


ORIGINAL ARTICLE

The affordability and obtainability of gluten-free foods for adults with coeliac disease following their withdrawal on prescription in England: A qualitative study

Helen Crocker¹  | Thomas Lewis² | Mara Violato¹ | Michele Peters¹ 

¹Nuffield Department of Population Health, University of Oxford, Oxford, UK

²Myeloma UK, Edinburgh, UK

Correspondence

Helen Crocker, Nuffield Department of Population Health, University of Oxford, Richard Doll Building, Old Road Campus, Headington, Oxford, OX3 7LF, UK.
Email: helen.crocker@ndph.ox.ac.uk

Funding information

National Institute for Health and Care Research (NIHR) Applied Research Collaboration (ARC) Oxford and Thames Valley; Coeliac UK; National Institute for Health and Care Research (NIHR) Oxford Health Biomedical Research Centre (BRC)

Abstract

Background: Changes to prescribing policies in England have restricted or stopped access to gluten-free food on prescription for people with coeliac disease in some geographical areas. The present study aimed to explore the impact of these changes on the affordability and obtainability of gluten-free foods for adults with coeliac disease.

Methods: Semi-structured qualitative interviews ($n = 24$) were conducted with people with coeliac disease living in areas where prescriptions for gluten-free foods were no longer available, were restricted or followed national guidelines. Interviews explored the impact of gluten-free prescribing changes on the affordability and obtainability of gluten-free food, as well as dietary adherence.

Results: All participants considered gluten-free substitute foods to be expensive. Participants felt the availability of gluten-free foods has improved over time, also acknowledging some challenges remain, such as limited local availability. For most, the withdrawal of prescriptions had minimal impact requiring small adjustments such as reducing the quantity of foods obtained. However, greater challenges were faced by those less mobile, permanently sick or disabled and/or on lower incomes.

Conclusions: The majority of participants affected by the withdrawal of prescriptions were able to adapt to cope with these changes. However, participants with mobility issues, who are permanently sick or disabled and/or on lower incomes were struggling to afford and obtain gluten-free substitute foods from elsewhere. The withdrawal of prescriptions may further widen health inequalities. Further research should focus on the long-term impacts of prescription withdrawal for the vulnerable groups identified.

KEYWORDS

coeliac disease, gluten-free, health policy, personal finances, prescriptions

Key points

- Prescriptions for gluten-free substitute foods have been restricted or withdrawn in some areas of England, but the impact of these changes on people with coeliac disease is unknown.
- The present study found that the majority of people with coeliac disease were able to adapt to cope with prescribing changes, but certain groups (people with mobility issues, who are permanently sick or disabled and/or on lower incomes) were struggling to afford and obtain gluten-free foods.

This is an open access article under the terms of the [Creative Commons Attribution](https://creativecommons.org/licenses/by/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2023 The Authors. *Journal of Human Nutrition and Dietetics* published by John Wiley & Sons Ltd on behalf of British Dietetic Association.

- Future research should focus on the longer-term impacts of no access or restricted access to gluten-free substitute foods on prescription, with specific focus on the groups identified above.

INTRODUCTION

Coeliac disease is an autoimmune disease for which the only treatment is a gluten-free diet, comprising a diet free from wheat, barley and rye. Following a gluten-free diet can be burdensome.¹ People with coeliac disease often encounter a variety of challenges, including difficulties obtaining gluten-free food and concerns about cross-contamination, especially when eating outside of the home.^{2,3}

Studies in the UK and elsewhere found that gluten-free substitute foods, such as bread and pasta, are less available and less affordable than their gluten-containing counterparts.⁴⁻⁷ To help people to adhere to a gluten-free diet, some countries provide support with the cost of gluten-free substitute foods, such as the provision of government subsidies in Italy, and tax relief on gluten-free substitute food purchases in Ireland.⁸⁻¹¹ In England, support is provided in the form of prescriptions for gluten-free substitute foods. Prescriptions for gluten-free food are obtained from a general practitioner (GP) and filled by a pharmacist, in the same way as medications. Each prescription is subject to a prescription charge, although some groups of individuals are entitled to prescriptions free of charge (e.g., those aged under 16 years or those who are 60 years or over, or those on a low income). The prescription charge at the time of the study was £8.60 per medicine dispensed, or a prescription prepayment certificate allowing unlimited prescriptions for a given period of time, could be purchased for £29.10 for 3 months or £104 for 12 months.

National Health Service (NHS) bodies responsible for planning and commissioning services for their local area, hereafter referred to as local bodies, are responsible for setting local policies stating the types of food items and quantities (number of units) that people with coeliac disease are eligible to obtain on prescription. Types of food item typically available on prescription included bread, flour mixes, crackers, pizza bases and pasta. At the time of the study, these bodies were Clinical Commissioning Groups (CCGs), which, in 2022 were replaced with Integrated Care Boards. In 2015, PrescQIPP, an NHS-funded organisation producing prescribing guidance, recommended restricting the type of food items and number of units of gluten-free substitute foods available on prescription as an NHS cost reduction strategy.¹² The publication of this guidance began a trend for local bodies to restrict or withdraw access to prescriptions for gluten-free substitute foods,^{10,13} resulting in 'substantial variations in

prescribing rates'.¹⁴ Linton et al.¹⁵ found that areas who had stopped gluten-free prescriptions, or had only prescribed for certain age categories, reduced their expenditure on gluten-free food by approximately 80%. However, Linton et al.¹⁵ called for qualitative work to explore the impact of policy changes on patients, also cautioning that any longer-term impacts on patients were unknown.

