Prescriptions for all)*

*People on low incomes are disproportionately affected by the increase in living costs. Removing prescription for GF products for low income patients will further widen the gap between health outcomes (relating to CD) between social classes. (Prescriptions for greatest need)*

### **Alternative solutions and policy recommendations**

Participants in both groups suggested alternatives to the current prescription system, including vouchers, pre-paid cards, or monthly allowances, which were viewed as more flexible, cost-effective, and empowering while maintaining access to essential dietary items.

*Given what you say about how much it costs the NHS I understand why you would want to stop it, give vouchers to put towards gluten free bread in the supermarkets. (Prescriptions for all)*

*I hope prescriptions / financial help continues for those on lower incomes, with children, those with disabilities etc. (Prescriptions for greatest need)*

## **No, people should buy their own (n=181)**

### **NHS spending and resource allocation**

Respondents were concerned about the financial efficiency of providing gluten-free products on prescription. Many highlighted that items such as bread mixes cost the NHS several times more than their supermarket equivalent, which is seen as poor value for money in a pressured healthcare system.

*NHS should not pay for anything that no one would spend their own money on. No one (regardless of their income) would spend £9.57 - £11.57 on gluten-free bread mix. It is simply not value-for-money.*

Many argued that resources should focus on essential medical treatments such as cancer care, mental health services, and emergency provision rather than subsidising everyday dietary products.

*Indulging in these takes away valuable resources from those who really need urgent care (ie cancer treatments, emergencies, GP services etc). Its reprioritizing those who need it most.*

Suggested alternatives included voucher schemes or NHS discount cards, which would allow patients to buy gluten-free items at retail prices while reducing costs to the NHS.

*People should ideally be provided with vouchers for Gluten Free food to be purchased in supermarkets avoiding unnecessary costs to the NHS*

### **Availability and accessibility of gluten-free products**

Respondents felt the availability of gluten-free products in mainstream supermarkets had increased. Bread, flour, and pasta are now widely stocked, often at prices more competitive than in the past. Some felt this reduced the need for prescriptions, suggesting that individuals can now self-manage their diets without NHS provision.

*Gluten free foods are widely available in supermarkets. However, the prices should be brought in line with other non gluten products.*

Many also pointed to naturally gluten-free alternatives such as rice and potatoes, questioning whether prescribed bread is essential.

*People can manage without bread and pasta as a carbohydrate source, there are alternatives such as rice (including rice crackers etc) and potatoes.*

While recognising that gluten-free foods remain more expensive than standard products, many proposed that support should be targeted at those on lower incomes rather than applied universally.

*I think people should buy their own but those on low income should be provided with vouchers to use in the supermarkets*



## **NHS funding priorities and fairness**

Some respondents argued that prescribing gluten-free products is inconsistent with how other dietary needs, such as lactose intolerance or nut allergies, are treated.

*Gluten-free foods are not an essential part of their diet and can be omitted like people have to do when they are lactose intolerant or have food allergies e.g. nut allergies.*

There was concern that continuing prescriptions for coeliac disease could divert resources away from more urgent or life-saving services, such as specialist treatments, preventative care, or access to medications.

*I think the money saved by stopping this could be better used within other NHS services such as cancer care and treatment*

Several respondents also highlighted broader frustrations with NHS procurement and management, suggesting that inefficiencies are driving unnecessary costs.

*NHS procurement needs sorting out -they shouldn't be paying more than a consumer.*

## **Not sure / no response (n=88)**

### **Lifelong condition and support needs**

Many felt that financial help or free prescriptions are justified, as the condition is a medical necessity rather than a lifestyle choice. Some compared this to other health conditions supported by the NHS, such as diabetes or addiction, and warned that removing support would unfairly penalise people for something beyond their control.

*It's a life long condition with no fault so we should get free prescriptions*

There was a strong view that support should be inclusive and consistent, particularly for those on low incomes. Some suggested government-level interventions, such as benefits or allowances, to help cover the cost of gluten-free essentials.

*Financial assistance for those in need would help those on lower incomes purchase their own at less cost to the NHS*

### **Cost and procurement inefficiency**

Respondents noted that some gluten-free products, such as bread mixes, cost the NHS several times more than retail prices, describing this as ridiculous, disgraceful, and inefficient. Many felt the system showed poor accountability and called for better contracts, bulk purchasing, and direct supplier negotiations.

*The question is why is the NHS being charged obscene amounts of money?*

### **Alternative models of support**

Some people identified alternatives to prescriptions, particularly vouchers, pre-paid cards, or monthly allowances. Respondents widely supported these options as more flexible and cost-effective, allowing patients to buy gluten-free products at retail prices while avoiding inflated procurement costs.

*Clearly the system is ridiculous. We should be given vouchers so we can obtain them from a local supermarket.*

The Welsh model was frequently cited as a positive example, with many suggesting similar schemes should be adopted in England.

*I think adopting what Wales have done and offering a card topped up to spend makes so much more sense when seeing the costs the NHS are paying for each item.*

## Final thoughts

Survey respondents were invited to give their final thoughts the proposal to stop gluten-free foods on prescription, and 942 chose to leave a comment. Their responses can be grouped into the below themes.

### Economic hardship and affordability

Respondents repeatedly stressed the financial strain of removing prescriptions, particularly for those on low incomes. Prescriptions were described as essential, not a luxury.

*This is an illness not a life choice. Gluten free products are a shocking price. Bread and flour are staple foods not luxury*

Others highlighted the unfairness of expecting families to shoulder excessive costs.

*Don't take this option away from people that cannot afford these prices. It's unfair.*

### Accessibility and availability

Many criticised the postcode lottery of support across England, calling for a fairer, standardised approach.

*It should not be a postcode lottery as to what support is available, that is discrimination.*

Concerns were also raised about those in rural areas with limited access to supermarkets.

*My main concern would be the rural population... For example Maryport main supermarket is Lidl which does not supply gluten free bread, wraps, rolls or flour mix.*

### Policy, advocacy, and system support

Respondents questioned NHS procurement practices, arguing that the NHS was overpaying for products and should negotiate better contracts rather than withdraw support.

