

Public consultation on stopping NHS prescriptions for gluten free bread and bread mixes in Cheshire and Merseyside

Report of Findings

Report Prepared for:

NHS Cheshire and Merseyside

By:

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1.0 Introduction

In January 2025, NHS Cheshire and Merseyside Integrated Care Board (ICB) commenced a six-week public consultation about proposed changes to gluten free prescribing across Cheshire and Merseyside.

Praxis CIC (Community Interest Company) was appointed to analyse the feedback received during the public consultation and produce a report which could be used to inform final decision-making.

2.0 Public Consultation

What is being proposed?

NHS Cheshire and Merseyside is proposing that in the future, gluten free bread and bread mixes are no longer available on NHS prescription. This would mean that GPs wouldn't be able to prescribe them, so if people wanted them, they would need to buy these products themselves. If the change went ahead, it would apply to all areas of Cheshire and Merseyside, and to both adults and children.

Why is this change being proposed?

In the public consultation, NHS Cheshire and Merseyside set out four key reasons why it is proposing this change:

- To achieve consistency across different areas
- The need for the NHS to achieve value for money
- The increased availability of gluten free products
- The fact that bread and bread mixes are not the only way for people to get essential nutrients into their diet

Further detail is available in the supporting information produced for the public consultation, which is shown in appendix 22.

3.0 Consultation Methodology

NHS Cheshire and Merseyside produced supporting information about the proposal, which provided background to the issue, and included details of who would be likely to be impacted and how.

The information was accompanied by a questionnaire (appendix 23) containing both qualitative and quantitative questions, designed to gather people's views and perspectives on the proposals. Both the information and questionnaire were also made available in Easy Read format.

All materials were available on the NHS Cheshire and Merseyside website, with printed versions and alternative formats/languages available on request (via email or telephone). During the consultation period NHS Cheshire and Merseyside webpage received 2,376 page views. By email, 15 enquiries were received. People who were unable to complete the questionnaire had the option to provide their feedback over the telephone.

The consultation was promoted across NHS Cheshire and Merseyside's internal and external communication channels. Wider partners and stakeholders, including providers of

NHS services (hospitals, community and mental health providers and primary care), local authorities, Healthwatch, and voluntary, community, faith and social enterprise (VCFSE) organisations, were asked to share information using their own channels, utilising a toolkit produced for this purpose.

To ensure that those who would be most impacted by any potential change had an opportunity to share their views, NHS Cheshire and Merseyside put a particular focus on asking colleagues in general practice and local pharmacies to share information about the consultation with those who currently receive gluten free bread and bread mixes on prescription.

Analysis and Reporting

NHS Cheshire and Merseyside commissioned Praxis CIC to support analysis and reporting, based on the following requirements:

- a) Analysis and reporting of responses to the consultation questionnaire addressing the engagement objectives set out above, and any differing views/needs expressed by particular groups, including equalities groups. All data was provided as a single Excel dataset. Closed questions were analysed descriptively and statistically where relevant and possible. Open questions were analysed qualitatively – and where possible undertaking a thematic analysis of the responses.
- b) As part of this consultation there was a need to understand any equalities implications by exploring information presented by groups with protected characteristics. This required responses to be cross tabulated with each protected characteristic to better understand any differences of view. This is clearly identified in the report of findings to inform development of a full Equalities Impact Assessment.
- c) During the consultation further feedback was received from members of the public via email to NHS Cheshire and Merseyside, a local MP on behalf of their constituent and a written response from Coeliac UK. The feedback is not included in this report but has been shared with the NHS Cheshire and Merseyside programme team leading on work around gluten free prescribing, to review and take into consideration when submitting final papers to the Board of NHS Cheshire and Merseyside.
- d) The profile of respondents' indication of their interest in this consultation are shown in Tables 1 to 5 in the appendices.

4.0 Summary

A. Profile of the respondents

- **4.1** The analysis was based on a total sample size of 1064 respondents to the questionnaire.
- **4.2** 601 respondents defined themselves as having coeliac disease. 77% of this sample were female and 20% male. 50% were under 54 and 50% were 55 and over.
- **4.3** 57 respondents had another diagnosed condition which required them to follow a gluten free diet.
- **4.4** 229 respondents were a parent/guardian/carer of a child with coeliac disease, or another diagnosed condition that required them to follow a gluten free diet.

- **4.5** 63 respondents were a carer of an adult with coeliac disease, or another diagnosed condition which required them to follow a gluten free diet.
- **4.6** Of the 620 respondents who answered the question about whether they got their gluten free bread and/or bread mixes on NHS prescription 61% (379) said yes, 37% (227) said no and 2% preferred not to provide an answer.
- **4.7** Of the respondents who said they got their gluten free bread and/or bread mixes on NHS prescription 47% said they paid for their prescription and 50% said they did not pay for their prescription. 3% preferred not to provide an answer.
- **4.8** 69% of parents, guardians or carers of a child or an adult with coeliac disease or another diagnosed condition which requires them to follow a gluten free diet got their gluten free bread and/or bread mixes on prescription. 28% of respondents did not and 3% preferred not to provide an answer.
- **4.9** 23% of parents, guardians or carers of a child or an adult with coeliac disease pay for their prescription. 74% don't and 3% preferred not to say.

B. Opinions of the respondents

- **4.10** Of the total sample of 1064 respondents (including those with a general interest in coeliac disease) 833 respondents (78%) disagreed or strongly disagreed with the proposal to stop providing gluten free bread and bread mixes on prescription.
- **4.11** 94% of those with coeliac disease disagreed or strongly disagreed with the proposal to stop providing gluten free bread and bread mixes on prescription.
- **4.12** 71% of those with another diagnosed condition requiring a gluten free diet disagreed or strongly disagreed with the proposal to stop providing gluten free bread and bread mixes on prescription.
- **4.13** 90% of parents/guardians/carers of a child with coeliac disease, or another diagnosed condition requiring a gluten free diet disagreed or strongly disagreed with the proposal to stop providing gluten free bread and bread mixes on prescription.
- **4.14** 87% of carers of an adult with coeliac disease, or other diagnosed condition disagreed or strongly disagreed with the proposal to stop providing gluten free bread and bread mixes on prescription.
- **4.15** By contrast only 31% of 'interested' respondents disagreed or strongly disagreed with the proposal to stop providing gluten free bread and bread mixes on prescription. 68% strongly agreed or agreed with the proposal.
- **4.16** Health professionals were equally divided with 51% disagreeing or strongly disagreeing with the proposal to stop providing gluten free bread and bread mixes on prescription.
- **4.17** The main reasons cited in **support** of the decision to stop providing gluten free bread and bread mixes on prescription were:
- the high cost to the NHS.
- the money spent on gluten free products could be better spent elsewhere.
- there are other medical conditions just as worthy of financial support.
- there are adequate supplies of gluten free products at reasonable prices in supermarkets.
- should be stopped for people not on benefits.