The present study aimed to explore the affordability, availability and accessibility of gluten-free substitute foods for adults with coeliac disease following the restriction and withdrawal of prescriptions for gluten-free foods in England. The presented data form part of a wider mixed-methods study (a cross-sectional survey followed by qualitative interviews) exploring the impact of the withdrawal of prescriptions for gluten-free food on individuals' finances, quality of life and access to gluten-free food. Findings in relation to the impact of the withdrawal of prescriptions on quality of life, including participants' views about whether and how the NHS should support people with coeliac disease with the cost of purchasing gluten-free substitute foods, are presented elsewhere.¹⁶

METHODS

In depth, semistructured interviews were conducted with adults with coeliac disease to explore: (i) the impact of gluten-free prescribing changes on the affordability and obtainability of gluten-free food, and dietary adherence; (ii) experience of following a gluten-free diet, including dietary adherence; and (iii) history of using prescriptions to obtain gluten-free substitute foods. Interview participants were recruited from respondents to a related survey of 4050 Coeliac UK members, across 26 geographically spread CCGs, who had consented to be invited for an interview to discuss their questionnaire answers in greater depth.¹⁶ Purposive sampling was used to invite a diverse sample, and although maximum variation was sought, those who no longer had access to prescriptions were oversampled, because a key aim of the study was to understand the impact of withdrawing prescriptions. In addition, more participants were recruited from deprived backgrounds (i.e., those from lower income groups, the most deprived areas (index of multiple deprivation quintiles), while also considering employment status and educational qualifications achieved) because it was anticipated that this group would be the most affected by prescribing changes. All participants self-reported that they had received a medical diagnosis of coeliac disease.

The interviews were conducted between August and December 2017, with the duration of interviews lasting between 21 and 97 min. The interviews were transcribed verbatim, systematically coded in NVIVO, version 12 (QSR International Pty Ltd) and the data were analysed thematically. Full details of the methods used in this study are reported elsewhere.¹⁶ The University of Oxford's Central University Research Ethics Committee granted ethical approval for this study. The reporting of results was guided by the following hierarchy of descriptors: most or majority ($\geq 75\%$ of participants); many or often (51% – 74% of participants); some or several (26% – 50% of participants); a few or limited ($\leq 25\%$ of participants).

RESULTS

Twenty-four people with coeliac disease (13 women and 11 men) participated in an in-person ($n = 16$, 66.7%) or telephone ($n = 8$, 33.3%) interview. The majority of participants ($n = 17$, 70.8%) lived in areas that no longer prescribe gluten-free foods, with the remainder residing in areas where prescriptions were restricted ($n = 1$, 4.2%) or prescribed according to national guidelines ($n = 6$, 25.0%). In areas where prescriptions were available, three participants chose not to receive them. Participants lived in areas reflecting a broad range of levels of deprivation, covering all five quintiles of the index of multiple deprivation (Table 1), with a skew toward areas of greater deprivation

TABLE 1 Demographic details of qualitative interview participants.

ID	Age (years)	Gender	Marital status	Employment	Household income (£)	IMD quintile ^a	Time since diagnosis (years)	Access to prescriptions ^b
1	68	Female	Single	Retired	10,000–20,000	2	3	No
2	18	Female	Single	Full-time education	40,001–50,000	3	<1	No
3	77	Female	Married	Retired	10,000–20,000	4	19	No
4	69	Female	Divorced	Retired	<10,000	3	25	No
5	65	Male	Married	Retired	–	5	15	No
6	59	Male	Single	Unemployed	30,001–40,000	2	4	Yes - Restricted
7	–	Male	Married	Retired	10,000–20,000	1	9	No
8	–	Male	Single	Full-time paid work	10,000–20,000	1	1	Yes
9	54	Male	Married	Volunteering	50,001–60,000	2	16	Yes
10	–	Male	Single	Full-time paid work	10,000–20,000	1	1	Yes
11	55	Male	Married	Permanently sick or disabled	20,001–30,000	2	<1	No
12	26	Female	Single	Full-time paid work	–	4	1	Yes
13	79	Female	Married	Retired	40,001–50,000	2	17	Yes
14	61	Male	Widowed	Part-time paid work	10,000–20,000	2	19	No
15	43	Female	Single	Self-employed	<10,000	1	1	No
16	82	Female	Married	Retired	20,001–30,000	3	19	No
17	84	Female	Widowed	Retired	10,000–20,000	2	44	No
18	62	Female	Married	Self-employed	30,001–40,000	5	15	No
19	47	Female	Married	Permanently sick or disabled	20,001–30,000	3	9	No
20	43	Male	Single	Self-employed	–	2	1	No
21	85	Male	Single	Retired	–	4	29	No
22	22	Female	Single	Full-time education	–	3	4	No
23	64	Male	Widowed	Retired, and permanently sick or disabled	<10,000	2	10	No
24	67	Female	Single	Retired	<10,000	3	14	Yes

^aThe level of deprivation for the geographical areas in which participants lived were obtained from the Index of Multiple Deprivation¹⁷ and presented as quintiles, with 1 representing the 20% most deprived areas and 5 representing the 20% least deprived areas.