*You need to look at where the NHS sources their products and why it costs so much—that's your problem.*

### **Psychological and social wellbeing**

The emotional toll of removing prescriptions was described as significant, with many feeling punished for having a medical condition.

*I think it's disgusting to stop it. They can't help having this auto immune disease... They need this to be healthy.*

There was also a strong sense that coeliac disease was not being taken seriously compared to conditions treated with medicines.

*It is discriminatory - just because diet is the treatment doesn't mean support shouldn't be there from the NHS.*

### **Voucher provision**

Several respondents suggested vouchers, as used in Wales, as a more flexible alternative to prescriptions. While not without drawbacks, vouchers were seen as preferable to removing support entirely.

*Vouchers towards gluten free foods would be an alternative to prescriptions and be a more cost effective way for the NHS to support patients...*

# Online focus group and community group findings

## Overall profile

### Online focus group respondents

In total, we collected feedback from 17 people through the online focus groups. Not all respondents provided demographic information. A summary is included below.

- Nine respondents had coeliac disease or dermatitis herpetiformis.
- Four respondents were the parent, guardian, or carer of a child under 16 with coeliac disease or dermatitis herpetiformis, and one person identified caring for someone aged 16 or over who has coeliac disease or dermatitis herpetiformis.
- Four respondents identified themselves as professionals. Including two dietitians, and two community group representatives.
- 15 participants who shared a postcode were from the North East and North Cumbria area. Six participants were from rural areas and seven participants were from the top 20% most deprived areas.
- 14 participants were female, and three participants were male.
- Five participants were from low income households.
- 11 participants identified a long-term health problem, of which 10 people were affected a little or a lot.
- All respondents who shared the information identified as straight or heterosexual.
- Two respondents identified their ethnicity as mixed or multiple ethnic groups. The remaining participants were from a white ethnic background.
- Eight participants identified their religion as Christian, and seven said they had no religion or belief.
- Participants from a range of age groups attended the focus groups, including: 16 – 24 (x1); 25-34 (x1); 35-44 (x2); 45-54 (x8); 55-64 (x2); 65-74 (x1); 75-84 (x1)

### Community groups

We spoke with members of the public through the following two County Durham forums.

- County Durham Patient Reference Group: This group brings together patients from local GP practices in County Durham. The group meets every six weeks to talk about local services and share ideas for improvement. Eight people attended the meeting on 24 July 2025.

- County Durham Health and Care Engagement Forum: A monthly meeting for public and community members to plan how we talk with local people about health and care. It also includes people from local services who work together to make things better. 15 people attended the meeting on 7 August 2025

## Impacts of removing gluten-free prescriptions

This theme explores the potential impacts of removing gluten-free prescriptions. Participants' concerns about the potential changes highlighted the significant financial burden of increased costs, health and wellbeing risks, and the unique challenges faced by vulnerable groups such as children, disabled individuals, low income households, rural communities, and older adults.

### Burden of increased costs

Participants repeatedly highlighted the high cost of gluten-free products compared to standard gluten containing items. This financial strain is especially acute for those on low incomes, with families and individuals struggling to absorb the additional expense:

*It's going to cost £240 a year for somebody, you know, if you remove the prescription [I'm] really worried how they're going to manage.*

The potential financial burden of purchasing gluten-free products is a significant concern for many individuals and families, particularly those with limited incomes. The high cost of these items, exacerbated by the ongoing cost of living crisis, places additional strain on those who require gluten-free diets for health reasons.

### Health and wellbeing risks

The proposed removal of gluten-free prescriptions raised significant concerns about the health and wellbeing of individuals with coeliac disease. Participants highlighted potential risks to dietary compliance, nutritional deficiencies, and negative long-term physical and mental health outcomes.

### Dietary adherence and risk of non-compliance

Participants repeatedly emphasised that without prescriptions, many individuals would struggle to maintain a strict gluten-free diet due to cost and accessibility. This could lead to serious health consequences:

*The chances of them [people with coeliac] actually following a gluten free diet if we take it off the prescription are reduced. So they're going to have increased health problems because they're not following the diet.*

Another health professional echoed this concern, noting that some patients already struggle with compliance and that removing prescriptions would exacerbate the issue:

*I've had patients who haven't been compliant with their gluten free diet... then have wanted to start on nutritional supplements which are additional cost.*

### **Nutritional deficiencies and physical health risks**

Participants discussed the nutritional value of gluten-free prescription items, particularly fortified bread and flour, and the risks of substituting them with less nutritious alternatives:

*Bread is fortified... with B vitamins and all sorts of stuff. If people substitute with rice and potatoes, they're getting less iron and calcium.*

There were concerns about long-term health conditions resulting from untreated or poorly managed coeliac disease:

*Possible small bowel cancer, osteoporosis, infertility, neurological conditions – all of which can be caused by untreated coeliac disease.*

These risks were seen as preventable with proper dietary support, making prescriptions a vital part of disease management.

### **Mental health and emotional wellbeing**

The psychological toll of managing coeliac disease without support was another key concern. Participants described stress, anxiety, and feelings of isolation:

*It's not just the physical symptoms – mental health deteriorates when people can't follow their diet.*

One participant shared a personal story:

*I used to suffer from panic attacks... as soon as I went on a gluten free diet, they stopped. I haven't had another panic attack in 18 years.*

This illustrates how dietary adherence can directly affect mental health and quality of life.

### **Preventative healthcare and NHS costs**

Several participants argued that prescriptions are a form of preventative healthcare, helping individuals stay healthy and avoid more costly interventions later:

*To me it seems very short sighted to take something away that helps people live a healthy diet... the cost to the NHS of future health issues will far outweigh this.*

This perspective was shared by both patients and professionals, who warned that removing prescriptions could lead to increased demand for medical services, including nutritional support and treatment for complications.

*It will have some long-term effects on these patients and therefore have long-term cost implications to the NHS.*

The removal of gluten-free prescriptions raises concerns about the health and wellbeing of individuals with coeliac disease, as it could lead to dietary non-compliance, nutritional deficiencies, long-term physical and mental health issues, and increased future healthcare costs.

## **Impacts on vulnerable groups**

The impacts of removing prescriptions for gluten-free products on various vulnerable groups were discussed in all focus groups. Participants highlighted concerns and potential challenges faced by children and young people, disabled individuals, low income households, rural communities, and older adults.