- in other parts of the country gluten free products are not available on the NHS.
- NHS should be taking steps to encourage people to eat more healthily.
- **4.18** The main reasons cited **against** the decision to stop providing gluten free bread and bread mixes on prescription were:
- gluten free products are expensive.
- gluten free products are not always readily available in supermarkets.
- coeliac disease is a serious disease and why should treatments not be available on the NHS?
- a gluten free diet is the medical treatment for coeliac disease therefore it is not an optional dietary choice.
- coeliac disease is a lifelong autoimmune condition that nobody enjoys or wants to have.

MAIN FINDINGS

5.0 The profile of people with coeliac disease and their carers

- **5.1** 601 respondents defined themselves as having coeliac disease.
- **5.2** The profile of the respondents who have defined themselves as having coeliac disease in terms of age and gender are shown in Tables 1 and 2 below. (It should be noted not all respondents who indicated they have coeliac disease indicated either their age or their gender. Therefore, the base figure (451) of respondents to each question is lower than the number of respondents (601) identifying themselves as having coeliac disease.)

Table 1: Profile of respondents with coeliac disease by age

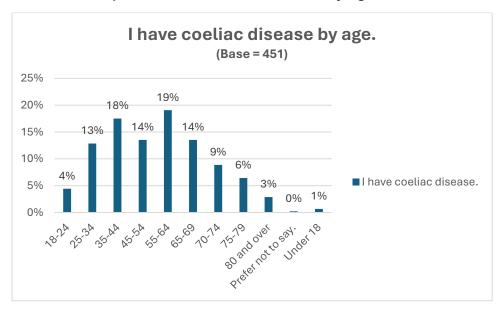
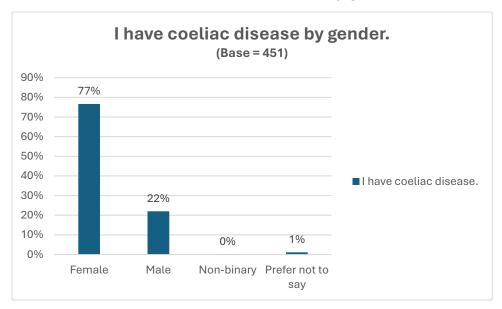


Table 2: Profile of respondents with coeliac disease by gender



5.3 57 respondents had been diagnosed with a condition which required them to follow a gluten free diet. The profile of the respondents who are diagnosed with conditions that required them to follow a gluten free diet are shown in Tables 3 and 4. (Again, it should be noted not all these respondents indicated either their age or their gender.)

Table 3: Profile of those with other diagnosed condition by age

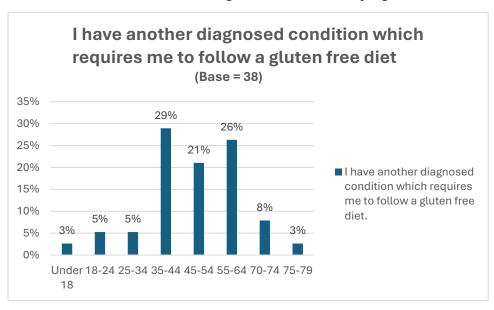
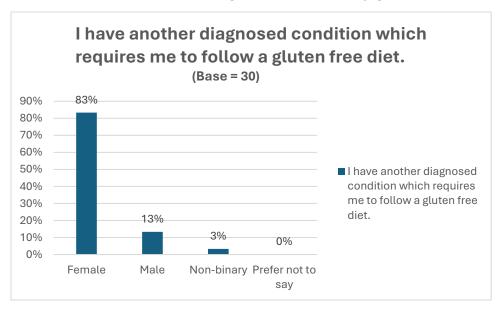


Table 4: Profile of those with other diagnosed condition by gender



5.4 229 respondents defined themselves as a parent/guardian/carer of a child with coeliac disease, or another diagnosed condition which required them to follow a gluten free diet. The profile of the parents/guardians/carers of a child with coeliac disease or other diagnosed condition by age and gender is shown in Table 5 and 6. (Again, it should be noted not all respondents indicated either their age or their gender.)

Table 5: Profile of parents/guardians/carers of child with coeliac disease or other condition by age

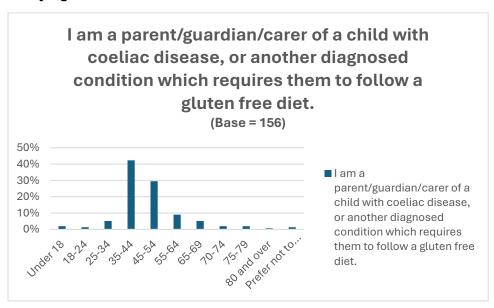
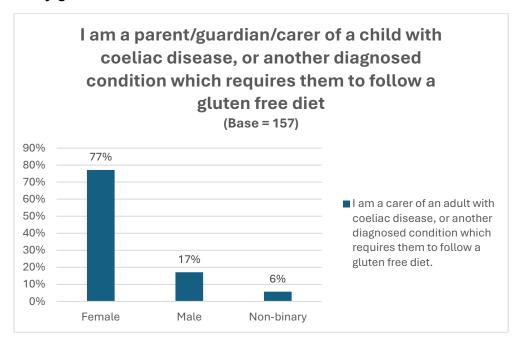


Table 6: Profile of parents/guardians/carers of child with coeliac disease or other condition by gender



5.5 63 respondents defined themselves as a carer of an adult with coeliac disease, or another diagnosed condition which required them to follow a gluten free diet. The age and gender profiles of carers of an adult with coeliac disease or other condition are shown in Tables 7 and 8.

Table 7: Profile of carers of an adult with coeliac disease or other condition by age

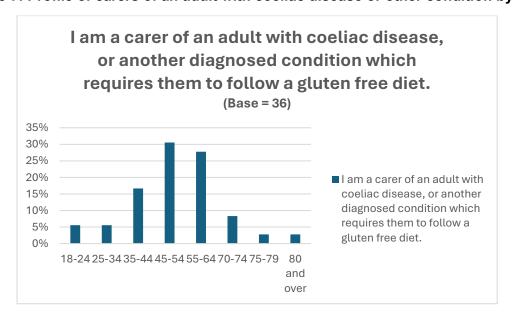
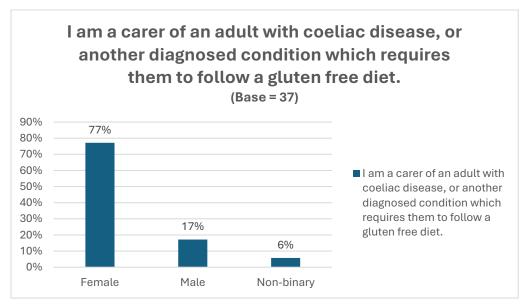


Table 8: Profile of carers of an adult with coeliac disease or other condition by gender



6.0 Those with coeliac disease or another diagnosed condition - who get gluten free bread and/or bread mixes on NHS prescription.