^bDenotes whether the individual has access to prescriptions: 'Yes', the participant lives in an area that is following national prescribing guidelines; 'Yes - Restricted', the participant lives in an area that prescribes a limited range or quantity of gluten-free foods; 'No', the participant lives in an area that has stopped prescribing gluten-free foods. Abbreviation: IMD, index of multiple deprivation.

(13 participants [54.2%] lived in the most deprived 40% of small areas in England, and five participants [20.8%] lived in the least deprived 40% of small areas in England). Household income ranged from less than £10,000 to £60,000. The mean age of participants was 59 years old (range 18–84 years) with participants diagnosed with coeliac disease for a mean of 10.7 years (range 6–44 years). Just under half of participants were retired ($n = 11$; 45.8%), with the remaining participants in full- or part-time work ($n = 4$; 16.7%), self-employed ($n = 3$; 12.5%), permanently sick or disabled ($n = 3$; 12.5%), in full-time education ($n = 2$; 8.3%), unemployed ($n = 1$; 4.2%) or volunteering ($n = 1$; 4.2%). The majority of participants were single ($n = 11$; 45.8%) or married ($n = 9$; 37.5%), with the remainder widowed ($n = 3$; 12.5%) or divorced ($n = 1$; 4.2%). All participants were white. Some participants reported additional health conditions, such as osteoporosis, diabetes and rheumatoid arthritis, whereas a few had additional dietary requirements or preferences (e.g., food allergies, veganism). Participant characteristics are reported in full in Table 1.

Themes

This paper reports two of the key themes identified from the analysis: the cost and affordability of gluten-free substitute foods, and the availability of gluten-free substitute foods. Each theme is discussed in turn.

Cost and affordability of gluten-free substitute food

The cost and affordability of following a gluten-free diet was one of the key issues raised by participants during the interviews. All participants considered the cost of gluten-free substitute foods to be expensive when compared with their gluten-containing equivalents. Participants attributed the high prices to the manufacturing process (i.e., the need to manufacture products separately to avoid cross-contamination), lower demand (compared to gluten-containing foods), and profiteering (charging premium prices to a 'niche' market). Furthermore, a few participants noted that food products labelled as 'gluten-free' are likely to command a higher price than similar unmarked products. Some participants expressed anger and irritation at having to pay much more than they would for gluten-containing equivalents, particularly as their need to follow a gluten-free diet is for medical reasons as opposed to a lifestyle choice. A man diagnosed for 16 years remarked:

You know there's a market out there for people like myself and all the other coeliacs, and the manufacturers know there's a market and they know they can ask you to

pay a premium price for it. Unfortunately, I can't see an end to that really (Participant 9, man, 54 years old)

Participants were keen to differentiate themselves from the increasing number of people choosing to follow a gluten-free diet as a lifestyle choice, by stressing that their need to follow a gluten-free diet is a medical necessity. A few participants felt that the withdrawal of prescriptions further blurred the distinction between these two groups, and in addition, indicated a lack of support from the NHS for people living with the condition:

It makes other people see us as if we're faddy eaters even more ... now that the medical fraternity are saying basically, 'Well no, you don't need food on prescription,' I just feel like they're exacerbating that ... because, you know if the GPs aren't even going to give you the medicine you need, prescription food, then why should the normal people out there understand (Participant 19, woman, 47 years old)

Affordability of gluten-free food

Although most participants resented having to pay much more than they would for gluten-containing equivalents, many reported that, even though expensive, substitutes were affordable for them and they were able to buy the food that they need:

I think it's annoying that it's more expensive. But there's less demand for it, so it's understandable that it's going to be a bit more expensive ... I think I'm quite fortunate in that I've always been able to afford it; I've not been like, 'Oh god, I've really got to cut down on what I'm buying,' or 'I've got to eat less because I can't afford to eat the food' ... I reckon I probably spend a third more than most people do on food (Participant 22, woman, 22 years old)

The withdrawal of prescriptions had an impact on participant behaviour. Some participants reduced the quantity or range of gluten-free substitute foods obtained, with such strategies usually undertaken as money saving initiatives. A common example was reducing the amount of bread consumed, with other strategies mentioned including looking for special offers, being less wasteful, and cutting back on other expenses, such as eating out. A 55-year old man, who does not find following a gluten-free diet affordable, described how a reduced supply of gluten-free substitute foods is attributing to difficulties maintaining his weight:

Say I wanted three slices of bread, I might think, "We can't afford another loaf this week, I'd better only have two". And then I've got a constant battle where I'm constantly sort of losing weight, if you know what I mean? (Participant 11, man, 55 years old)

In some instances, despite finding gluten-free substitute items affordable, participants decided to reduce or exclude items from their diet as they were not willing to pay such high prices. A 65-year old man explains:

The price differential is frightening. Some of the things are up to ten times dearer for comparable non-gluten-free. Most things are sort of three or four times the price ... I used to get the bread mix on prescription and make my own bread. But don't do that anymore; I haven't made any since they stopped doing the prescriptions. So I'm eating far less bread type stuff than I ever have done, because I just won't pay ten times the price, which is what it quite often is for bread (Participant 5, man, 65 years old)

The withdrawal of prescriptions made the affordability of gluten-free substitute foods a much greater issue for a few participants, whom are permanently sick or disabled and/or on lower incomes. A 47-year old woman who uses a wheelchair discussed the difficulties she faces to afford gluten-free substitute foods:

By the time you've bought a couple of loaves of bread and some pasta every week. And paid for your delivery charges and things like that, it's about ten pounds a week just for me to have the very basics ... you know when you're on employment support allowance, like I am for disability, of eighty pounds a week. So, that's, you know that's a huge percentage of your living costs. So, therefore you have to find that money somewhere else (Participant 19, woman, 47 years old)

To afford basic gluten-free substitute foods, she described having to make compromises, for example, purchasing less bread during the winter in order to heat her home. However, she describes how this is becoming increasingly challenging:

The problem I'm finding now over the last few years is where is less that you can cut back. You know, I've given up smoking, we don't drink, ... you know we don't gamble, we don't even do the National Lottery; we don't do anything like that. And it's where,

there's nothing left to cut back, and that's where [it] is getting harder; much, much harder (Participant 19, woman, 47 years old)

Although, in some cases, interview participants had reduced the quantity of gluten-free substitute foods purchased, there was no narrative to suggest that participants were not adhering to a gluten-free diet as rigorously as before any changes to prescribing were made, with all but one interview participant appearing to follow the diet strictly. Indeed, it was evident that most participants were committed to following a gluten-free diet, for example, a 77-year-old woman, living on a state pension and budgeting carefully, commented: 'to keep my health as it is, I'm determined to stick to the rules. Yes, however expensive it is' (Participant 3, woman, 77 years old).

Many participants also speculated about the affordability of gluten-free substitute foods for others with coeliac disease, particularly those on low incomes, those with multiple family members with coeliac disease (particularly children) and the elderly. Some raised specific concerns that the high cost of gluten-free substitute foods together with the withdrawal of prescriptions may lead to reduced dietary adherence in the above-mentioned groups. These speculations were predominantly made by those who found gluten-free foods affordable. A man in full-time work shared his concerns:

For a standard bread with rice flour, or whatever, I struggle to know how they justify the prices, to be honest. And I do a lot of voluntary work at Citizen's Advice, and see people on extremely low incomes, and to be honest I don't know; in fact, I know they can't afford to buy that sort of bread (Participant 8, man, age unknown)

As well as considering how the prescribing changes impact on the affordability of foods for themselves and others, participants also raised questions about the potential long-term costs to the NHS as a result of other health problems developing should people no longer be able to adhere to a gluten-free diet, if prescriptions remain unavailable:

I think it [prescriptions for gluten-free food] would benefit an awful lot of people, and it would probably, in the long run, it would probably improve the health of the coeliac group if you like. Because perhaps people wouldn't then be taking chances with stuff they shouldn't be having, then saving the NHS money by not being ill and having to be perhaps hospitalised ... it's a longer-term thing to look at rather than just, oh we'll save ourselves a few million, or whatever it

is, now by doing it (Participant 14, man, 61 years old)

Moving forward, although participants acknowledged the financial challenges faced by the NHS and recognised the need for spending cuts, many felt that the NHS should support people with coeliac disease with the cost of purchasing gluten-free substitute foods. There was however, variation between participants about which foods should be supported. A 69-year-old woman, who has a range of additional health conditions, suggested that this support should be tailored to the needs of the individual. For example, she values oats and biscuits over the more usual staple foods, such as bread and flour mixes, as they were of particular value in the management of her diverticulitis and diabetes alongside her coeliac disease. Participants also raised concerns around inequity within the healthcare system, with many questioning the fairness for certain health conditions to continue to receive support when support for people with coeliac disease is withdrawn. A few participants specifically highlighted the continued support for people with, what they referred to as, "self-inflicted" illnesses, such as smokers and drug addicts.