### **Impacts: children and young people**

Parents and carers expressed concern about how the removal of prescriptions would affect children with coeliac disease. The cost and availability of gluten-free products were seen as barriers to maintaining a safe and healthy diet for young people:

*I worry about how they're [parents] going to manage, if they don't get the flour and the bread.*

School meals were a particular concern, with parents noting the difficulty of ensuring gluten-free options in educational settings:

*My children need safe options at school. The removal of prescriptions makes it hard to ensure they aren't exposed to gluten.*

There was also anxiety about the long-term implications for young people transitioning into adulthood, especially regarding financial independence:

*Without this prescription, he's got an extra expense on his weekly, monthly salary that other people don't have. And that is a burden.*

Overall, the removal of gluten-free prescriptions poses significant challenges for parents and carers, impacting the dietary management, financial burden, and overall wellbeing of children with coeliac disease.

### **Impacts: disabled people**

Disabled individuals may face additional logistical barriers if prescriptions were removed, especially if they cannot easily travel to supermarkets or rely on others for shopping. One participant shared their experience:

*I've got a disability, which means I can't drive and I rely heavily on things and other people having to go out and get me things.*

The same participant described issues with online shopping, such as receiving expired or short-dated products:

*I got delivered a gluten free cake that was a month out of date... I had to get it refunded.*

This illustrates how disabled people who depend on delivery services may be more vulnerable to poor product quality and limited resources, especially if prescriptions are no longer available.

### **Impacts: low income households**

Participants repeatedly emphasised the financial strain that removing prescriptions would place on those with limited incomes. Gluten-free products are significantly more expensive, and many families are already struggling due to the cost of living crisis:

*Everyone's seen their bills go up through the cost of living crisis, and gluten free food is expensive to shop for.*

There was a strong sense that removing prescriptions would exacerbate food insecurity and force families to make difficult choices:

*So it's very rare [to have gluten free food at the food bank]...so when you go and you get your little parcel, you get gluten in the parcel. So, then I have to stand, you have to give it all back because you can't eat that. So, then you're getting like there's just nothing. There's just nothing.*

The removal of prescriptions for gluten-free products would likely exacerbate financial strain and food insecurity for low income households, forcing them to make difficult choices and potentially compromising their health and wellbeing.

### **Impacts: rural communities**

Access issues were a major concern for participants living in rural areas. Limited availability of gluten-free products in local shops and the need to travel long distances were frequently mentioned:

*Out in a rural area [it is] really difficult in small shops to find gluten-free bread and things like that. It's just not there now...if you live in one of those areas, that's where you live your whole life, this prescription, which turns up every month, at least it's there. It is product that you can eat and you can have. And it means you don't have to maybe travel 20 miles to get to the nearest Tesco. It's not, it's not just about the finances involved, it's just the availability of it..*

Participants also noted that voucher schemes might not be effective in rural areas unless paired with delivery options or online access:

*I thought the voucher system was a really good idea until I kind of realised that not everyone can get to a supermarket to use the voucher.*

Rural communities face unique challenges accessing gluten-free food which raises issues about equitable availability of gluten-free products.

### **Impacts: older people**



Older adults were identified as another group likely to be disproportionately affected. Participants highlighted issues such as comorbid health conditions and digital exclusion:

*The elderly often have additional health issues – removing their access to gluten free items might worsen comorbidities.*

There was concern that older people may not be able to navigate alternative systems, such as online shopping or voucher schemes:

*Older people who might not use things like debit cards or online ordering would struggle with a voucher system.*

Consideration of the challenges faced by older adults is essential to ensure that they are not disproportionately affected by changes in access to essential services and goods.

This theme explored the potential impacts of removing gluten-free prescriptions, focusing on the significant burden of increased costs, health and wellbeing risks, and the unique challenges faced by vulnerable groups such as children, disabled individuals, low income households, rural communities, and older adults. Participants raised concerns about the health and wellbeing of individuals with coeliac disease, as it could lead to dietary non-compliance, nutritional deficiencies, long-term physical and mental health issues, and increased future healthcare costs. Addressing the unique challenges faced by vulnerable groups is, in their view, essential to ensure equitable access to gluten-free products and maintain support for those who rely on these prescriptions to manage their health and wellbeing.

## **Procurement costs of gluten-free prescriptions**

This theme explores the views of participants in relation to perceived disproportionate costs faced by the NHS, the contrasts between prescription and retail prices, and the potential for stimulation of market competition to deliver better value while maintaining support for those in need.

### **Disproportionate costs to the NHS**

Across all focus groups participants discussed the inflated costs that the NHS pays for the provision of gluten-free foods on prescription compared to the cost of gluten-free foods in a retail setting. This disparity was a central point of discussion:

Disbelief and frustration were central to the discussions in the first instance. As the participant below noted:

*Why does it cost the NHS that much? Can they get an exclusive contract? Can they get a better deal?*

The perceived inefficiency in procurement was seen as a key driver behind the proposed removal of prescriptions, but many felt this was a symptom of poor management rather than an unavoidable cost. Participants questioned the procurement process and suggested that better deals could be negotiated with suppliers:

*Have they explored everything? Is every absolutely everything being explored where they've actually got people that work in sales to actually broker a deal with these companies?*

There was a strong sense that the NHS should not simply remove support but instead improve its procurement strategy:

*The figure that it's costing the NHS is absurd... the first thing the NHS needs to look at is how can we be more efficient?*

This was not just about cost cutting but about ensuring that patients who rely on these products are not penalised due to systemic inefficiencies. However, these discussions were often tempered by some participants acknowledging that these inflated costs to the NHS included not only the cost of the item, but the administration and management of delivering prescriptions. As one participant discussed:

*Why it costs £9.57 [is] because of the big departments. It's, you know, it's the same if I drive to the supermarket. The actual cost of the bread that I buy isn't £3. It's, you know, my loss the whatever my hourly wage is, the petrol, the wear and tear on the car so that £9.57 figure or whatever it is, is actually more reflective of real life...whatever systems [are] in place there is an administrative cost...whatever we do - people moan about a delivery charge from a supermarket but it's often a damn site cheaper than your time and effort and petrol and wear and tear.*

There was general agreement that the current system of providing gluten-free food on prescription was an unsustainable cost to the NHS and that alternative systems needed to be considered that still supported people who need to eat gluten-free foods to stay healthy, offset the additional costs for patients, but simultaneously reduced costs for the NHS.

