


Engagement analysis on proposed changes to Gluten-Free prescribing in Coventry and Warwickshire

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Introduction

Coventry and Warwickshire Integrated Care Board (ICB) is reviewing how gluten-free (GF) foods are prescribed for adults and children who have been diagnosed with coeliac disease or dermatitis herpetiformis



At present, a limited range of GF bread loaves and mixes can be prescribed for individuals who meet the criteria - capped at 8-10 units per month. Prescribing of GF foods was introduced at a time when GF foods were expensive and hard to access in supermarkets. Now GF foods are widely available in supermarkets, with a broad range of affordable options. Naturally gluten-free foods such as rice, potatoes, meat, fish, vegetables, fruit, and most dairy products remain accessible.

Prescriptions for GF foods cost the NHS more than it costs to buy them directly in the shop, through a combination of clinician time, dispensing fees, and delivery charges. Currently the ICB spends £240,000 per year on prescription of GF foods. Across England, some ICBs have already stopped prescribing gluten-free foods.

In order to understand the impact of reducing or stopping the prescribing of gluten-free foods, the ICB undertook an engagement exercise to understand the views of people who may be affected by this change.

Methodology

Information was gathered via an online survey where the aim was to ensure that all interested parties received:

- A clear explanation of the question and the rationale behind it, being clear that removing gluten-free products from prescription was an option
- An open invitation to share feedback via the online survey

The survey received **232 responses** and was promoted widely through a range of channels to reach as many affected individuals and stakeholders as possible.

Methods of communication included:

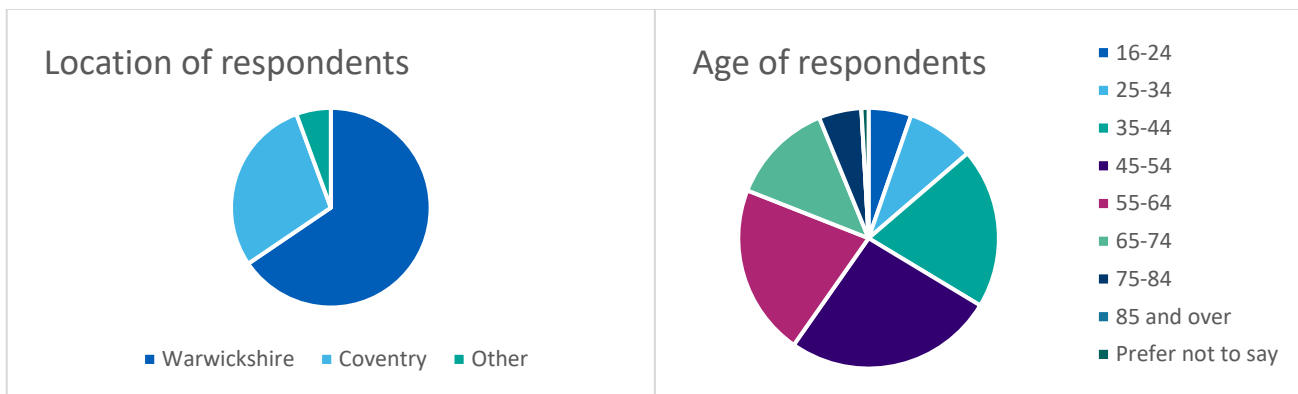
- Creation of a dedicated webpage on the ICS website outlining the proposal, rationale, and survey link.
- Letters sent to key stakeholders, advocacy groups and dieticians encouraging them to share information with patients who may be affected.
- Direct communications to GPs and primary care providers informing them of the proposal and inviting participation.
- A meeting with Coeliac UK to discuss concerns and incorporate feedback about the survey process.
- Social media posts, including in local Facebook groups for individuals accessing gluten-free foods.
- Promotion through the ICS stakeholder newsletter, reaching system partners, communications leads, VCSE colleagues, and through the ICB internal newsletter
- Support from both Coeliac UK and the the department of Nutrition and Dietetics at UHCW to forward the survey link to their contacts, service users and patients