The availability of gluten-free substitute food

Most participants thought that the availability of gluten-free food has improved over time, with an increased range of gluten-free foods now available in supermarkets, restaurants and cafes. However, some participants reported problems obtaining gluten-free foods from smaller supermarkets and local shops, resulting in a few having to travel greater distances to reach larger providers. A man in full-time employment describes how the availability of gluten-free food varies in his locality:

The area that I'm living in, it's quite OK for the shops like [Supermarket 1] mainly, or [Supermarket 2], that they got quite a variety of the gluten-free stuff. However, I'm working quite far away from the town where basically, I can't get anything of gluten-free. ... So, I basically have to bring my food with myself because I can't get anything close to my workplace, or at my workplace really (Participant 10, man, age unknown)

Where supermarkets stocked gluten-free substitute foods, some participants were not able to rely on items being in stock, which made obtaining them more difficult. Some participants discussed strategies for coping with poor availability; for example, keeping a small stockpile of items such as bread, and following a naturally gluten-free diet where possible to minimise the purchase of gluten-free substitute foods.

Where participants had additional dietary needs (e.g., food allergies) or preferences (e.g., vegan diet), they described greater difficulties obtaining food to suit both their gluten-free diet and additional dietary requirements. A 59-year old man who follows a gluten-free vegan diet described difficulties with locating suitable foods in the supermarket and when eating out:

Lots of places that they do gluten-free and they do vegan but there's no overlap, so Quorn's a really good example. You can get vegan Quorn and you can get gluten-free Quorn, but you can't get vegan and gluten-free Quorn. And I think lots of sort of pub meals and things like that they've got a gluten-free menu and a vegan menu and bugger all that's on both. So, that does make life complicated (Participant 6, man, 59 years old)

Availability following the withdrawal of prescriptions

Following the withdrawal of prescriptions for gluten-free substitute foods in certain geographical areas, some participants reported that this had little impact on their lives or that they experienced a short period of adjustment or increased planning as they adapted to procuring gluten-free substitute foods from elsewhere. Some participants reported difficulties obtaining gluten-free substitute foods from other sources as a result of the same or equivalent products not being readily available or items regularly being out of stock. This resulted in some visiting multiple supermarkets or visiting one supermarket on a number of occasions to try and obtain the necessary items. A 69-year old woman describes this experience:

It's [fresh gluten-free bread] sometimes not even on the shelves here. Sometimes it's completely gone. The other coeliacs have got it. They're alright this week but I'm not; that's what happens, it happens in a small town ... And then of course I try and buy two and then one of them goes off (Participant 4, woman, 69 years old)

A few participants also raised concerns about whether they could trust the gluten-free status of products purchased at supermarkets compared with that of foods obtained on prescription:

The other element not to forget is the reassurance people get from knowing something is done to a standard that is, if you

like, medically gluten free. I think some people don't trust the supermarket brands. We don't trust supermarkets, understandably with all the things going on at the moment with chicken and stuff like that (Participant 6, man, 59 years old)

By contrast, for a few participants, obtaining gluten-free substitute foods following the withdrawal of prescriptions was more challenging. Two of the participants had impaired mobility as a result of health issues and relied on the use of a wheelchair. One of these participants, a 69-year old woman, also reported a number of co-morbidities including fibromyalgia, diabetes and diverticulitis, which makes getting to the shops to purchase gluten-free food more challenging. She also finds carrying food home from the supermarket physically demanding and is therefore unable to purchase large quantities; the need to purchase foods that she used to have on prescription increases this burden. Furthermore, fluctuations in her health can leave her housebound for days at a time. Because of these difficulties, she experiences anxiety around the amount of gluten-free food she has remaining in her home:

The system pulled the rug out from under us. So suddenly, you know I'm in a, from having the stuff brought right in to my kitchen in that whole thing of it becomes like the main reason I go out, which is to get my gluten-free food from somewhere; it's nothing else. That is my focus, is really all, well, I would say every time I go, get out I have to get something to fill the gluten-free gaps (Participant 4, woman, 69 years old)

A third participant, an 84-year old single man, although coping at present, raised concerns about how he would obtain gluten-free substitute foods as his mobility reduces as he ages.

DISCUSSION

In recent years, an increasing number of local bodies in England have removed or restricted access to prescriptions for gluten-free substitute foods for people with coeliac disease.¹³ In the present study, the majority of participants affected by prescribing changes were able to adapt to afford and obtain gluten-free substitute foods from elsewhere, but some participants were struggling. Participants struggling with the affordability of following a gluten-free diet had additional health problems and regarded themselves as 'permanently sick or disabled', and/or were lower income households. Some, but not all, participants with lower household incomes struggled to afford gluten-free substitute foods, making cutbacks

elsewhere to do so (e.g., not eating meat). Participants who described significant challenges with obtaining gluten-free substitute foods had limited mobility (i.e., were wheelchair users) or were not easily able to reach larger supermarkets. These results provide some evidence to support concerns from others that those most impacted by high costs and limited availability of gluten-free substitute foods are those with limited mobility and those on low incomes.^{4,5}

It is well documented in the literature that the cost of gluten-free substitute foods is more expensive than their gluten-containing counterparts.^{4,7} All participants in the present study considered this to be the case, with some expressing anger and irritation about high prices. It is of note that some participants made compromises to their diet because of the lack of affordability of gluten-free substitute foods, such as reducing the quantity of foods purchased. In a few cases, this was to meet other basic needs, such as heating their home. Elsewhere, others have also discussed their experiences of offsetting (i.e., going without or minimising other expenses to afford gluten-free substitute foods).¹⁸