## **Comparisons with NHS and online prices**

Participants frequently compared NHS costs with their own experiences buying gluten-free products. Some items that are available on prescription are not available in retail stores, for example Juvella products. They are, however, available to purchase online. Participants noted with a little bit of planning these items could be sourced for much less than the NHS currently pays:

*I can get the same bread myself through paying for it... £27 for eight loaves of bread, so that works out at £3.50 and it's free delivery.*

These comparisons highlighted the stark contrast between NHS procurement and consumer purchasing, leading to conversations about how removing prescriptions could have a beneficial effect on the choice and variation available to people in retail settings.

## Stimulating market competition and reducing costs

Several participants suggested that voucher schemes could encourage supermarkets and suppliers to improve their gluten-free offerings and reduce prices:

*[providing] vouchers is a brilliant scheme because then I think it will increase the competitiveness amongst companies and they would bring their costs down.*

This reflects a belief that market forces, if properly harnessed, could lead to better availability and affordability of gluten-free products.

*If the companies are charging extortionate amounts, something needs to be done about that, either through negotiation from the NHS or through a voucher scheme.*

This theme explored perceptions about the disproportionate costs faced by the NHS in providing gluten-free foods on prescription compared to retail prices. Participants expressed disbelief and frustration over the inflated costs and questioned the efficiency of the NHS procurement process. However, some people acknowledged that the higher costs included administrative and management expenses. There was hope that if prescriptions were stopped, it could lead to producers of gluten-free foods to increase their availability and reduce costs to the consumer. There was a consensus that the current system was unsustainable and that alternatives need to be explored.

## Alternatives and solutions to gluten-free prescriptions

Building on the last theme, participants identified that the current way of providing gluten-free food was not sustainable and discussions turned to alternative support options to identify solutions. This theme delves into the range of solutions proposed in response to the potential removal of prescriptions. The focus is on community-based support and financial assistance, both aimed at ensuring equitable access to necessary resources for individuals managing coeliac disease. affected by the condition.

*It's not just a black and white area of prescriptions provided, prescriptions stopped. There's a whole area of other support that needs to be considered.*

## Community-based support

### Dietitian support

Dietetic support was highlighted as a potential support mechanism. Participants discussed the varying experiences they had with dietetic support for managing coeliac disease. As one participant illustrated.

*[dietetic support] Didn't really help me too much because I felt like a lot of the advice I got was like quite basic, but that was just my experience.*

Participants emphasised the need for more specialised and focused dietetic support, suggesting that online group settings with expert dietitians could be beneficial.

*The NHS could look at the dietitians. Maybe have more specialist dietitians. I think there's been, you know, one or two. We've spoken to where their knowledge I felt wasn't very focused, quite general. You know you we can have meetings like this [online via Teams]. It doesn't need to be face to face...[with] a group of expert dietitians who you could have meetings with on an annual [or] bi- annual basis...Maybe that would be helpful. Possibly.*

## **Social media**

Participants provided insights into the supportive role that online communities, particularly Facebook groups, play in helping individuals manage a gluten-free diet. Participants shared their experiences with these groups, emphasising their value in offering practical advice, sharing product recommendations, and fostering a sense of community among those navigating the challenges of living gluten-free:

*There's a there's a Facebook group. I don't know if you're aware of it called: gluten free dupes, and it's an absolute lifeline. Honestly, it's amazing. So, people will go on and they'll show you. They'll say been in Iceland, this is the haul that I've got... and its basically things that you wouldn't expect to be gluten free that are gluten free. And so, I come across that group. So, I suppose if there was some literature that the government produced around that, that would be super helpful.*

## **Educating the general population**

The importance of educating the general public about coeliac disease was raised by some participants. Raising awareness among those who do not have the condition is crucial to prevent casual cross-contamination and to ensure that people understand the serious health risks, such as cancer, associated with gluten contamination.

*I think educating people who aren't celiac is more important than educating people who are*

The varying experiences participants had with dietetic support for managing coeliac disease were highlighted. While some found the advice to be basic and not particularly helpful, there was a call for more specialised and focused dietetic support. Participants suggested that online group settings with expert dietitians could be beneficial, allowing for more accessible and tailored guidance. This approach could enhance the overall management of coeliac disease and improve the quality of life for those affected.

## **Voucher/cash schemes as an acceptable alternative**

The most frequently cited and most acceptable solution was the introduction of a voucher/cash scheme to replace prescriptions of gluten-free food. These schemes were referenced as a promising alternative to traditional prescriptions. Many cited the Welsh model, where

prepaid debit cards are used to subsidise the cost difference between gluten-free and standard products:

*I really love what they're doing in Wales, where they're basically giving people vouchers to use in supermarkets.*

### **Precedents and comparisons**

Participants drew comparisons with existing schemes, such as Healthy Start vouchers, which are used to purchase milk and fruit and veg:

*They've got the NHS, has a voucher system that they use for people to buy milk and fruit and veg with. So it would be a very similar system I would presume.*

This suggests that the infrastructure and precedent for such schemes already exist, making implementation more feasible.

### **Subsidies to offset additional cost**

Voucher schemes and cost-sharing models were frequently suggested as alternatives to prescriptions. These were seen as potentially more equitable and cost-effective:

*Instead of having the entire cost of a loaf of bread, it would just be the difference that was paid so that everybody was at the same kind of level.*

These suggestions highlight a strong preference for financial support to offset the additional cost of gluten-free foods.

### **Equity and accessibility concerns**

While voucher schemes were broadly supported, participants raised concerns about accessibility and digital inclusion.

*It wouldn't suit everybody for many of the reasons we've just mentioned, which I totally understand. Yeah, you know the elderly, that's difficult. Maybe they wouldn't be able to use it if you don't have access to the shops where you could spend it, that would make it difficult. If you can't get online.*

This highlights the need for any alternative system to be inclusive and adaptable to different living situations. Suggestions included linking vouchers to online shopping or delivery services to ensure equitable access.