These combined efforts ensured the survey was accessible, transparent, and inclusive of a wide range of views from across Coventry and Warwickshire

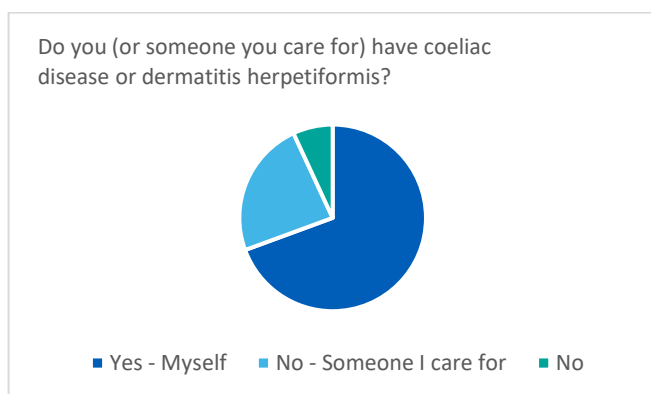
A profile of our respondents

The survey attracted 232 responses, with the majority of participants living in Warwickshire. Around two-thirds of respondents (152 people) reported that they live in Warwickshire, while just over a quarter (66 people) live in Coventry. A small proportion, approximately six percent, indicated that they live elsewhere or did not specify their location.

In terms of age, the profile of respondents leans toward mid-life adults. The largest age group represented was 45-54 years, accounting for just over a quarter of responses. This was closely followed by those aged 55-64 and 35-44, meaning that individuals between 35 and 64 years old made up roughly two-thirds of the sample. Older adults aged 65-74 and 75-84 together comprised about 18 percent of respondents, while younger adults aged 16-24 and 25-34 represented around 14 percent. Only a very small number of people preferred not to disclose their age.



Out of 232 respondents, most reported a direct link to coeliac disease or dermatitis herpetiformis. Specifically, 69% answered “Yes - Myself,” and a further 24% selected “No - Someone I care for.” A smaller number (7%) indicated “No”, including people who identified themselves as GPs.