In the literature, concerns have been raised about the potential impact that a withdrawal of prescriptions could have on the ability of those with coeliac disease to adhere to a gluten-free diet. Muhammad et al.¹⁹ assessed dietary adherence in Caucasian and South Asian adults with coeliac disease, finding that those not receiving gluten-free food on prescription had lower dietary adherence. Consequently, Muhammad et al.¹⁹ called for robust studies to urgently evaluate the impact of the withdrawal of gluten-free food on prescription. Furthermore, Burden et al.⁴ raised concerns that poor availability of gluten-free substitute foods coupled with their high cost is likely to impact dietary adherence in deprived groups. In the present study, there was no narrative from interview participants to suggest that levels of dietary adherence had changed. Indeed, some were keen to stress the importance that they place on following a gluten-free diet, despite facing challenges to adapt to new ways of obtaining gluten-free substitute foods following their withdrawal on prescription. Although participants did not describe any changes to their personal levels of dietary adherence, some speculated that the withdrawal of prescriptions would lead to non-adherence in others. The results of a previous survey that was conducted as part of a broader study do not support this, with little evidence of poor dietary adherence found.¹⁶ Furthermore, a survey of people with coeliac disease living in four areas where prescriptions had been restricted or removed found that only 6.7% felt the changes had directly affected their health.¹³

Participants placed additional values on the prescription of gluten-free substitute foods beyond their primary role of enabling people with coeliac disease to access suitable foodstuffs. For participants, prescriptions also signify that the NHS supports people living with coeliac

disease and acknowledges the medical necessity of a gluten-free diet for this group. This was a particularly important issue for participants given the rise in the number of people following a gluten-free diet for non-medical reasons, such as for a lifestyle choice.²⁰ Some participants described prescriptions as a way of distinguishing this group of individuals from people with coeliac disease, at the same time as validating their health condition. These findings are echoed in a study by Kurien et al.¹³ who found that almost 60% of respondents felt less supported in the management of their coeliac disease as a result of changes to their prescription.

Although many participants were aware of limited resources within the NHS, they questioned the equity of the NHS, with certain health conditions able to obtain treatments and support, whereas others are not. As such, there appears to be a need for greater transparency and communication around commissioning decisions, particularly around decisions to provide greater support for some health conditions. Validation of participants' coeliac disease could be achieved through means other than the provision of prescriptions, such as by ensuring that people with coeliac disease are offered their annual follow-up appointment. In addition to providing validation, this would also ensure that the NHS are meeting the NICE quality standard for coeliac disease.²¹

In 2017, during this study, the UK Government's Department of Health and Social Care conducted a public consultation about the provision of gluten-free foods on prescription in England.²² The result of the consultation, published after the completion of the present study, was to limit prescriptions to gluten-free bread and flour mixes.²³ Despite this outcome, at the time of writing, the provision of gluten-free prescriptions across England still varies considerably,²⁴ with many areas maintaining a partial or complete withdrawal of prescriptions. Although most participants in the present study considered that only basic items should be available on prescription, there was variation regarding what constitutes a 'basic' item and which food items each participant considered the most valuable. As such, some consideration should be given as to whether prescriptions can be tailored to meet the needs of the individual, thus providing patient-centred care,²⁵ at the same time as targeting limited NHS resources toward those who are most in need.

It is increasingly recognised that more innovative models of gluten-free food provision, such as pharmacy-led or voucher schemes, may offer reduced costs to the NHS and increased convenience to patients.^{26–28} The present study highlights the importance of trialling alternative schemes in those that need them most, such as those who are permanently sick or disabled, have reduced mobility or have lower incomes. This will help ensure that a gluten-free diet is accessible to all adults with coeliac disease.

A limitation of the present study is that participants self-reported their diagnosis of coeliac disease; however, all participants confirmed that they had been diagnosed by a medical professional. A further limitation is that participants self-reported dietary adherence. It cannot be known whether participants who completed the associated survey¹⁶ and who were willing to be interviewed differed with respect to their dietary adherence from people who did not participate. It is possible that members of a support group are more inclined to follow a gluten-free diet regardless of barriers such as cost. Although a diverse sample was achieved across many demographic and disease-specific variables, there was no diversity in terms of ethnicity because all participants were white. It is possible that the experience of white people with coeliac disease differs from that of people from other ethnic groups.

Subsequent to the conclusion of the study, the cost of living in the UK has increased as a result of global and political factors, such as the COVID-19 pandemic and war in Ukraine. As such, the cost of food has risen, which is likely to further reduce the affordability of gluten-free substitute foods, and potentially increase the number of people with coeliac disease for whom gluten-free substitute foods are unaffordable. A recent survey of individuals in Glutafin's (food manufacturer) database explored the cost of living for people with coeliac disease in the UK.²⁹ It found that 59% of people felt that increasing food prices have affected their ability to stick to a gluten-free diet and, furthermore, that people in England were more likely to be impacted (62% compared to 48% in Scotland, it is unclear whether this was statistically significant). It must be noted that there are limitations to this survey (e.g., amount of missing data and lack of clarity around how respondents interpreted the above question). Nevertheless, the additional pressures of living with coeliac disease through a cost of living crisis is a valuable area for further research.