*It will be really important to continue with prescriptions for people who couldn't get out to a supermarket or didn't have availability in their area.*

## Flexibility and personalisation

Voucher systems were seen as offering greater flexibility than prescriptions, which are often limited to specific products:

*It would give you more range of products that you could have because the prescription list is very, very rigid.*

Participants valued the ability to choose products that suit their tastes and dietary needs, rather than being restricted to a narrow list.

*The bread is so much better that you can buy in the supermarkets... I would love to see people given vouchers to spend in stores.*

This approach was seen as potentially more flexible and empowering, allowing individuals to choose products that suit their preferences and dietary needs while reducing NHS procurement costs.

Participants discussed the unsustainability of the current gluten-free prescription system and explored alternative support options. They explored the need for more specialised dietetic support, suggesting online group settings with expert dietitians. The supportive role of online communities, particularly Facebook groups, was highlighted for their practical advice and sense of community. Educating the general public about coeliac disease was deemed crucial to prevent cross-contamination. The introduction of voucher/cash schemes was the most acceptable alternative to prescriptions, with the Welsh model cited as a promising example. Comparisons were drawn with existing schemes like Healthy Start vouchers, suggesting feasibility. Voucher schemes and cost-sharing models were seen as more equitable and cost-effective. Concerns about accessibility and digital inclusion were raised, highlighting the need for an inclusive system.

## Letters and email responses

In addition to the survey responses and focus groups, an additional 16 responses were received by letter and email. discussions.

- Members of the public (x13, one of which forwarded by a second local MP).
- A representative from a Facebook support group.
- An MP.
- Coeliac UK.

## Financial burden and accessibility

**Public:** Many individuals highlighted the high cost of gluten-free products, especially bread and flour mixes, which are essential for those with coeliac disease. Pensioners and families with children diagnosed with coeliac disease expressed particular concern, noting that gluten-free items can add £15 or more to weekly shopping bills. Some respondents suggested alternatives such as a voucher scheme or a subscription model to ease the financial strain.

**Facebook support group:** Members echoed similar concerns, with detailed examples of how much more expensive gluten-free products are compared to standard items. The group shared that prescriptions help mitigate these costs, especially for families and individuals with specific dietary needs that cannot be met by supermarket products.

**MP:** The MP's response emphasised that gluten-free staples are four to six times more expensive than their gluten-containing counterparts and often unavailable in budget or convenience stores, particularly affecting rural and low income constituents.

**Coeliac UK:** Coeliac UK provided extensive evidence showing that gluten-free products are two to four times more expensive, with some items costing up to 22 times more per gram than standard equivalents. They also highlighted poor availability in budget supermarkets, especially in deprived and rural areas.

## Health implications of non-adherence

**Public:** Several respondents stressed that removing prescriptions could lead to non-adherence to the gluten-free diet, especially among those who cannot afford the products. This could result in serious health consequences, including malnutrition and long-term complications.

**Facebook support group:** Members shared personal stories of severe symptoms when consuming gluten and the critical role of prescriptions in maintaining health. Some noted that specific brands available only via prescription are the only ones they can tolerate.



**MP:** The MP warned of preventable complications such as osteoporosis, anaemia, and growth issues in children, arguing that removing prescriptions would undermine treatment adherence and increase NHS costs in the long-term.

**Coeliac UK:** Their response detailed the clinical risks of non-adherence, including increased rates of osteoporosis, cancer, and growth delays in children. They cited research showing that prescription access improves dietary adherence and reduces long-term NHS costs.

## Inequality and vulnerability

**Public:** Respondents on pensions or low incomes expressed concern about being disproportionately affected. Some suggested that limiting product choice or introducing a modest annual fee could be fairer than full withdrawal.

**Facebook support group:** The group highlighted that not everyone can shop online or afford upfront costs, and that prescriptions are a lifeline for many vulnerable individuals.

**MP:** The MP focused on health inequalities, noting that the policy change would disproportionately affect low-income, rural, and disabled individuals, and families with multiple coeliac members.

**Coeliac UK:** They emphasised that the North East and North Cumbria includes some of the most deprived areas in England, and that withdrawal of prescriptions would exacerbate existing inequalities. They urged the ICB to consider alternative models used in Wales and Scotland that better support vulnerable populations.

## Policy and procurement critique

**Public:** Some respondents questioned why the NHS pays significantly more for gluten-free products than consumers do, suggesting inefficiencies in procurement.

**Facebook support group:** There was frustration over restricted access to specific brands and cutbacks in prescription allowances, with calls for more transparency and fairness.

**MP:** The MP criticised the lack of strategic procurement and urged the ICB to consider NICE and Department of Health guidance, which supports gluten-free prescribing.

**Coeliac UK:** They provided detailed analysis of inefficient NHS procurement practices, arguing that this should be addressed rather than used as a reason to withdraw support. They also outlined alternative prescribing models used successfully in other UK regions.



## Discussion

The following discussion brings together the key findings from across all strands of the patient and public involvement activities, including survey data, focus groups, open survey comments, and written submissions. This is to provide a comprehensive understanding of the experiences, challenges, and perspectives of individuals managing coeliac disease and accessing gluten-free prescriptions.

### Diagnosis and disease management

Most respondents (91%) had been diagnosed more than a year ago, though recent diagnoses were more common among children and young adults. Qualitative narratives highlighted the challenges of navigating a new diagnosis, with one parent stating:

*I didn't even know this was a thing. No one has told me about this... My daughter was diagnosed a month ago and we're navigating this.*

This underscores the need for early support and clear guidance for newly diagnosed individuals and their families.

### Access to prescriptions

Nearly three-quarters (72%) of survey respondents received prescriptions for gluten-free bread and flour. Access was more prevalent among older adults, South Asian respondents, and carers of children. Prescriptions were widely viewed as essential, with one respondent noting:

*It's really quite expensive to buy and couldn't afford it without having my prescription.*

This sentiment was echoed across both survey data and qualitative feedback, reinforcing the role of prescriptions in enabling dietary adherence.

