

**04 April 2022**

**Questions received from Coeliac UK ahead of the BLMK CCG Governing Body held on 29 March 2022.**

In addition to the written responses below, Questions 1 and 2 were responded to during the Governing Body meeting held in public.

- 1) We understand the Bedfordshire exemptions model (based on eligibility for income assessed Universal Credit or Pension credit) is the CCG's preferred approach to maintain access to support on prescription for low income coeliac patients, should Option 1 be approved. As laid out in our consultation response, this is of real concern. The percentage of people who are accessing support in this way in Bedfordshire (~0.4% of those diagnosed with coeliac disease) is significantly below the expected uptake, based on the reported levels of deprivation in the area (~10% categorised as income deprived). Furthermore, no evidence has been provided to demonstrate this policy has had a non-detrimental impact on the health of the coeliac community in Bedfordshire. With this in mind, on what basis does the CCG believe it appropriate to roll out this model to Luton and Milton Keynes, especially in the face of majority opposition to option 1 from consultation respondents?

From the consultation several stakeholders raised the issue of low income and the impact on low-income families being heightened during the Covid pandemic. The responses were relatively even in terms of supplying gluten-free foods routinely on prescription and withdrawing routine supply. Having listened to stakeholders it was felt that it was necessary if the routine provision of gluten-free foods was withdrawn in Luton, in line with Bedfordshire and Milton Keynes that those patients on a low income, which could be disproportionately impacted by the decision, were supported with ongoing access to gluten-free foods. Those at risk of dietary neglect would include patients in receipt of means assessed benefits, and other patients would be considered on a case-by-case basis.

At the time Bedfordshire CCG withdrew the routine provision of gluten-free foods on prescription (April 2017) the number of patients that applied to continue provision and were approved was significantly higher. 34 patients were approved to continue to access gluten-free foods. The estimated number of patients accessing gluten-free foods monthly was approximately 330 and every patient received written notification of the change of availability on prescription and the process for continuation and example criteria. The process for accessing gluten-free foods has not changed since April 2017 but the number of patients accessing this route has reduced.

There are several possible reasons for this however two that are likely to have influenced this are that the Department of Health in England restricting the provision on prescription to bread and bread mixes / flour coupled with the growing range of gluten free foods in food retailers and wider provision of lower cost choices.

If option one is approved all patients currently receiving gluten-free foods on prescription would receive written notification on how to apply for continuation. The dietetic teams at the trusts are aware of the process and can support this as part of the annual review. GP practices would also be made aware.

- 2) What measures will be put in place to monitor the impact on health outcomes of the recommended policy? What evidence does the CCG have to demonstrate that this approach has worked successfully and not impacted the health of people with coeliac disease living in Bedfordshire? As the majority of respondents (59.1%) were not in favour of withdrawal, can the CCG point to any benefit of this policy change to the coeliac community in the CCG?

All patients with Coeliac disease are offered dietetic support and an annual review. This provision will continue. The dietetic review includes routine bloods to assess compliance with diet, and support as necessary.

The dietetic teams are aware of the process for accessing gluten-free foods and can assist patients where they feel continued provision is necessary.

- 3) The NHS Constitution for England states “access to NHS services is based on clinical need, not an individual’s ability to pay”. Yet the recommendation to the board states that “Those at risk of dietary neglect should include people with a diagnosis of coeliac disease or dermatitis herpetiformis on an income assessed benefit such as Universal Credit”. Can the CCG explain how provision of gluten free prescriptions, based on an assessment of income, is in keeping with the NHS constitution?

The information highlighted from the NHS Constitution relates to NHS care being free at the point of delivery, a key value supported by Bedfordshire, Luton and Milton Keynes Clinical Commissioning Group. However, the proposal to provide gluten-free products to those on means tested benefits relates to the prescription costs and as such does not go against the constitution.

The CCG feels it is important to ensure those patients on a low income, who could be disproportionately impacted by the decision, continue to be supported with ongoing access to gluten-free foods, to ensure those at risk of dietary neglect are still able to access gluten-free products.

- 4) The majority of consultation respondents (59.1%) were in favour of Option 2 yet the CCG wishes to proceed with Option 1, (withdrawal of gluten prescriptions in Luton). On what basis was this recommendation reached, knowing - as highlighted in our submission – that the current Bedfordshire model is accessed by only ~0.4% of the coeliac community in the area, despite deprivation rates of 10%?

The CCG continually reviews how we commission services to ensure we are doing so in the most cost effective way, whilst continuing to deliver high quality services for the residents of Bedfordshire, Luton and Milton Keynes.

The CCG sometimes has to make difficult commissioning decisions, these decisions are based on a number of contributing factors, one of those contributing factors being patient feedback.

Taking into account the feedback from patients and stakeholders we will review the way in which those in risk of dietary neglect can access gluten-free food and ensure there is parity across the BLMK system. The feedback received focused heavily on ensuring those on a low income were able to access gluten-free bread and flour within the NHS system to protect the most vulnerable and reduce health inequality. Those at risk of dietary neglect should include people with a diagnosis of coeliac disease or dermatitis herpetiformis on an income assessed benefit such as Universal Credit.