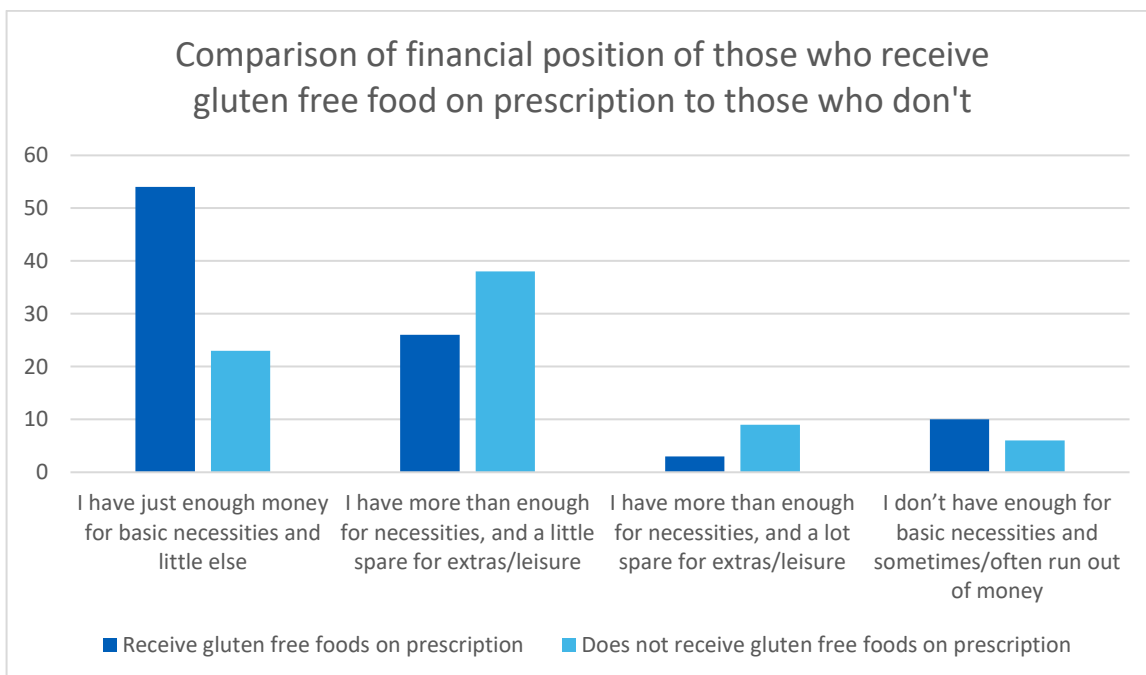


When asked whether they had received gluten-free foods on NHS prescription in the last 12 months, responses were broadly balanced. 51% said “Yes,” 48% said “No,” and 1% were “Not sure.” Taken together, these results show that the survey predominantly reached people directly affected by the condition (either personally or as carers) and that about half of those reported recent access to gluten-free prescriptions.

Financial circumstances varied across the group, but a significant proportion reported being financially constrained. About 42% said they either have just enough money for basic necessities or do not have enough and sometimes run out of money. In contrast, roughly 37% indicated that they have more than enough for necessities, with either a little or a lot spare for extras and leisure. The remaining fifth of respondents preferred not to share details about their financial situation or selected “not known.”

Among respondents who either have coeliac disease or dermatitis herpetiformis themselves or care for someone who does, there are clear differences in financial circumstances between those who received gluten-free foods on NHS prescription and those who did not. People who received prescriptions were more likely to report financial constraints. Nearly half of this group said they have just enough money for basic necessities and little else, and a further small proportion indicated that they do not have enough for essentials and sometimes run out of money. Together, these responses suggest that a significant share of prescription recipients are living with limited financial flexibility.

By contrast, those who did not receive prescriptions were more likely to describe their situation as comfortable. A larger proportion of this group reported having more than enough for necessities, with either a little or a lot spare for extras and leisure. While some respondents in this group also reported financial strain, the overall pattern shows that non-recipients are more financially secure compared to those who rely on prescriptions.





The impact of removing gluten free foods on prescription

Availability on prescription

When asked what the potential impact of removing gluten-free foods from prescription, respondents indicated that this would most commonly increase household food costs - 56% of people selected this. A substantial share (35%*) also said it would make it harder to stick to a gluten-free diet. At the same time 41% indicated they do not currently receive gluten-free foods on prescription (so the immediate impact on them would be limited), and a small minority (4.3%*) felt it would not make much difference.

Additional free-text comments reinforced the financial pressures mentioned above and flagged practical concerns such as the availability and cost of specific flour mixes, the inconvenience of sourcing suitable products, and the potential impact on older people and carers. Overall, the findings suggest that policy changes removing prescriptions would most likely be felt through higher food bills and reduced dietary adherence among many of those affected.

* Because this question allowed multiple selections, percentages do not add up to 100%.


Accessing gluten free services and support to adhere to a gluten free diet

Most people said they could access gluten-free alternatives, but many flagged challenges. Just under half (44%) said they could access alternatives easily, while a further 42% felt they could do so but with some difficulty. Taken together, 87% believed they could obtain products in principle, though the substantial “with difficulty” share indicates practical barriers remain for a large group.

At the same time, 10% said they would not be able to access gluten-free alternatives, and 3% were not sure. This suggests that around one in eight respondents either cannot access alternatives or are uncertain they could, highlighting a meaningful risk of reduced access if prescriptions were withdrawn - especially for those already facing financial or availability constraints.