### Economic hardship and affordability

Affordability was a dominant theme. Gluten-free products were consistently described as expensive, with many respondents relying on prescriptions to manage costs. One participant shared:

*Currently I can afford to buy my gf products, but I am unsure of what the economic future holds for me.*

The cost of living crisis further exacerbated financial strain, particularly for pensioners, students, and families not eligible for benefits.

### Health necessity and dietary management

Prescriptions were seen as medically necessary, not optional. Respondents described how they supported complex dietary needs, including autoimmune conditions and diabetes. One individual explained:

*I have other autoimmune diseases and require low GI and high fibre diet in addition to gluten free... my one box per month is my lifeline.*

This highlights the intersection of coeliac disease with broader health management.

### **Quality, nutrition and satisfaction**

Many respondents valued the quality and nutritional benefits of prescription products, especially flour used for baking. A 90-year-old participant shared:

*I make my own bread buns... they are more palatable than the buns available in the shops.*

However, others expressed dissatisfaction with limited variety and poor quality of some prescription items, preferring supermarket alternatives.

### **Accessibility and availability**

Access to gluten-free products outside prescriptions was described as inconsistent and often inadequate. Respondents noted that some prescription items were unavailable in retail settings, and rural residents faced additional barriers.

*The flour mix we get on prescription... is not possible to buy, it is only available on prescription.*

This theme was particularly strong among older adults and those with mobility issues.

### **Psychological and social wellbeing**

The emotional impact of managing coeliac disease was significant. Respondents described anxiety, depression, and social exclusion.

*Everyone else can live a normal life & go out & enjoy food but us coeliacs cannot & it is very depressing & causes a lot of anxiety.*

Prescriptions were seen as a source of reassurance and dignity, helping individuals feel supported and included.

### **Concerns about removal of prescriptions**

The potential withdrawal of prescriptions raised widespread concern. Quantitative data showed 73% believed their costs would increase, and 33% were worried about access to gluten-free products. Qualitative responses added depth:

*I would feel that this autoimmune disease was not taken seriously.*

*You are forcing people to eat gluten as they could not afford gluten-free.*

These comments reflect fears of worsening health outcomes and increased inequality.

### **Alternative support models and suggestions**

Respondents proposed various alternatives, with voucher schemes being the most popular (65%). The Welsh model was frequently cited as a positive example. Suggestions included:

- Pre-paid cards for supermarket use.
- Subsidies to offset cost differences.
- Tiered support based on income or health needs.

Qualitative feedback also emphasised the value of:

- Dietetic support: Calls for more specialised, accessible services, including online group sessions.
- Community resources: Facebook groups and peer networks were described as lifelines.
- Public education: Raising awareness about coeliac disease to prevent cross-contamination and stigma.

### **Procurement costs and NHS efficiency**

Participants expressed frustration with NHS procurement practices, noting that gluten-free products cost significantly more when purchased through prescriptions.

*Why does it cost the NHS that much? Can they get an exclusive contract? Can they get a better deal?*

There was strong support for improving procurement efficiency rather than removing support altogether.

### **Impacts on vulnerable groups**

Focus group discussions and letters highlighted the disproportionate impact on vulnerable populations:

- Children and young people: Concerns about school meals and long-term financial burden.
- Disabled individuals: Barriers to shopping and reliance on delivery services.
- Low income households: Risk of food insecurity and poor dietary adherence.
- Rural communities: Limited access to gluten-free products locally.
- Older adults: Challenges with digital systems and comorbidities.

These insights underscore the need for inclusive, equitable support systems.

## Appendix 1 – Survey demographics

AREA	N=1414
Central (Sunderland, South Tyneside, County Durham)	17%
North (Newcastle, Gateshead, Northumberland, North Tyneside)	43%
Tees Valley (Hartlepool, Middlesbrough, Stockton, Redcar, Darlington)	26%
North Cumbria	9%
North East and North Cumbria	1%
Boarder or part of strategic NHS planning	2%
Either within North East and North Cumbria or on the boarder	1%
AGE	N=1376
16 – 24	3%
25 – 34	10%
35 – 44	21%
45 – 54	20%
55 – 64	20%
65 – 74	16%
75 – 84	8%
85+	1%
GENDER	N=1378
Female	78%
Male	22%
Non-binary	0.2%
SAME GENDER AS BIRTH	N=1384
Yes	99.6%
No	0.4%
BENEFITS OR LOW INCOME	N=1298
Yes – I get a benefit (e.g., Universal Credit)	13%
Yes – Someone in my home gets a benefit	5%
No – I do not get any benefits	73%
I would describe myself or my home as low income	8%
LONG-TERM HEALTH PROBLEMS OR DISABILITIES	N=1322
Yes	62%
No	38%

<b>HEALTH CONDITION AFFECTS DAILY LIFE</b>	<b>N=816</b>
Yes – a lot	44%
Yes – a little	44%
No	10%
<b>PREGNANT OR PREGNANT IN LAST 6 MONTHS</b>	<b>N=1209</b>
Yes	2%
No	98%
<b>SEXUAL ORIENTATION</b>	<b>N=1273</b>
Straight or heterosexual	95%
Gay or lesbian	2%
Bi or bisexual	2%
Other	1%
<b>ETHNIC BACKGROUND</b>	<b>N=1323</b>
Asian or Asian British (Includes: Indian, Pakistani, Bangladeshi, Chinese or any other Asian background)	2%
Black, black British Caribbean or African (Includes: black British Caribbean, African or any other black background)	0.2%
Mixed or multiple ethnic groups (Includes: white and black Caribbean, white and black African, white and Asian or any other mixed or multiple background)	1%
White Includes: English, Welsh, Scottish, Northern Irish or British; Irish; Gypsy or Irish Traveller; Roma, or any other white background	97%
Other Includes: Arab or any other ethnic group	0.1%
<b>RELIGION</b>	<b>N=1295</b>
No religion or belief	44%
Christian (including Church of England, Catholic, Protestant)	53%
Buddhist	0.3%
Muslim	1%
Jewish	0.1%
Sikh	0.2%
Hindu	0.2%
Other	1%

## Appendix 2 – Survey<sup>1</sup>

### Tell us what you think about NHS Prescriptions for gluten-free bread, rolls, and flour mix



North East and  
North Cumbria

The NHS North East and North Cumbria Integrated Care Board (ICB) is thinking about stopping gluten-free food prescriptions. **Currently, the ICB only offers prescriptions for gluten-free bread, rolls and flour.**

People with coeliac disease or dermatitis herpetiformis need gluten-free food to stay healthy. Some people with other conditions might also need it. Right now, they can get some gluten-free food on prescription from the pharmacy. But things have changed:

- Gluten-free food is easier to buy in shops and online.
- Food labels are clearer, so it's easier to pick the right things.
- These foods still cost more than normal food.
- The NHS has a limited budget and needs to spend money in the best way.