- **6.1** Of the 620 respondents who answered the question whether they got their gluten free bread and/or bread mixes on NHS prescription 61% said yes, 37% said no and 2% preferred not to provide an answer.
- **6.2** Of the respondents who said they got their gluten free bread and/or bread mixes on NHS prescription 47% said they paid for their prescription and 50% said they did not pay for their prescription. 3% preferred not to provide an answer.
- **6.3** 69% of parents, guardians or carers of a child or an adult with coeliac disease or another diagnosed condition which requires them to follow a gluten free diet got their gluten free bread and/or bread mixes on prescription. 28% of respondents said they do not and 3% preferred not to provide an answer.
- **6.4** 23% of parents, guardians or carers of a child or an adult with coeliac disease pay for their prescription. 74% of respondents said they do not and 3% preferred not to provide an answer.

7.0 Extent to which respondents agreed or disagreed with proposal to stop providing gluten free bread and bread mixes on prescription

7.1 Respondents were required to indicate their agreement or disagreement with the proposal that the NHS should stop providing gluten free bread and bread mixes on prescription. The opinions of respondents on this issue are shown in Table 9 below with the percentage distribution of responses shown in Table 10.

Table 9. Strength of agreement or disagreement to stop providing gluten free bread and bread mixes of prescription. (Actual Numbers)

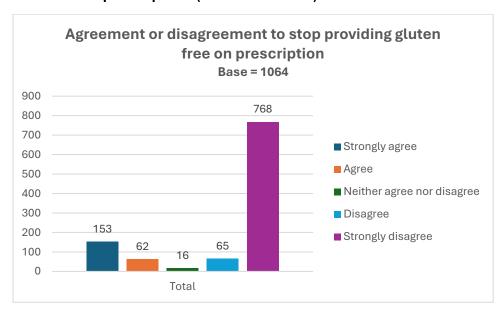
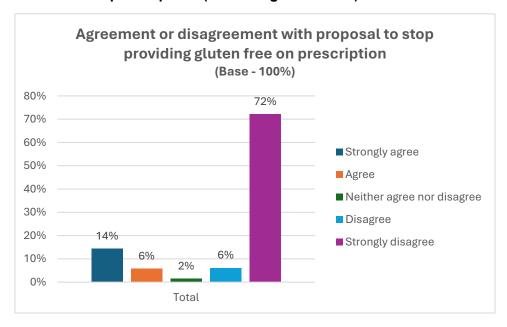


Table 10. Strength of agreement or disagreement to stop providing gluten free bread and bread mixes on prescription. (Percentage Numbers)



In total 78% of all respondents strongly disagreed or disagreed with the proposal to stop providing gluten free bread and bread mixes on prescription. This compares with 20% of all respondents who strongly agreed or agreed with the proposal.

What follows is a detailed comparison of the strength of feeling about this issue by key stakeholder groups.

7.2 Additional comments by respondents on proposed changes to gluten free prescribing

To provide insights into why respondents agreed or disagreed with the proposal to stop providing gluten free bread and bread mixes on prescription, they were asked to explain the reason behind their decision. What followed was over 800 wide-ranging and in-depth explanations of why this decision mattered to them.

To analyse and structure 800+ comments into a meaningful summary, a thematic analysis was used to identify the most frequently occurring opinions and concerns. To provide balance to the analysis, the most frequently occurring themes were identified for both those in favour and against the proposal. It should be noted that the ratio of those expressing an opinion was 4 to 1 against the proposal to stop providing gluten free bread and bread mixes on prescription.

Table 11. Those expressing opinions in favour of the proposal

A selection of comments reflecting frequently occurring themes for those in favour of the proposal – stop providing gluten free bread and bread mixes on prescription.

There is a large range of readily acceptable gluten free products in supermarkets at reasonable cost. They are now much more affordable to all. Lots of high street shops have good and varied range of options for gluten free. I do not believe public money should be spent on prescriptions for food, whether it is because of intolerances / allergies or not.

People with allergies/diabetes don't get free prescriptions. I do not believe public money should be spent on prescriptions for food, whether it is because of intolerances / allergies or not. Everyone has to buy food, and to keep taxing the public more to pay for special food for others, means they have less money to buy food for themselves.

Should be stopped for adults and those not in receipt of benefits. Other areas in England do not offer free gluten free, even for children. All areas should be the same.

NHS should start encouraging people to take responsibility for their own health. NHS has bigger problems to deal with. Monies saved could be put to better use.

The volume of products given on prescription is very wasteful and products supplied are not my preferred choice of brand. Local supermarkets have a wide range of choice of better brands

Gluten-free products are widely available in most food retailers and appear to be similarly priced to general products. Providing them on prescription is very costly for the NHS and the money would be better spent on items which are not readily available at a reasonable cost. It would not impact me or my family, but I would rather see the money go to other more worthy causes.

I think a lot of people do struggle with this but when you look at the bigger picture the NHS has bigger problems right now than bread. As long as people are aware where they can go and places/people that can help them there shouldn't be any issues.

Gluten free products are freely available to buy and our budget for medicines should be reserved for prescription medicines.

I agree GF products should be stopped for adults, there is a lot more availability for GF products in shops at a better price than there was 10yrs ago. However, I think there should be some availability for children.

When this was introduced gluten free items were very hard to find and expensive. Whilst they may still be slightly more expensive, they are commonly available now.

GF foods are now widely available at all retail outlets, this was never the case 20+ years ago. It will be argued that these are much more expensive than 'normal' bread but it is possible to have a diet that does not require bread. We do not provide diabetics with low sugar foods.

I feel that lots of people now have to follow adapted diets due to allergies and they are not prescribed any food or drink to support this.

I am gluten intolerant and have been for more than 10 years. I have never had a prescription for gluten free bread, and this has not been detrimental in any way. I was asked if I wanted the prescription but declined as the bread that you can get on the prescription is nowhere near as nice as the breads you can buy in the supermarket.

Table 12. Those expressing opinions against the proposal

A selection of comments reflecting frequently occurring themes for those against the proposal – stop providing gluten free bread and bread mixes on prescription.

People don't choose to be born with a gluten intolerance and I think it is absolutely abhorrent to even think about taking this off prescription, as the cost of living rises so does the cost of food – and the cost for gluten free food is extortionate anyway so taking gluten free prescribing away from 30% of the population who have been clinically diagnosed with coeliac disease not counting people who medically need a gluten free diet I think is a crazy proposition to even think of.

A gluten free diet is the medical treatment for coeliac disease therefore it is not an optional dietary choice. Gluten free products are 4x more expensive than regular products so it would have a real impact on our family finances if gf prescribing was stopped.

Gluten free food is 35% more expensive without any additional help. There is very little available on prescription so stopping bread mixture and bread will impact further on people who already have ridiculous expensive food bills

These changes would be detrimental to the health of my daughter aged 11 yrs. She is Type 1 Diabetic as well and the gluten free products in the supermarkets are so expensive for us to buy that she wouldn't be able to eat a balanced diet as we can't afford the nicer gluten free bread

A food shop for a person with Coeliac disease costs 35% more. Bread is a staple, yet a gluten free loaf can cost £3.50 making it unaffordable for people on low incomes. Coeliac poverty makes people feel that they have no option but to eat food cheaper food containing gluten that then causes other health issues.

