Dr Hugh Porter
Nottingham City CCG
1 Standard Court
Park Row
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22 June 2018

Dear Dr Porter,

Re: Greater Nottingham CCGs consultation on gluten free prescribing

We are contacting you in response to the launch of your consultation on gluten free prescribing and would like to submit this letter as a formal response.

We are concerned that the decision has been made to launch a consultation when the Department of Health and Social Care (DHSC) has only recently undertaken a national consultation and concluded that gluten free bread and flour mixes should continue to be available on prescription.

We would like to highlight our concerns regarding the decision to move to consultation when this issue has been reviewed at a national level. Access to gluten free food on prescription is a service providing essential NHS support to help people manage a lifelong autoimmune disease. We are particularly concerned that if approved, this policy would result in health inequality due to the higher cost and limited availability of gluten free food and would have a disproportionate impact on the most vulnerable. Our concerns are shared by the British Dietetic Association, British Society of Gastroenterology and are reflected in the National Institute of Health and Care Excellence (NICE) quality standard for coeliac disease published at the end of 2016.

Review by the Department of Health and Social Care (DHSC)
The review carried out by the DHSC on the future of gluten free prescribing was a substantial exercise that received an unprecedented number of responses from clinicians and professional bodies as well as patients. The decision to retain access to gluten free bread and flour mixes on prescription was based on a significant amount of evidence highlighting the issues of cost and availability to patients and the impact on patient health and long term cost to the NHS due to inability to comply with the gluten free diet.

The DHSC report therefore warrants attention from commissioners. How can the Nottinghamshire CCGs justify holding a local consultation and the use of public money when a position has been reached at a national level?

Impact of policy change in Mansfield and Ashfield and Newark and Sherwood CCGs
Mansfield and Ashfield CCG and Newark and Sherwood CCG have removed access to gluten free food on prescription and one of the proposals would see this policy implemented across Nottinghamshire. Can you provide information on how the impact of

the policy change in these areas has been monitored and assessed, particularly with regard to the impact on patients?

The significance of the gluten free diet
Coeliac disease is an autoimmune disease caused by a reaction to gluten, found in wheat, barley and rye. Adherence to the gluten free diet remains the complete medical treatment and having coeliac disease therefore requires significant dietary modification. Rates for adherence to the gluten free diet can vary between 42-91% [1] and access to gluten free staples on prescription can be related to adherence [2].

Following a strict gluten free diet allows the gut to heal and reduces the risk of long term complications. Non adherence to the gluten free diet is associated with an increased risk of long term complications, including osteoporosis, ulcerative jejunitis, intestinal malignancy, functional hyposplenism, vitamin D deficiency and iron deficiency [3]. For children, non-adherence to the diet can have additional consequences including faltering growth and delayed puberty [4]. These long term complications will impact upon quality of life for the patient and treating these complications will result in financial implications for the NHS.

The consultation document refers to people without coeliac disease who exclude gluten as part of a lifestyle choice, this is confusing as this group of individuals are not able to access gluten free food on prescription. Why is reference made to this patient group?

Cost and availability of gluten free staple foods
Although availability of gluten free foods has improved in retail, gluten free staple foods are not readily available to purchase in budget supermarkets and convenience stores [5,6]. Policy makers must consider the needs of all patients, not just the people who have the economic and physical means to shop in large supermarkets. Access to gluten free food on prescription is vital for the most vulnerable, the elderly, those with limited transport options and helps to address the financial burden due to the higher cost of gluten free products

Gluten free staple foods are significantly more expensive than gluten containing equivalents. Research shows that gluten free staple foods are 3-4 times more expensive than gluten containing equivalents [5,6]. An example of the increased cost of gluten free staple foods is gluten free bread. Gluten free white bread is still on average 5 times the cost of gluten containing by volume. The price difference is even greater if you compare the cheapest loaves, in September 2017 the cheapest loaf would cost you 37.5p per 100g for gluten free compared to the price for gluten containing bread, 4.4p per 100g [7]. Those shopping for the cheapest loaf will be paying more than 8 times the price.

We understand that there is a need to control costs within the NHS but are concerned that this proposal will have an impact on long term health outcomes. This raises the issue of false economy, where small savings in prescription costs could lead to higher treatment costs associated with poor health outcomes and increased health complications. It costs approximately £195 a year per patient to support gluten free food on prescription [8]. The average cost to the NHS of an osteoporotic hip fracture is £27,000 [9] – the equivalent of 138 years of gluten free prescribing. This is significant given that osteopenia and osteoporosis are found in 40% of adult patients at diagnosis of coeliac disease [10].

Factors affecting adherence to the gluten free diet
We would also like to draw your attention to a paper which has been published in the last year. The research explores the factors associated with adherence to the gluten free diet and differences between Caucasians and South Asians [11]. A number of factors were identified as having a role in adherence to the gluten free diet, including understanding food labels, membership of Coeliac UK and access to gluten free food on prescription.

Not understanding food labels was significantly associated with poorer adherence to the diet, of those who said that they did not understand food labels, 73% were not adherent to the diet. Not understanding food labels was found to be more common in South Asians (53%) compared to Caucasians (4%).

This research also supports continued access to gluten free food on prescription as respondents who were not receiving gluten free food on prescription had lower dietary adherence scores compared to those accessing prescriptions.

The role of gluten free substitute foods in the diet
Your consultation document states that gluten is not essential to people's diets. This statement underestimates the complexity of maintaining a balanced gluten free diet.

Starchy carbohydrates are an important component of a healthy diet and the Public Health England Eatwell Guide recommends that carbohydrates should contribute 50% of energy to the diet. Complete replacement of gluten containing staple foods is not easy and gluten free substitute foods are important for both practical reasons and for their nutritional contribution to the diet.

It must also be considered that those who would be most affected by the withdrawal of prescriptions are likely to be the least able to manage the complexity of the multiple adaptions required to maintain the nutritional balance of the Government's own recommendation in the Eatwell Guide, while also ensuring their diet is gluten free.

Cereals and cereal products contribute significant amounts of iron and calcium to the diet. Data from the National Diet and Nutrition Survey shows that cereals and cereal products contribute 44% of total iron intake and 30% total calcium intake to the diet [12]. The complete removal of cereals therefore has a significant impact on the diet. For example, replacing 72g (the equivalent of two slices) [13] of gluten free bread with a portion of rice containing the same amount of calories would reduce the iron content by 96% and the calcium content by 90%. Similarly, replacing gluten free bread with a portion of peeled, boiled potatoes containing the same amount of calories would reduce the iron content by 71% and the calcium content by 93%.

Calcium recommendations for people with coeliac disease are higher (1000mg) than the general population (700mg) [14] therefore including good sources of calcium in the diet is particularly important for people with coeliac disease.

Monitoring
The National Institute for Health and Care Excellence (NICE) recommends that all patients with coeliac disease are offered an annual review in their clinical guideline, Recognition, Assessment and Management of coeliac disease (NG20, 2015). Are all patients with coeliac disease currently offered an annual review? If not, will annual review for patients with coeliac disease be introduced alongside any changes to the gluten free prescribing policy?

I look forward to hearing from you and would welcome the opportunity to discuss this further.

Yours sincerely,

Sarah Sleet

Chief Executive, Coeliac UK

cc. Dr James Hopkinson, Chair Nottingham North and East CCG, Dr Stephen Shortt, Chair of Rushcliffe CCG, Dr Nicola Atkinson, Clinical Chair Nottingham West CCG

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