We haven't made any decisions yet. We want to know what you think. This survey will take 5 to 10 minutes. Your answers are private. We will not share your name or answers with anyone. Your feedback will be used to help the ICB make decisions.

#### 1: About the person filling in this survey

##### 1. Are you filling this survey out as...?



Please tick one box

<input type="checkbox"/>	I have coeliac disease or dermatitis herpetiformis	(go to Q2)
<input type="checkbox"/>	I am the parent, guardian or carer of someone with coeliac disease or dermatitis herpetiformis	(go to Q2)
<input type="checkbox"/>	I am responding in a professional role (e.g. healthcare, council, voluntary sector)	(go to Q3)
<input type="checkbox"/>	I do not have coeliac disease or dermatitis herpetiformis and do not care for someone who does	(go to Q12)
<input type="checkbox"/>	I'm not sure or haven't been diagnosed	(go to Q12)
<input type="checkbox"/>	Other (tell us more in the space below)	(go to Q12)

<sup>1</sup> Please note – the survey has been reduced in font size for the appendices. The space for open-ended comments has also been reduced. The original survey was 12 pages

**2. Please tell us about your experience of coeliac disease or dermatitis herpetiformis**

✓ Please tick all that apply

<input type="checkbox"/>	I have coeliac disease or dermatitis herpetiformis	(go to Q4)
<input type="checkbox"/>	I am the parent, guardian, or carer of a child under 16 with coeliac disease or dermatitis herpetiformis	(go to Q4)
<input type="checkbox"/>	I care for someone aged 16 or over who has coeliac disease or dermatitis herpetiformis	(go to Q4)

**3. Please tell us more about your role or interest in this survey**

✓ Please tick all that apply

<input type="checkbox"/>	I am a pharmacist / GP / dietitian / health worker	(go to Q11)
<input type="checkbox"/>	I work for another public organisation (e.g. council, NHS, education)	(go to Q11)
<input type="checkbox"/>	I work or volunteer for a public service or community group	(go to Q4)
<input type="checkbox"/>	Other	(go to Q4)

**4. If you work or volunteer for a public service or community group, or answered 'other', please tell us more in the space below**

--

**Now please move to Question 12 on page 5**

**2: Your experience of coeliac disease or dermatitis herpetiformis**

**5. When were you (or the person you care for) diagnosed with coeliac disease and/or dermatitis herpetiformis**

✓ Please tick one box

<input type="checkbox"/>	In the last 3 months
<input type="checkbox"/>	3 to 6 months ago
<input type="checkbox"/>	6 to 12 months ago
<input type="checkbox"/>	Over 12 months ago
<input type="checkbox"/>	I haven't been diagnosed
<input type="checkbox"/>	Not applicable

**6. Do you (or the person you care for) get gluten-free bread, rolls and flour mix on NHS prescription?**

✓ Please tick one box

	Yes – bread and / or rolls only
	Yes – flour mix only
	Yes – both bread, rolls and flour mix
	No – I used to, but I now buy my own
	No – I never had them on prescription
	Not sure

**7. How important is it to have the option of gluten-free bread, rolls and flour mix available on prescription?**

✓ Please tick one box

	Very important
	Important
	Not very important
	Not important at all
	Not sure / does not apply

**8. Why is this important or not important to you? (Please tell us in your own words)**

--

**9. What difference would it make if gluten-free bread, rolls and flour mix were no longer available on NHS prescription, if any. (Please tell us in your own words)**

--



**10. If NHS prescriptions for gluten-free bread, rolls and flour mix were no longer available, how would this affect you?**

✓ Please tick all that apply

<input type="checkbox"/>	No change - I never had prescriptions
<input type="checkbox"/>	No change - I already buy my own gluten-free bread, rolls and flour mix
<input type="checkbox"/>	It would cost me more
<input type="checkbox"/>	It would be harder to find gluten-free bread, rolls, and flour mix
<input type="checkbox"/>	I wouldn't know what food is safe
<input type="checkbox"/>	Other (please say):

**11. How confident would you feel managing a gluten-free diet without a prescription for gluten-free bread, rolls and flour mix?**

✓ Please tick one box

<input type="checkbox"/>	Very confident
<input type="checkbox"/>	Somewhat confident
<input type="checkbox"/>	Not very confident
<input type="checkbox"/>	Not at all confident
<input type="checkbox"/>	Not sure / does not apply

**3. What do you think about NHS spending on gluten-free bread, rolls and flour mix?**

The NHS is thinking about stopping gluten-free bread, rolls and flour mix on prescription for people with coeliac disease or dermatitis herpetiformis.

**12. How much do you agree or disagree with this idea?**

✓ Please tick one box

<input type="checkbox"/>	Strongly agree
<input type="checkbox"/>	Agree
<input type="checkbox"/>	Disagree
<input type="checkbox"/>	Strongly disagree
<input type="checkbox"/>	Not sure

**13. How easy or hard do you think these things are for people who need a gluten-free diet?**

✓ Please tick one box on each row

	Very easy	Quite easy	Quite hard	Very hard	Not sure
Finding gluten-free bread, rolls and flour mix near you?					
Affording gluten-free bread, rolls and flour mix near you?					