As a parent of a coeliac daughter, I'm struggling to pay for the essential foods that she needs. Like bread for her lunches.

The sheer overwhelming lack of most food choices already limits my child and what gluten free food we can buy is already so much more expensive. We have no other choice; the only medical advice is to not eat gluten. Having gf flour on prescription gives us the ability to cook a lot of items we simply cannot purchase in supermarkets or are often out of stock. Such as our own pastry, bread, other items. We already have to provide our child with packed lunches as school do not provide gf and any social outings or parties we need to take our own food. We simply cannot "go out" without gf food with us. Having gf flour on prescription means we can visit places and still go out with friends. The sheer amount of extra sugar and additives in gf food which can be purchased in shops is really high and if we are forced to purchase gf bread from shops this will impact the health of our child giving longer term impact on medical requirements.

The cost of living plus the price of gluten free food in general is hitting our pockets hard. Having the free bread and bread mix helps.

I strongly believe that gluten-free bread should remain available on NHS prescription. For people with coeliac disease, a strict gluten-free diet is the only treatment, and gluten-free alternatives are often significantly more expensive and harder to access than standard bread. The NHS provides essential medications for chronic conditions and gluten-free prescriptions should be treated no differently. Maintaining access ensures equality in healthcare and prevents unnecessary strain on NHS resources from complications arising from poor dietary management. Not all supermarkets or local shops stock gluten free products. Without a prescription for gluten free products, we may have to travel further or go without for our daughter making it harder to follow a strict gluten free diet.

Gluten free food is unaffordable. We get the basic bread and /or flour on prescription. We are limited to 8 units. Schools cannot safely provide food for our children. This means I need bread products to cover breakfasts and lunches. We are a one earning household who take no benefits. The bread products required to provide even the basics like sandwiches and toast are so expensive we can't afford to pay for it on top of other ingredients we pay our selves like pasta. Either keep prescriptions or provide subsidies like in Wales in the form of

food tokens. With children especially you can't just eat 100% naturally gluten free food. This proposal is a disgrace.

My child relies on the flour and bread on prescription. I cannot afford the increased cost in the supermarkets

Coeliac disease is a lifelong autoimmune condition that nobody enjoys or wants to have. Food is on average FOUR times the cost of gluten products and it's outrageous to suggest that people should be penalised for having a medical condition.

I feel sick with worry about this. My child was diagnosed 6 months ago and getting her to eat gluten free has been a big struggle. The bread from the GP really helped and I don't know how I'm going to manage to buy the food I need for her if it's taken away.

I disagree with the proposal to withdraw gluten free bread mixes from prescriptions. I encounter a variety of people in their own homes every day. In many communities' families cannot afford sufficient nutrition to maintain their health. This is only exacerbated in those adhering to a gluten free diet and the removal of gluten free mixes from prescriptions would only worsen this issue for countless deprived families and individuals. The removal of gluten free bread mixes runs the risk of removing a staple macronutrient and energy source from these individuals and further exacerbates health inequality and increases malnutrition risk in a region where spending on oral nutritional supplements indicated for use on malnutrition far exceeds the national average. The removal of gluten free bread mixes would only be a false economy.

8.0 Comparison of opinions to the proposal to stop providing gluten free bread and bread mixes on prescription by equality monitoring groups

Tables 13 to 20 provide a comparison of opinions towards the proposal to stop providing gluten free bread and bread mixes on prescription by different groups.

From the self-selected sample of respondents to the questionnaire there wasn't any significant difference of opinion based on groups of respondents by equality characteristics or other groupings. Rather differences in opinion were based on respondents interest in the consultation i.e. whether they reported having coeliac disease, another diagnosed condition or being a parent, guardian, carer of a child or adult which required them to follow a gluten free diet.

Table 13: Opinions about stopping providing gluten free bread and bread mixes on prescription by age

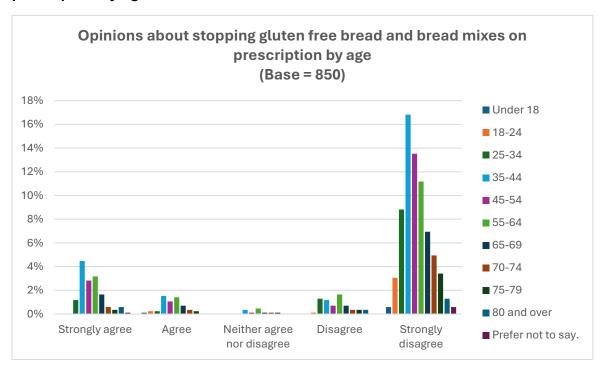


Table 14: Opinions about stopping providing gluten free bread and bread mixes on prescription by gender

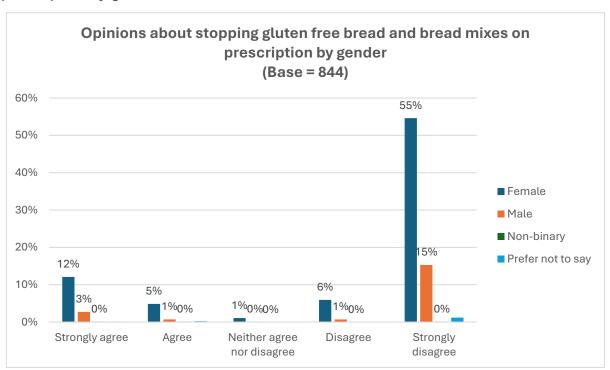


Table 15: Opinions about stopping providing gluten free bread and bread mixes on prescription by those with coeliac disease

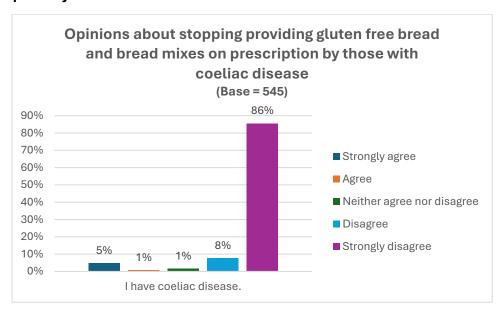


Table 16: Opinions about stopping providing gluten free bread and bread mixes on prescription by those with another diagnosed disease

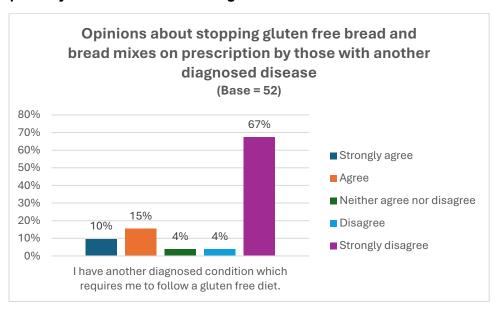


Table 17: Opinions about stopping providing gluten free bread and bread mixes on prescription by parent/guardian/carer of a child with coeliac disease