It is worth noting that people who currently receive prescriptions are much less likely to say they could access alternatives easily and much more likely to anticipate difficulty or inability. Only 25% of prescription recipients said “Yes, *easily*”, compared with 64% among those who said “No/Not sure” to receiving prescriptions (a -39 percentage point difference). A majority of recipients (55%) selected “Yes, *with some difficulty*” (vs 29% in the No/Not sure group, a +26 pp difference), and recipients were also more likely to say “No” outright (16.9% vs 3.5%, a +13.4 pp gap). The share answering “Not sure” was small and similar across groups (~2-3%). In short, current prescription recipients foresee substantially more access challenges if prescriptions were withdrawn.

When asked what kind of support that people would need to maintain a gluten free diet, the most common form of support requested was information about affordable gluten-free alternatives, selected by 29% of respondents. This suggests that cost and availability are major concerns for people managing a gluten-free diet. The second most frequent response was “I wouldn’t need any extra support,” chosen by 26% respondents, indicating that while many respondents feel confident in managing their diet, a significant proportion still require assistance.



Other responses were more fragmented and often combined multiple options, such as dietitian advice, help with reading food labels, and financial support, but each of these appeared far less frequently in isolation. A small number of respondents mentioned specific ideas like vouchers for gluten-free food, better labelling, or transport to shops, highlighting diverse needs beyond basic information. Overall, the findings point to a strong demand for practical guidance on affordable options, alongside targeted financial and professional support for those who struggle most.

Outside of the specified options, other ideas suggested for support centred around financial help (e.g., vouchers, payment cards, funding/allowances, discounts). Several also referenced specific products (e.g., flour mixes), improving the availability of products or voucher schemes like Wales.

As would be expected people who currently receive prescriptions are notably more likely to say they need practical help. Among the “Yes” group, 66% asked for information about affordable gluten-free alternatives, compared with 42% among those answering “No/Not sure.” Recipients were also more likely to want dietitian advice (29% vs 20%) and help with reading food labels (16% vs 10%). In addition, requests for financial support in the free text answers, including mentions of vouchers or payment cards, were higher among recipients (9% vs 4%), reflecting greater perceived cost pressures in this group.

Concerns and suggestions

In addition to the questions above, respondents to the survey were offered the opportunity to utilise a free text box to tell us about the concerns and suggestions they had about the proposal to remove gluten free food.

166 respondents used this option and their comments are themed and categorised below. The majority of respondents expressed concerns and disappointment in the potential change to prescribing, while a smaller minority were neutral or for the idea.


Key overall themes identified for retaining gluten free prescribing

Affordability dominates: The single strongest theme is that withdrawing prescriptions would increase household food costs, with many people saying gluten-free (GF) staples remain *significantly* more expensive and sometimes difficult to source (stock, freshness, range). People consistently reference bread and flour as core staples.

Adherence risk: Many respondents anticipate reduced adherence to a GF diet if prescriptions stop—especially among lower-income households, carers, students and pensioners—linking this to longer-term clinical risks and cost-shifting back to the NHS/social care.

Targeted mitigation, not “no support”: Even among those open to change, there is widespread support for means-tested help or a voucher / pre-paid subsidy card, with multiple references to the Welsh model. Others suggest retaining bread/flour for defined cohorts (children, low-income, elderly).

Product availability & quality: Numerous comments say some prescription-only mixes (e.g., Juvella, Glutafin) are not available or not equivalent in supermarkets; users feel supermarket GF bread is expensive, perishes quickly, or is inferior nutritionally/taste-wise.



Inequalities & consistency: People highlight inequity (Core20-type concerns), inconsistent practice-level access, historic awareness gaps (“I didn’t know prescriptions existed”), and ask for clear, proactive communication if decisions change. GP respondents also request robust comms to avoid unmanaged spill-over to practices.