CONCLUSIONS

The majority of participants affected by changes to the prescribing of gluten-free substitute foods were able to adapt. However, participants with mobility issues, who are permanently sick or disabled and/or on lower incomes, struggled to access and afford gluten-free substitute foods following the withdrawal of gluten-free food on prescription. Despite these challenges, participants reported continued adherence to a gluten-free diet. Although the primary purpose of prescriptions for gluten-free substitute food is to aid those with coeliac disease to obtain and afford gluten-free food, the present study highlights that people with coeliac disease also view prescriptions as signifying support from the NHS in the management of their long-term condition. Furthermore, prescriptions play a role in validating coeliac

disease as a health condition rather than a lifestyle choice. Future research should focus on assessing any long-term impacts of no access or restricted access to prescriptions for gluten-free food in areas that maintain restrictions, including any impacts on the nutritional quality of individual's diets. In areas reversing the withdrawal of prescriptions, in line with the outcome of the Government's consultation, the responses to and impact of the reversal could be explored. It is particularly important that any such research should focus on those who are permanently sick or disabled, have poor mobility, or lower incomes.

AUTHOR CONTRIBUTIONS

Michele Peters and Mara Violato conceived of the study and its design. All authors contributed to the development of the interview topic guide. Thomas Lewis carried out the qualitative interviews under the supervision of Michele Peters. Helen Crocker led on data analysis with input from Michele Peters. Helen Crocker led on drafting the manuscript with input from Thomas Lewis, Michele Peters, and Mara Violato. All authors critically reviewed and approved the final version of the manuscript.

ACKNOWLEDGEMENTS

We thank the participants for their time and Coeliac UK for assisting with recruitment. The study was funded by Coeliac UK, an independent charity for people with coeliac disease. Mara Violato was partly supported by the National Institute for Health and Care Research (NIHR) Oxford Health Biomedical Research Centre (BRC) and the National Institute for Health Research (NIHR) Applied Research Collaboration (ARC) Oxford and Thames Valley. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

CONFLICTS OF INTEREST STATEMENT

The authors declare that there are no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ETHICAL STATEMENT

The University of Oxford's Central University Research Ethics Committee granted ethical approval for this study (Reference number: R45890/RE001).

TRANSPARENCY DECLARATION

The lead author affirms that this manuscript is an honest, accurate, and transparent account of the study being reported. The lead author affirms that no important aspects of the study have been omitted and that any discrepancies from the study as planned have been explained.

ORCID

Helen Crocker  <http://orcid.org/0000-0002-9786-0749>

Michele Peters  <http://orcid.org/0000-0002-0076-5981>

PEER REVIEW

The peer review history for this article is available at <https://www.webofscience.com/api/gateway/wos/peer-review/10.1111/jhn.13231>.

REFERENCES

- Shah S, Akbari M, Vanga R, Kelly CP, Hansen J, Theethira T, et al. Patient perception of treatment burden is high in celiac disease compared with other common conditions. *Am J Gastroenterol*. 2014;109:1304–11.
- Sverker A, Hensing G, Hallert C. 'Controlled by food' – lived experiences of coeliac disease. *J Hum Nutr Diet*. 2005;18:171–80.
- Crocker H, Jenkinson C, Peters M. Quality of life in coeliac disease: qualitative interviews to develop candidate items for the Coeliac Disease Assessment Questionnaire. *Patient Relat Outcome Meas*. 2018;9:211–20.
- Burden M, Mooney PD, Blanshard RJ, White WL, Cambray-Deakin DR, Sanders DS. Cost and availability of gluten-free food in the UK: in store and online. *Postgrad Med J*. 2015;91:622–6.
- Chrysostomou S, Andreou SN, Andreou C. The development of the gluten free healthy food basket in Cyprus. Is it affordable among low-income adults diagnosed with celiac disease? *J Public Health*. 2020;42:270–6.
- Estévez V, Ayala J, Vespa C, Araya M. The gluten-free basic food basket: a problem of availability, cost and nutritional composition. *Eur J Clin Nutr*. 2016;70:1215–7.
- Hopkins S, Soon JM. Nutritional quality, cost and availability of gluten-free food in England. *Br Food J*. 2019;121:2867–82.
- Celiac Disease Foundation. Policies around the world. <https://celiac.org/gluten-free-living/global-associations-and-policies/policies-around-the-world/>. Accessed April 2022.
- Gorgitano MT, Sodano V. Gluten-free products: from dietary necessity to premium price extraction tool. *Nutrients*. 2019;11:1997. <https://doi.org/10.3390/nu11091997>
- Kurien M, Trott N, Sleet S, Sanders DS. Prescribing gluten-free foods in general practice. *Br J Gen Pract*. 2018;68:364–5.
- Pinto-Sanchez MI, Verdu EF, Gordillo MC, Bai JC, Birch S, Moayyedi P, et al. Tax-deductible provisions for gluten-free diet in Canada compared with systems for gluten-free diet coverage available in various countries. *Can J Gastroenterol Hepatol*. 2015;29:104–10.
- PrescQipp. (2015). Guidance on the prescribing of gluten-free foods. <https://www.prescquipp.info/umbraco/surface/authorisedmediasurface/index?url=%2fmedia%2f1324%2fb69-gluten-free-42.pdf>. Accessed April 2022.
- Kurien M, White W, Trott N, Sanders D. PWE-057 does restriction of gluten-free prescription foods affect people with coeliac disease? *Gut*. 2016;65:A166.2–A166.
- Walker AJ, Curtis HJ, Bacon S, Croker R, Goldacre B. Trends, geographical variation and factors associated with prescribing of gluten-free foods in English primary care: a cross-sectional study. *BMJ Open*. 2018;8:e021312. <https://doi.org/10.1136/bmjopen-2017-021312>
- Linton MJ, Jones T, Owen-Smith A, Payne RA, Coast J, Glynn J, et al. Breaking bread: examining the impact of policy changes in access to state-funded provisions of gluten-free foods in England. *BMC Med*. 2018;16:119. <https://doi.org/10.1186/s12916-018-1106-7>
- Peters M, Crocker H, Jenkinson C, Violato M. Withdrawing gluten-free food from prescriptions in England: a mixed-methods study to examine the impact of policy changes on quality of life. *J Hum Nutr Diet*. 2019;33:453–64.
- Ministry of Housing, Communities & Local Government. (2019). The English Indices of Deprivation 2019 (IoD2019). <https://www>.