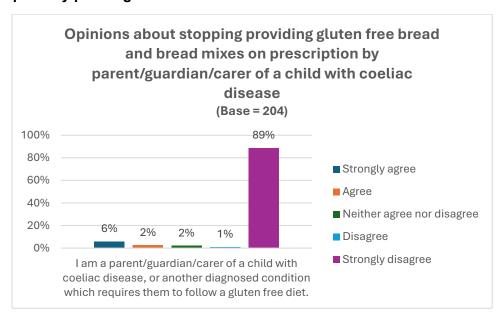


Table 18: Opinions about stopping providing gluten free bread and bread mixes on prescription by carer of adult with coeliac

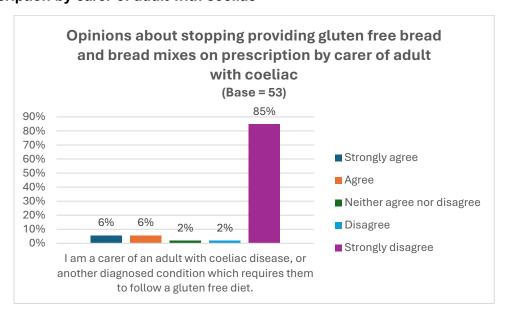


Table 19: Opinions about stopping providing gluten free bread and bread mixes on prescription by 'Interested' respondent

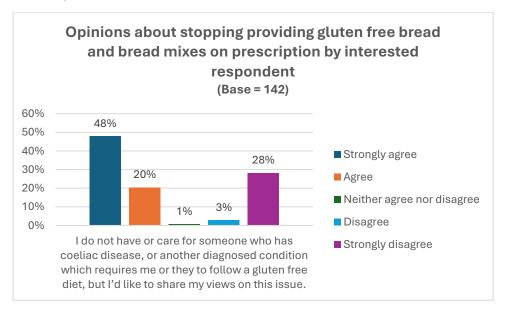
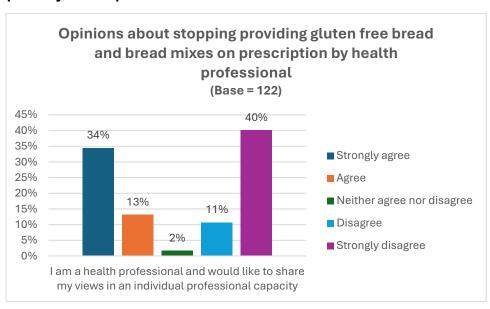


Table: 20: Opinions about stopping providing gluten free bread and bread mixes on prescription by health professional.



APPENDICES

1: Profile of respondents indicating their interest in the public consultation

Personal interest of respondents	No.	%
I have Coeliac disease	601	46.2
I have another diagnosed condition which requires me	57	4.4
to follow a gluten free diet		
I am a parent/guardian/carer of a child with Coeliac disease, or	229	17.6
another diagnosed condition which requires them to follow a gluten free diet.		
I am a carer of an adult with Coeliac disease, or another diagnosed condition	63	4.8
which requires them to follow a gluten free diet.		
I do not have or care for someone who has Coeliac disease, or another	162	12.5
diagnosed condition which requires them to follow a gluten free diet, but I'd		
like to share my views on this issue.		
I am a health professional and would like to share my views in an individual	136	10.5
capacity.		
I am responding on behalf of a group, charity or organisation	8	0.6
Other categories. Includes friends, spouses, grandparents and other relatives	45	3.5
of someone with coeliac disease.		

N.B. The total number of responses is 1301 indicating that some of the 1184 respondents taking part in the survey classified themselves in more than one category. The percentages are based on the total number of responses (1301) and not the total sample size (1184).

2: Home location of respondents

Home location of respondents	No.	%
Cheshire East	159	14
Cheshire West	160	14
Halton	73	7
Knowsley	64	6
Liverpool	136	12
Sefton	100	9
St Helens	32	3
Warrington	168	15
Wirral	156	14
Outside of Cheshire and Merseyside	65	6
Total	1113	100%

N.B. 71 respondents did not answer this question.

3: Work location of those responding in an individual professional capacity or on behalf of a group, charity or organisation

Location of respondents	No.	%
Cheshire East	29	12
Cheshire West	42	18
Halton	16	7
Knowsley	10	4
Liverpool	46	21
Sefton	10	4
St Helens	8	3
Warrington	38	16
Wirral	27	12

Outside of Cheshire and Merseyside	/	3
Total	233	100

N.B. The total number of respondents answering this question is 233, which exceeds the 144 respondents who self-classified themselves as health professionals or responding on behalf of a group, charity or organisation in question one.

4: Type of work-based organisation

Type of work-based organisation	No.	%
NHS organisation (Trust or ICB)	88	45
General practice (GP)	31	16
Pharmacy	11	6
Local authority	9	5
Voluntary, Community, Faith or Social enterprise	12	6
Other group	3	2
Other	42	20
Total	196	100

5: Where did you hear about this consultation?

Where did you hear about this consultation?	No	%
From GP practice	77	8
From local pharmacy	19	2
Person cared for sent an email	65	6
Social media	341	33
NHS website	38	4
Patient group/Voluntary sector	83	8
NHS staff communication	84	8
Friend or family member	123	12
Other	194	19

6: Ethnic group of respondents

Ethnic group of respondents (n=849)	No	%
White: English/Welsh/Scottish/Northern Irish/British	800	94.2
White: Irish	11	1.3
White: Gypsy or Irish Traveller	0	0
White: Any other White background	16	1.9
Mixed/Multiple Ethnic Groups: White and Black Caribbean.	2	0.2
Mixed/Multiple Ethnic Groups: White and Black African	1	0.1
Mixed/Multiple Ethnic Groups: White and Asian	2	0.2
Mixed/Multiple Ethnic Groups: Any other Mixed/Multiple Ethnic	2	0.2
Asian/Asian British: Indian	4	0.5
Asian/Asian British: Pakistani	2	0.2
Asian/Asian British: Bangladeshi	0	0
Asian/Asian British: Chinese	0	0
Asian/Asian British. Any other Asian background	1	0.1
Black/African/Caribbean/Black British: African	1	0.1
Black/African/Caribbean/Black British: Caribbean	0	0
Black/African/Caribbean/Black British: Any other background	0	0
Other ethnic group: Arab	1	0.1
Prefer not to say	6	0.7
Total	849	99.8

N.B. Percentages do not add to 100 because of rounding errors. This table uses one percentage decimal point to ensure small groups are represented.