Key themes supporting the removal of gluten free food on prescription

Although these themes did not come out as strongly, there was a clear (minority) cohort arguing that gluten-free (GF) prescribing should be stopped or significantly curtailed. Their comments cluster into a handful of recurring themes.

Retail availability has changed the context: They believe mainstream supermarkets now stock adequate GF basics, so prescriptions feel outdated

Prioritise NHS budgets for medicines/clinical care: With finite resources, food items are seen as a poor use of funds compared with drugs, treatment, or dietetic education.

Fairness with other dietary needs: People with other medical diets/allergies don’t receive food on prescription; GF should be treated consistently.

Waste/inefficiency in the current model: Practical problems—bulk ordering, short shelf life, uncollected items—are cited as reasons to stop the current approach.

Replace universal scripts with targeted financial support: Many suggest means-testing or a voucher/subsidy card (often referencing the Welsh model) to protect people on low incomes or families with coeliac children.

Nutrition and product quality concerns: Some describe prescription items as ultra-processed, arguing for education and “naturally GF” choices instead.

A full breakdown of the themes by stakeholder group can be found at the end of this document.



Summary of findings

- The majority of respondents (63%) report either having just enough money for basic necessities or less, and 40% say they would only be able to access gluten-free alternatives with difficulty or not at all if prescriptions were stopped. These numbers rise amongst those currently in receipt of gluten-free foods on prescription and highlights significant financial vulnerability in the population.
- The most common anticipated impact if gluten-free foods were no longer available on NHS prescription is increased household food costs (mentioned in 49% of responses), often combined with concerns about difficulty maintaining a gluten-free diet (27%). This suggests that the impact of removing gluten free foods on prescription would potentially be an increase levels of illness due to lack of adherence to a gluten free diet.
- The most frequently requested support to manage a gluten-free diet without NHS prescriptions is information about **affordable** gluten-free alternatives (28%), followed by dietitian advice and help with reading food labels. Many respondents also express a need for financial support or vouchers to offset the higher costs and there were many requests that other models are explored if products are removed from prescription.

Throughout the survey, the key concern for people was financial, which a significant majority of responses expressing real concern that removing gluten-free prescriptions would disproportionately affect those with limited financial means and therefore could lead to poorer dietary adherence and increased health risks.

Detailed Demographic Information

Place of residence

Most respondents live in **Warwickshire** (about two-thirds), with just under a third from **Coventry**, and a small minority from neighbouring/other areas.

Area	Responses	%
Warwickshire	152	65.5
Coventry	67	28.9
Outside area	13	5.6

Relationship to the condition

Around **seven in ten** respondents live with coeliac disease or dermatitis herpetiformis themselves, and almost **one in four** are carers completing the survey on behalf of someone else. A small share reported **no** direct link. This mix gives a strong first-person perspective while also capturing caring roles.

Relationship	Responses	%
Self (has condition)	161	69.4
Carer for someone with condition	55	23.7
No	16	6.9

However, only **just over half (55%)** of those currently living with coeliac disease or dermatitis herpetiformis are in receipt of gluten-free foods on prescription

In receipt of gluten free foods	Responses	%
Yes	118	51
No	111	48
Not sure	3	1

This was split equally across Coventry and Warwickshire respondents

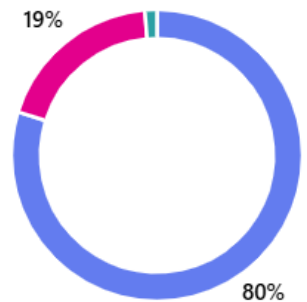
Total respondents living in **Warwickshire**: 152 → **50.0%** of which received prescriptions.

Total respondents living in **Coventry**: 67 → **52.2%** of which received prescriptions.

Sex/gender identity

The sample is predominantly **women**, with a smaller share of **men** and a small number identifying as **non-binary**. A handful did not state their gender identity. This skew is typical of many health consultations and may reflect patterns in condition awareness, help-seeking, and caregiving.

