



ADDITIONAL REPRESENTATIONS

This is a supplement to the original agenda and includes a representation which is in addition to the original agenda.

NOTTINGHAM CITY COUNCIL
HEALTH SCRUTINY COMMITTEE

Date: Thursday, 18 October 2018

Time: 1.30 pm

Place: Ground Floor Committee Room - Loxley House, Station Street, Nottingham, NG2 3NG

Governance Officer: Zena West **Direct Dial:** 01158764305

AGENDA

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Representation from Coeliac UK

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Agenda Item 5

From: Ruth Passmore []
To: Jane Garrard
Subject: Health Scrutiny Committee meeting

Dear Jane,

I am contacting you regarding the paper on gluten free prescribing for the Health Scrutiny Committee meeting this Thursday.

Point 3.2 of the paper states that "The Government advised commissioners to undertake their own local consultation to inform local decision making about what to prescribe.". I was concerned to read this as this is not in line with advice that we have seen from the Department of Health and Social Care (DHSC). I would be grateful if you would be able to clarify what advice is being referred to here?

I also wanted to draw your attention to the [latest consultation document](#) from the DHSC which outlined the draft regulations to implement the changes to gluten free prescribing in England. Section 4.3 states that "*Subject to any comments received in relation to the proposed changes in the Prescribing Regulations, it is expected that NHS England will issue guidance to CCGs urging them to comply with the national arrangements for GF prescribing.*" The statement made in the paper for Nottingham County Council is totally at odds with this and states that the DHSC is recommending that CCGs conduct their own local consultations.

NHS England also referred to gluten free prescribing in [their 2017 consultation document](#) on items which should not routinely be prescribed in primary care. They stated: "*The Department of Health has recently consulted on proposals to make changes to the availability of gluten free (GF) foods that are prescribed in primary care. NHS England and NHS Clinical Commissioners support this consultation and as such, it would not be appropriate for NHS England or NHS Clinical Commissioners to further consult on the availability of GF foods on prescription in this document. It is anticipated that CCGs will take the outcome of that consultation into account as and when it becomes available.*"

Finally, could I request that Coeliac UK's response to the Nottingham CCGs consultation (attached) be made available to members of the Health Scrutiny Committee? The summary of our letter outlines issues relating to two points (access and cost of gluten free foods) but fails to summarise several other points which we raised in the attached letter, including our concern at the CCG holding a local consultation when a national review has been carried out.

If we can help with any further information relating to gluten free prescribing or if you would like to catch up over the phone please do let me know.

Kind regards,

Ruth

Ruth Passmore
Health Policy Officer

www.coeliac.org.uk

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Dr Hugh Porter
Nottingham City CCG
1 Standard Court
Park Row
Nottingham
NG1 6GN

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 adaptations 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%.

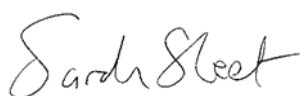
Calcium recommendations for people with coeliac disease are higher (1000mg) than the general population (700mg) [14] therefore including good sources of calcium in the diet is particularly important for people with coeliac disease.

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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