7: Age group of respondents

Age group of respondents (n=850)	No	%
Under 18	6	1
18 – 24	29	3
25 – 34	98	12
35 – 44	207	25
45 – 54	155	18
55 – 64	152	18
65 - 69	86	10
70 – 74	54	6
75 - 79	38	4
80 and over	19	2
Prefer not to say	6	1
Total	850	100

8: Religious belief of respondents

Religion or belief of respondents (n=850)	No	%
No Religion	307	36.1
Christian	494	58.1
Buddhist	7	8.0
Hindu	4	0.5
Jewish	2	0.2
Muslim	5	0.6
Sikh	0	0
Other religion	31	3.7
Prefer not to say	0	0
Total	850	100

N.B. This table uses one percentage decimal point to ensure small groups are represented.

9: How respondents identify

How respondents identify (n=844)	No	%
Male	165	19.6
Female	663	78.6
Trans-Man	0	0
Trans-Woman	0	0
Non-binary	3	0.4
Gender-Non-Conforming	0	0
Other	13	1.5
Prefer not to say	0	0
Total	844	100

N.B. This table uses one percentage decimal point to ensure small groups are represented.

10: Sexual orientation of respondents

Sexual orientation of respondents (n = 842)	No	%
Heterosexual	754	89.5
Lesbian	4	0.5
Gay	11	1.3
Bisexual	20	2.4
Asexual	3	0.4
Other	0	0
Prefer not to say	50	5.9
Total	842	100

N.B. This table uses one percentage decimal point to ensure small groups are represented.

11: Relationship status of respondents

Relationship status (n = 849)	No	%
Married	524	61.7
Civil Partnership	4	0.45
Single	134	15.8
Lives with partner	103	12.1
Separated	6	0.7
Divorced	38	4.5
Widowed	18	2.1
Other	22	2.6
Prefer not to say	0	0
Total	849	100

N.B. This table uses one percentage decimal point to ensure small groups are represented.

12: Day to day activities

Day to day activities (n = 845)	No	%
Yes, limited a lot	98	12
Yes, limited a little	188	22
No	559	66
Total	845	100

13: Respondents consider themselves to have a disability (As defined by The Equality Act 2010)

Respondent considered to have a disability (n = 810)	No	%
Physical disability	50	8
Sensory disability	19	22
Mental health condition	29	4
Learning disability or difficulty	16	2
Long-term illness	71	9
Prefer not to say	68	8
Other	129	16
No, don't consider themselves to have a disability	546	67

N.B. Percentages add to more than 100% because of multiple responses by some respondents

14: Respondents providing care

Providing care for someone (n = 843)	No	%
Yes – For person aged 24 and under	109	13
Yes – For adults aged 25 to 49	23	3
Yes – For older person(s) aged 50+	100	12
Prefer not to say	33	4
No	595	71

N.B. Percentages add to more than 100% because of multiple responses by some respondents

15: Respondent pregnant at time of questionnaire completion

Pregnant at this time (n = 847)	No	%
Yes	11	1
No	823	97
Prefer not to say	13	2
Total	847	100

16: Respondent recently given birth

Recently given birth (n = 844)	No	%
Yes	2	0.2
No	830	98.4
Prefer not to say	12	1.4
Total	844	100

17: Respondent served in armed services

Served in armed services (n = 847)	No	%
Yes	18	2
No	813	96
Prefer not to say	16	2
Total	847	100

18: Gender and agreement/disagreement with proposal to stopping NHS prescriptions for gluten free bread and bread mixes

	Female	Male	Non-Binary	Prefer Not to Say	No.
Strongly agree	102	23	1	1	127
Agree	41	6	1	2	50
Neither agree nor disagree	9	1			10
Disagree	50	6			56
Strongly disagree	461	129	1	10	601
Total	663	165	3	13	844

19: Age and agreement/disagreement with proposal to stopping NHS prescriptions for gluten free bread and bread mixes

	Under 18	18- 24	25- 34	35- 44	45- 54	55- 64	65- 69	70- 74	75- 79	80 and over	Prefer not to say.	Total
Strongly agree			10	38	24	27	14	5	3	5	1	127
Agree	1	2	2	13	9	12	6	3	2			50
Neither agree nor disagree				3	1	4	1	1	1			11
Disagree		1	11	10	6	14	6	3	3	3		57
Strongly disagree	5	26	75	143	115	95	59	42	29	11	5	605
Total	6	29	98	207	155	152	86	54	38	19	6	850

20: Day to day activities limited and agreement/disagreement with proposal to stopping NHS prescriptions for gluten free bread and bread mixes

	Yes, limited a lot	Yes, limited a little	No	Total
Strongly agree	8	18	102	128
Agree	6	12	32	50
Neither agree nor disagree	2	5	4	11
Disagree	8	11	37	56
Strongly disagree	74	142	384	600
Total	98	188	559	845

21: Disability and agreement/disagreement with proposal with proposal to stopping NHS prescriptions for gluten free bread and bread mixes

	Learning disability or difficulty	Long-term Illness	Mental health cond.	Physical disability	Sensory disability	Total
Strongly agree	1	10	1	6	2	20
Agree	2	5	3	6	1	17
Neither agree nor disagree	-	1	-	1	-	2
Disagree	-	4	-	7	-	11
Strongly disagree	13	52	25	42	16	148
Total	16	72	29	62	19	198

22: Public consultation on stopping NHS prescriptions for gluten free bread and bread mixes in Cheshire and Merseyside

Share your views

What's happening?

Gluten free bread and bread mixes are sometimes prescribed to individuals who live with coeliac disease, or other diagnosed conditions which mean that people have to follow a gluten free diet.

NHS Cheshire and Merseyside Integrated Care Board (ICB) – the organisation responsible for planning local health care services – is proposing to stop making these products available on prescription.

Between 28 January and 11 March 2025, we are holding a public consultation, so that people can find out more about this and share their views. We will then use the feedback we receive to make a final decision.

Background

Coeliac disease is a long-term autoimmune condition, where the immune system mistakes substances found inside gluten as a threat to the body and attacks them, which damages the surface of the small bowel, disrupting the body's ability to absorb nutrients from food.

Dermatitis herpetiformis is a skin condition associated with coeliac disease and gluten intolerance, which occurs as an itchy skin rash that commonly appears on the elbows, knees and buttocks.

Coeliac disease and dermatitis herpetiformis are usually treated by excluding foods that contain gluten.

In the past, GPs were able to prescribe some gluten free foods to people with coeliac disease, or other diagnosed conditions that meant they weren't able to eat gluten.

In 2018, new national guidance was released recommending that only gluten free bread and bread mixes should be made available on prescription.

Currently, most areas of Cheshire and Merseyside follow this national guidance, however there are some differences, which we describe in the next section.

Who currently gets gluten free bread and bread mixes on prescription?

Cheshire and Merseyside is made up of nine areas, sometimes known as 'places'. These are: Cheshire East, Cheshire West, Halton, Knowsley, Liverpool, Sefton, St Helens, Warrington and Wirral.

These areas used to come under separate NHS clinical commissioning groups (CCGs), which were responsible for setting health policies for people living in their area, including policies for gluten free prescribing.