- Woman (including trans woman) 178
- Man (including trans man) 42
- Non-binary 3

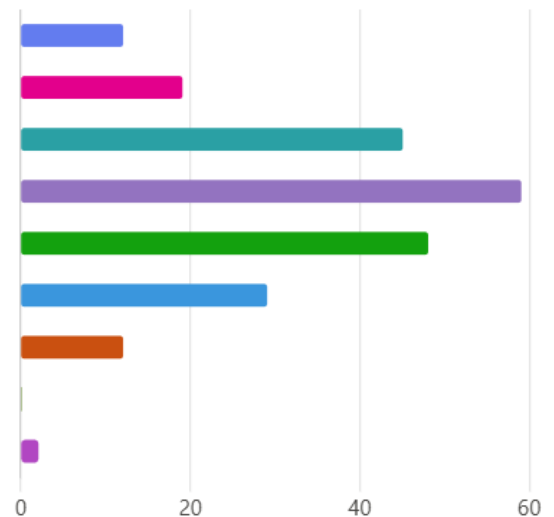


Sex / gender identity	Responses	%
Woman (including trans woman)	178	76.7
Man (including trans man)	42	18.1
nan	9	3.9
Non-binary	3	1.3

Age profile

Responses span the adult life course. The largest groups are **45–54** and **55–64**, followed by **35–44** and **65–74**. Younger adults (**16–24**, **25–34**) and **75–84** are also represented, though in smaller numbers. A small number did not state an age band.

- 16 to 24 12
- 25 to 34 19
- 35 to 44 45
- 45 to 54 59
- 55 to 64 48
- 65 to 74 29
- 75 to 84 12
- 85 and over 0
- Prefer not to say 2

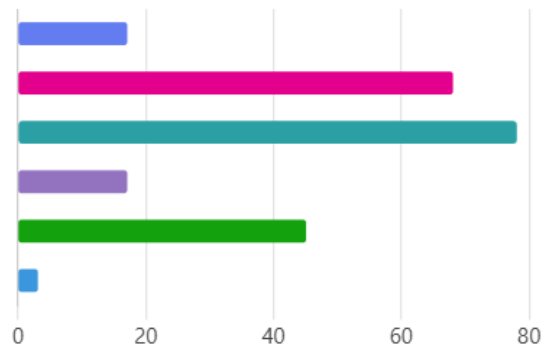


Age band	Responses	%
45 to 54	59	25.4
55 to 64	48	20.7
35 to 44	45	19.4
65 to 74	29	12.5
25 to 34	19	8.2

16 to 24	12	5.2
75 to 84	12	5.2
nan	6	2.6
Prefer not to say	2	0.9

Financial situation

● I have more than enough money for basic necessities, and a lot spare, that I can save or...	17
● I have more than enough money for basic necessities, and a little spare, that I can save or...	68
● I have just enough money for basic necessities and little else	78
● I don't have enough money for basic necessities and sometimes or often run out of money	17
● Prefer not to say	45
● Not known	3



When considering those only those who **answered either:**

1. "Yes – Myself", or
2. "No – Someone I care for"
to "Do you (or someone you care for) have coeliac disease or dermatitis herpetiformis?"

We compared the financial position of those who received the prescription to those who didn't.

- **Received prescription (Yes): 117**
- **Not received (No): 96**
- **Not sure: 2** (*shown for completeness; very small*)

Financial situation by receipt of prescription

Financial situation	Received (Yes) — n=117	Not received (No) — n=96
I have just enough money for basic necessities and little else	54 (46.2%)	23 (24.0%)
I have more than enough for necessities, and a little spare for extras/leisure	26 (22.2%)	38 (39.6%)

Financial situation	Received (Yes) — n=117	Not received (No) — n=96
Prefer not to say	24 (20.5%)	17 (17.7%)
I have more than enough for necessities, and a lot spare for extras/leisure	3 (2.6%)	9 (9.4%)
I don't have enough for basic necessities and sometimes/often run out of money	10 (8.5%)	6 (6.2%)
Not known (<i>survey category</i>)	0 (0.0%)	3 (3.1%)

Percentages are within each prescription group; rounding may cause totals to ≈100%.