- gov.uk/government/statistics/english-indices-of-deprivation-2019. Accessed August 2022.
18. Gleed G. Commentary: we're under financial strain without prescriptions for gluten-free food. *BMJ*. 2017;356:j119. <https://doi.org/10.1136/bmj.j119>
 19. Muhammad H, Reeves S, Ishaq S, Mayberry J, Jeanes Y. Adherence to a Gluten free diet is associated with receiving gluten free foods on prescription and understanding food labelling. *Nutrients*. 2017;9:705. <https://doi.org/10.3390/nu9070705>
 20. Jones AL. The gluten-free diet: fad or necessity? *Diabetes Spectrum*. 2017;30:118–23.
 21. National Institute for Health and Care Excellence. (2016). Coeliac disease: quality standard [QS134]. <https://www.nice.org.uk/guidance/qs134>. Accessed April 2022.
 22. Department of Health. (2017). The availability of gluten free foods on prescription in primary care: consultation on the availability of gluten free foods on prescription in primary care. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/604842/Gluten_free_foods_cons.pdf. Accessed April 2022).
 23. Department of Health and Social Care. (2018). Report of responses following the public consultation on gluten free prescribing: availability of gluten free food on prescription in primary care. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/678181/report_of_responses_-_gluten_free_food_prescribing_consultation.pdf. Accessed April 2022).
 24. Coeliac UK. Prescription policies. <https://www.coeliac.org.uk/information-and-support/coeliac-disease/once-diagnosed/prescriptions/prescription-policies/>. Accessed April 2022).
 25. Epstein RM, Street RL. The values and value of patient-centered care. *Ann Fam Med*. 2011;9:100–3.
 26. The British Dietetic Association. (2021). Policy statement: gluten free food on prescription. <https://www.bda.uk.com/uploads/assets/c59bd230-6e97-49ec-a051b8e6051f7df8/471f822a-21f6-4ead-9fea086a193a3457/glutenfreefoodonprescriptionpolicystatement.pdf>. Accessed April 2022).
 27. Tighe M, Sleet S, Currell S, Martin J, Puntis J. Gluten-free food prescriptions for children with coeliac disease: should families have to pay? *Br J Gen Pract*. 2017;67:348–9.
 28. Kurien M, Sleet S, Sanders DS, Cave J. Should gluten-free foods be available on prescription. *BMJ*. 2017;356:i6810. <https://doi.org/10.1136/bmj.i6810>
 29. Dr Schär. (2023). Cost of living survey: Glutafin, UK 2023. *Personal Communications*. Received April 2023.

AUTHOR BIOGRAPHIES

Helen Crocker is a researcher at the Nuffield Department of Population Health, University of Oxford. Her research focuses on patient experience, safety and outcomes of health care.

Thomas Lewis is a postdoctoral research assistant at Myeloma UK, a charity organisation. His work focuses on exploring the many psychological avenues that influence health.

Mara Violato is an associate professor at the Health Economics Research Centre, University of Oxford. Her economic and statistic research focuses on various diseases, including coeliac disease.

Michele Peters is an associate professor in Health Services Research at the University of Oxford and the teaching lead for Medical Sociology at the Oxford Medical School.

How to cite this article: Crocker H, Lewis T, Violato M, Peters M. The affordability and obtainability of gluten-free foods for adults with coeliac disease following their withdrawal on prescription in England: a qualitative study. *J Hum Nutr Diet*. 2024;37:47–56. <https://doi.org/10.1111/jhn.13231>