In July 2022, NHS Cheshire and Merseyside took over the responsibilities of CCGs, however the previous policies for each former CCG are still in place, which means that at the moment arrangements for gluten free prescribing are not the same for all areas. This is because some CCGs had previously decided to stop prescribing gluten free products.

The current picture is as follows:

- Gluten free bread and bread mixes are currently available on prescription to all eligible patients in Cheshire East, Halton, Knowsley, Liverpool, Sefton, Warrington and Wirral.
- In Cheshire West, eligible patients registered with a GP Practice in the former NHS Vale Royal CCG footprint (Winsford, Northwich, Middlewich and surrounding areas) can be prescribed gluten free bread and bread mixes, but this is not available to patients registered with a GP practice within the former NHS West Cheshire CCG footprint (Chester, Ellesmere Port and surrounding areas).
- No GP practices within St Helens Place can prescribe gluten free bread and bread mixes.

More than 13,300 people in Cheshire and Merseyside have a diagnosis of coeliac disease or other conditions which mean they need to follow a gluten free diet.

Of these people, around 2,300 currently receive gluten free bread and bread mixes on prescription. The breakdown for each area by age is as follows:

					Age F	Range						
Area	0-9	10- 19	20- 29	30- 39	40- 49	50- 59	60- 69	70- 79	80- 89	90+	Grand Total	% of total coeliac patients in area
Liverpool	16	61	28	20	34	67	120	104	66	5	521	23%
Cheshire East	19	64	18	23	22	38	97	98	67	6	452	21%
Wirral	13	42	20	27	28	48	81	75	55	7	396	21%
Sefton	9	34	13	19	10	53	69	74	49	6	336	18%
Warrington	11	24	8	8	8	19	37	35	23	8	181	14%
Knowsley	5	22	11	11	9	21	32	35	24	2	172	17%
Halton	4	17	3	14	10	22	28	31	9	3	141	18%
Cheshire West	2	8	5	3	11	10	18	19	11	2	89	11%
St Helens	0	0	0	0	0	0	0	1	1	0	2	0%
Grand Total	79	272	106	125	132	278	482	472	305	39	2290	

^{*}Separate figures for dermatitis herpetiformis are not provided as the majority of people with this condition also have a diagnosis of coeliac disease.

The NHS charges for most items given on prescription (currently this cost is £9.90 per item), however some people are eligible for free prescriptions, so don't need to pay this charge.

99% of prescriptions given for gluten free bread and bread mixes in Cheshire and Merseyside are not charged. The main category used for these free prescriptions is age: 60% are because someone is over 60, and 13% because someone is under 16 (or 18 if in full time education).

What we are proposing

NHS Cheshire and Merseyside is proposing that in the future, gluten free bread and bread mixes are no longer available on NHS prescription.

This would mean that GPs wouldn't be able to prescribe them, so if people wanted them, they would need to buy these products themselves. If the change went ahead, it would apply to all areas of Cheshire and Merseyside, and to both adults and children.

Why are we proposing this change?

1. Consistency across different areas

NHS Cheshire and Merseyside wants everyone who lives in Cheshire and Merseyside to have the same level of health care access, but currently this isn't the case for gluten free prescribing. The proposed change would mean that the same guidance would apply to everyone.

It would also mean that the approach for people who can't eat gluten is the same as for other food allergies and intolerances, such as those with lactose intolerance, who do not receive food products on prescription from the NHS.

2. Value for money

Gluten free bread and bread mixes are more expensive than the same products containing gluten, however the price paid by the NHS for these products on prescription is still much higher than in supermarkets.

It is estimated that ending the prescribing of gluten free bread and bread mixes would save the local NHS around £525,000 a year.

NHS Cheshire and Merseyside receives a fixed amount of money from NHS England for local health services, so we need to think about the best way to spend this to get the most benefit for our population.

3. Increased accessibility of gluten free products

One of the reasons gluten free foods were prescribed in the past was that their availability was limited. However, there is now increased awareness of coeliac disease and gluten intolerance, as well as a general trend towards eating less gluten, and these products are now more readily available in most supermarkets and other outlets.

4. Bread and bread mixes are not the only way to get essential nutrients in your diet

If you have coeliac disease, you must stop eating all sources of gluten for life, however it's possible to eat a balanced gluten free diet without the need for any special dietary foods. This proposal is about stopping prescribing of bread and bread mixes, and although these are a source of key nutrients, it is possible to obtain these from other naturally gluten free foods e.g. brown rice, potatoes, whole grains, leafy green vegetables to achieve a healthy diet. In addition, better labelling of foods means that people are more easily able to see whether ordinary foods are free from gluten.

What other options did we look at?

NHS Cheshire and Merseyside did not consider keeping things as they currently are, as this would mean continuing with a situation where the approach varies in different areas. Whatever decision we make, we want to make sure that we have a more consistent approach.

We did look at whether to make gluten free products available to **all** eligible patients in our area. It was estimated that to do this would cost around £130,000 extra each year. NHS Cheshire and Merseyside has a duty to make the best use of the limited funding we have available, and for the reasons set out above, we believe that ending all prescribing of gluten free products is a better approach.

We considered whether to limit prescribing to under 18s, however we felt that this would unfairly discriminate against older people, and 60% of prescriptions for gluten free bread and bread mixes are for those over 60 years old.

However, before we make a final decision, we want to understand the views of our population, which is why we are holding this public consultation.

How we will make a decision

Once this public consultation ends on 11 March 2025, an independent organisation will analyse the feedback received and present it in a report. We will use the findings in this report to make a final proposal about what we do with gluten free prescribing, which will be put to the board of NHS Cheshire and Merseyside for them to make a decision. A paper setting out what is being proposed, together with the public consultation report, will be published on the NHS Cheshire and Merseyside website with our board papers. Our plan is for this to happen at the end of May 2025. We will share the information about the decision once it has been made.

The best way to keep up to date with NHS Cheshire and Merseyside, including our engagement and consultation activity, is to sign up to receive our monthly emails https://www.cheshireandmerseyside.nhs.uk/latest/sign-up-for-updates/

How to share your views

NHS Cheshire and Merseyside wants to find out what people think about our proposal to stop prescribing gluten free bread and bread mixes.

Please complete the questionnaire to tell us your thoughts. The consultation closes on 11 March 2024 – please make sure you've submitted your views by then.

The questionnaire should take no more than ten minutes to complete. Please do not share any personal information in your response (i.e. information that could be used to identify you, such as your name).

Get in touch

If you would like some help to complete the questionnaire or need to request a printed version or an alternative format or language, please contact us using the details below. If you would prefer, we're happy for you to call us to share your questionnaire responses over the phone.

Phone: 0151 295 3052

Email: engagement@cheshireandmerseyside.nhs.uk

Ends

23: Survey questionnaire

Public consultation on proposed changes to gluten free prescribing in Cheshire and Merseyside

Introduction

This questionnaire is for you to share your views on NHS Cheshire and Merseyside proposal to stop prescribing gluten free bread and bread mixes.