Detailed thematic analysis - Responses to the potential for changes to gluten-free prescribing

Thematic analysis of respondents who expressed concern - broken down by key stakeholder groups

People with Coeliac Disease (Self-Reported)

- **Affordability:** Strong concern that removing prescriptions will significantly increase food costs, especially for bread and flour, which are much more expensive gluten-free.
- **Dietary Adherence:** Many fear they will struggle to maintain a strict gluten-free diet without support, risking health complications.
- **Product Availability:** Some prescription-only products (e.g., JuveLa, GlutaFin mixes) are not available or not equivalent in supermarkets.
- **Fairness:** Repeated comparisons to other long-term conditions (e.g., “You wouldn’t take away insulin for diabetics—this is our treatment”).
- **Awareness Gaps:** Some were unaware prescriptions were available, highlighting inconsistent information and access.



2. Carers and Parents

- **Children's Needs:** Emphasis on the importance of gluten-free prescriptions for children, especially for school lunches and social events where safe alternatives are limited.
 - **Household Impact:** Multi-coeliac households and carers report a significant financial burden, with some already struggling to afford gluten-free staples.
 - **Equity:** Concerns that children and vulnerable dependents will be disproportionately affected if support is withdrawn.
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3. Low-Income Households, Students, and Pensioners

- **Cost-of-Living Pressures:** These groups are most likely to report that they would be unable to afford gluten-free foods without prescriptions.
 - **Health Inequalities:** Fears that withdrawal will worsen health inequalities, particularly for those already facing deprivation or on fixed incomes.
 - **Mitigation Requests:** Strong support for means-tested support, vouchers, or a pre-paid card system (Welsh model) to protect those most at risk.
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4. People with Multiple Allergies or Complex Needs

- **Limited Alternatives:** Those needing gluten-free plus other dietary restrictions (e.g., dairy, egg, nut-free) report even fewer suitable supermarket options.
- **Risk of Malnutrition:** Fear that without prescriptions, they may go without essential foods, risking malnutrition and further health complications.



Thematic analysis supporting the removal of gluten free food on prescription – broken down by key stakeholder groups

As the respondents who supported the removal of GF prescribing were smaller, they have been broken down into two groups – patients and carers and GPs

1. Patients and Carers

1) Supermarket availability makes prescriptions unnecessary

Respondents argued GF staples are now easy to buy; some still favour a different kind of support (e.g., vouchers).

2) NHS funds should prioritise medicines/clinical care, not food

Several respondents framed scripts for food as a poor use of limited budgets.

3) Fairness with other dietary needs

People questioned why coeliac diets receive food on script when others don't.

4) Waste/inefficiency in the current model

Practical complaints about bulk ordering, shelf life, and uncollected items.

5) Replace universal scripts with targeted financial support


Even among those favouring withdrawal, many proposed means-testing or retail-based subsidy.

6) Quality/nutrition of prescription items

A smaller cluster argued prescription products are overly processed; prefer education/naturally GF foods.

2. GPs

GP/prescriber comments are not monolithic but lean toward ending routine GF prescribing, paired with operational caveats. The predominant clinical rationale is that retail access has improved while NHS spend



and dispensing inefficiencies remain; however, several GPs emphasise mitigation to avoid widening inequalities and adding practice workload.

Availability & cost case: Prescriptions are viewed as no longer clinically necessary given supermarket access, and as an avoidable draw on NHS budgets.

Equity & adherence risks: Some GPs warn that abrupt removal could reduce dietary adherence among lower income patients, with downstream health consequences; they advocate targeted support (e.g., means tested help or retail subsidy) rather than an unmitigated stop.