**14. If gluten-free prescriptions of bread, rolls, and flour mix were not stopped but changed, which would you support?**

✓ Please tick all that apply

	Only for people on low income or in greatest need
	Limit the amount each month of gluten-free bread, rolls and flour mix
	Give vouchers to help buy gluten-free products
	No prescriptions at all
	I don't know
	Other (please say):

**15. If NHS prescriptions for gluten-free bread, rolls and flour mix were no longer available, what support might help people manage a gluten-free diet?**

✓ Please tick all that apply

	Help from a dietitian or nutritionist
	Financial advice or support
	Information about cheap gluten-free food
	Cooking classes or support groups
	Online tools for meal planning or meal planning tools
	Support from a GP or health worker
	None needed
	I don't know
	Other (please say):

The NHS has a limited budget and must make difficult choices about how to spend it. What should it spend money on?

**16. Which of the following areas do you think the NHS should spend money on?**

✓ Please tick up to three boxes

<input type="checkbox"/>	A&E and ambulances
<input type="checkbox"/>	GP services
<input type="checkbox"/>	Mental health support
<input type="checkbox"/>	Cancer care and screening
<input type="checkbox"/>	Care for older people
<input type="checkbox"/>	Help for long-term health problems
<input type="checkbox"/>	Food or supplements on prescription (e.g., gluten-free, vitamins)
<input type="checkbox"/>	Children and young people's health
<input type="checkbox"/>	Other (please say):

**About NHS costs:**

A gluten-free bread mix costs about **£2.27** in a shop.

But the NHS pays around **£9.57**, plus up to **£2.00 for delivery**. That means the NHS might pay **five times more** than if someone bought it themselves.

**17. Do you think the NHS should pay for gluten-free bread, rolls, and flour mix on prescription?**

✓ Please tick one box

<input type="checkbox"/>	Yes, for everyone with coeliac disease or dermatitis herpetiformis
<input type="checkbox"/>	Yes, but only for those in greatest need (e.g., low income, rural areas)
<input type="checkbox"/>	No, people should buy their own
<input type="checkbox"/>	Not sure

**18. Why did you choose that answer?**

--

## 4: Final thoughts

- 19.** Do you have anything else you'd like to say about the proposal to stop gluten-free bread, rolls and flour mix on prescription? You can also suggest other ideas the NHS should think about.

## 5: About you

We'd like to ask some questions about you. You don't have to answer them, but we hope you will. This helps us understand who has taken part in the survey, and whether different groups of people have different views or needs. Your answers will be confidential. We won't share them in a way that could identify you.

- 20.** What are the first letters or numbers of your postcode.

For example: TS10, NE38, SR4

- 21.** How old are you?

✓ Please tick one box

<input type="checkbox"/>	16-24	<input type="checkbox"/>	25-34	<input type="checkbox"/>	35 – 44
<input type="checkbox"/>	45 - 54	<input type="checkbox"/>	55 – 64	<input type="checkbox"/>	65-74
<input type="checkbox"/>	75-84	<input type="checkbox"/>	85+	<input type="checkbox"/>	Prefer not to say

- 22.** What is your gender?

✓ Please tick one box

<input type="checkbox"/>	Female
<input type="checkbox"/>	Male
<input type="checkbox"/>	Non-binary
<input type="checkbox"/>	Prefer not to say
<input type="checkbox"/>	Prefer to self-describe (please write in)

**23.** Is this the same gender you were given at birth?

✓ Please tick one box

	Yes
	No
	Prefer not to say

**24.** Do you or anyone in your home get benefits or have a low income?

This helps us understand whether financial circumstances may affect views on prescriptions. You can skip this question if you prefer.

✓ Please tick one box

	Yes – I get a benefit (e.g., Universal Credit)
	Yes – Someone in my home gets a benefit
	No – I do not get any benefits
	I would describe myself or my home as low income
	I'm not sure
	Prefer not to say

**25.** Do you have any long-term health problems or disabilities?

✓ Please tick one box

	Yes
	No
	Prefer not to say

**26.** Do your health conditions affect your daily life?

✓ Please tick one box

	Yes – a lot
	Yes – a little
	No
	Not sure
	Prefer not to say

27. Are you pregnant or have you been pregnant in the last 6 months?

✓ Please tick one box

	Yes
	No
	Prefer not to say
	Not applicable

28. What is your sexual orientation?

✓ Please tick one box

	Straight or heterosexual		Bi or bisexual
	Gay or lesbian		Prefer not to say
	Other sexual orientation (please tell us)		

29. What is your ethnic background?

✓ Please tick one box

	<b>Asian or Asian British</b> Includes: Indian, Pakistani, Bangladeshi, Chinese or any other Asian background
	<b>Black, black British Caribbean or African</b> Includes: black British Caribbean, African or any other black background
	<b>Mixed or multiple ethnic groups</b> Includes: white and black Caribbean, white and black African, white and Asian or any other mixed or multiple background
	<b>White</b> Includes: English, Welsh, Scottish, Northern Irish or British; Irish; Gypsy or Irish Traveller; Roma, or any other white background
	<b>Other</b> Includes: Arab or any other ethnic group
	Prefer not to say

**30. What is your religion or belief?**

✓ Please tick one box

	No religion or belief		Jewish
	Christian (including Church of England, Catholic, Protestant)		Sikh
	Buddhist		Hindu
	Muslim		Prefer not to say
	Other (please tell us)		

**6: Would you like to join a focus group?**

We are running online and in-person focus groups to understand how these changes may affect people.

If you'd like to join, please fill in your details below. We will only use them to contact you about the group.

**Name:**

\_\_\_\_\_

**Email address:**

\_\_\_\_\_

**Phone number:**

\_\_\_\_\_

**What kind of group would you like to join?**

✓ Please tick one box

	Face-to-face
	Online
	I do not mind

**Do you need anything to help you take part?**

(e.g. large print materials, interpreters, wheelchair access)

\_\_\_\_\_

**Thank you for taking part in this survey.**

Your views will help the NHS North East and North Cumbria Integrated Care Board (ICB) make fair and informed decisions.

If you'd like this survey in another format or language, or have any questions, please contact us:

- **Email us at:** [nencicb.involve@nhs.net](mailto:nencicb.involve@nhs.net)
- **Call us on:** 0191 512 8484
- **Write to us at:** Gluten-free survey, North East and North Cumbria ICB,  
Pemberton House, Colima Avenue, Sunderland Enterprise  
Park, Sunderland SR5 3XB