You should read the supporting information booklet before answering this questionnaire. You can find the booklet on NHS Cheshire and Merseyside website <u>Gluten free - NHS Cheshire and Merseyside</u>

The questionnaire will close at midnight on 11 March 2025. Please make sure you have completed it by then.

How will my information be used?

NHS Cheshire and Merseyside is coordinating responses for this consultation. Your responses to these questions are anonymous - we don't link this information with any that identifies you.

Your data will be treated confidentially and stored in accordance with Data Protection law and NHS Cheshire and Merseyside Privacy Notice. You can read NHS Cheshire and Merseyside Privacy Notice here

Q1 – Please tell us about your interest in this consultation (please tick as many as apply):

a)	I have coeliac disease.	
b)	I have another diagnosed condition which requires me to follow a gluten free diet.	
c)	I am a parent/guardian/carer of a child with coeliac disease, or another diagnosed condition which requires them to follow a gluten free diet.	
d)	I am a carer of an adult with coeliac disease, or another diagnosed condition which requires them to follow a gluten free diet.	
e)	I do not have or care for someone who has coeliac disease, or another diagnosed condition which requires me or they to follow a gluten free diet, but I'd like to share my views on this issue.	
f)	I am a health professional and would like to share my views in an individual professional capacity (move to question two)	
g)	I am responding on behalf of a group, charity or organisation (move to question two)	
h)	Other (please specify)	

Q2 – What type of organisation do you work in? (Only answer if you selected f) or g) for Q1)

NHS organisation (trust or ICB)	
General practice (GP)	
Pharmacy	
Local authority	
Voluntary, community, faith or social enterprise organisation (Please state)	
Patient group (please state)	
Other (Please state)	

Q3 - Where do you live (if you are responding in a professional capacity, please state the area you are based in)?

Cheshire East	
Cheshire West	
Halton	
Knowsley	
Liverpool	
Sefton	
St Helens	
Warrington	
Wirral	
Outside of Cheshire and Merseyside (please specify)	

Q4 (Only answer if you selected a) or b) for Q1) Please tell us, which of the following apply:

I pay for my prescriptions	
I don't pay for my prescriptions	
Prefer not to say	

The person I care for doesn't pay for their prescriptions	
D (11	
Prefer not to say	
Q6 (Only answer if you selected a) or b) for Q1) Do you get glutenixes on NHS prescription? Please tick one box only.	en-free bread o
Yes	
No	
Prefer not to say	
No	
Q7 (Only answer if you selected c) or d) for Q1) Does the persor gluten-free bread or bread mixes on NHS prescription? Please t	
Yes	
No	
Prefer not to say	
Prefer not to say Q8 – To what extent do you agree or disagree with the proposal gluten free bread and bread mixes on prescription? Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree	to stop provid

Q10 – How did you hear about this consultation? Please tick all the boxes that apply.

From my GP practice	
Local pharmacy	
I (or the person I care for) was sent an email from NHS Cheshire and Merseyside	
Social media e.g. Facebook	
NHS website (for example, NHS Cheshire and Merseyside or hospital trust website)	
Through a patient group and/or voluntary sector organisation I am connected to	
NHS staff communication	
Other, please tell us:	

Equality monitoring

We are asking these questions because we want to make sure that we have asked lots of different people for their views.

All the information that you give will be recorded and reported anonymously – it will never be used with your name or contact details. NHS Cheshire and Merseyside collect this as part of its duty under the Equality Act 2010.

Your data will be treated confidentially and stored in accordance with Data Protection law and NHS Cheshire and Merseyside's privacy policy.

You do not have to answer these questions if you do not want to

1. What is your ethnic group? Choose one option that best describes your ethnic group or background.

White: English/Welsh/Scottish/Northern Irish/British	
White: Irish	
White: Gypsy or Irish Traveller	
White: Any other White background (please specify below)	
Mixed/Multiple ethnic groups: White and Black Caribbean	
Mixed/Multiple ethnic groups: White and Black African	
Mixed/Multiple ethnic groups: White and Asian	
Mixed/Multiple ethnic groups: Any other Mixed/Multiple ethnic background (please specify below)	

Asian/Asian British: Indian	
Asian/Asian British: Pakistani	
Asian/Asian British: Bangladeshi	
Asian/Asian British: Chinese	
Asian/Asian British: Any other Asian background (please specify below)	
Black/African/Caribbean/Black British: African	
Black/African/Caribbean/Black British: Caribbean	
Black/African/Caribbean/Black British: Any other Black/African/Caribbean background (please specify below)	
Other ethnic group: Arab	
Prefer not to say	

Any other ethnic group (please specify below):

2. How old are you?

16 - 19	
20 - 24	
25 - 29	
30 - 34	
35 - 39	
40 - 44	
45 - 49	
50 - 54	

55 - 59	
60 - 64	
65 - 69	
70 - 74	
75 - 79	
80 and over	
Prefer not to say	

3. What is your religion or belief?

No religion	
Christian (including Church of England, Catholic, Protestant and all other Christian denominations)	
Buddhist	
Hindu	

Muslim	
Sikh	
Prefer not to say	
Other (please specify):	

4. How do you identify?

Male	
Female	
Trans-Man	
Trans-Woman	
Non-binary	
Gender-non-conforming	

Non-binary	
Gender-non-conforming	
Prefer not to say	
Other (please specify):	

5. What is your sexual orientation?

Heterosexual	
Lesbian	
Gay	
Bisexual	
Asexual	

Prefer not to say	
Other (please specify):	ı

6. What is your relationship status?

Married	
In a civil partnership	
Single	
Divorced	
Living with partner	
Separated	

Widowed	
Prefer not to say	
Other (please specify)	

a 26-week period	-	=	-	is time?	giveii bii	itii witiiii
Yes						
No						
Prefer not to say						
	-	=	-	ho are pregnant or have en birth? (within the last	_	
Yes						
No						
Prefer not to say						
which has lasted	•			cause of a health probler at least 12 months?		•
Yes, limited a lot						
Yes, limited a little						
No						
Prefer not to say						
has a disability if t	they have a	physica	l or me	oility? (The Equality Act 20 ental impairment that has a effect on your ability to do	a 'substar	ntial' and
Physical disability				Prefer not to say		
Sensory disability (e hard of hearing, Blin impaired)	•			Other (please specify):		
Mental health condit	ion					
Learning disability o	r difficulty					
Long-term illness (e.	•					
cancer, diabetes, CC						
No, I do not conside to have a disability	r myself					

11. Do you provide care for someone? A carer is defined as anyone who cares, unpaid (or in receipt of Carer's Allowance, but not someone who is employed as a care professional), for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.

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

No	
Prefer not to say	

12. Have you ever served in the armed services?

Yes	
No	
Prefer not to say	

Please return this form by Tuesday, 11 March to.

Email: engagement@cheshireandmerseyside.nhs.uk

Postal address: Communications and Engagement Team NHS Cheshire and Merseyside No 1 Lakeside 920 Centre Park Square Warrington WA1 1QY

Thank you.