Report to Joint Health Overview and Scrutiny Committee for South Yorkshire, Nottinghamshire and Derbyshire 20th October, 2020

Report of:	Report on proposals to standardise the prescribing of Gluten Free products across South Yorkshire and Bassetlaw
Subject:	Proposed standardisation of Gluten Free prescribing
Author of Report:	Idris Griffiths, Chief Officer Bassetlaw CCG and South Yorkshire and Bassetlaw lead for medicines management

Summary:

Information relating to Gluten Free prescribing, including the differences between CCGs in terms of prescribing guidelines and cost differences, were presented to the South Yorkshire and Bassetlaw Joint Committee of Clinical Commissioning Groups (JCCCG) for consideration of whether all 5 CCGs should adopt the same prescribing recommendations.

To get an initial public viewpoint on this and some principles to guide future work the JCCCG instructed that focused engagement take place. This paper sets out the relevant issues relating to Gluten Free prescribing and seeks the views of the Joint Scrutiny Committee regarding next steps.

Type of item: The report author should tick the appropriate box

Reviewing of existing policy	Yes
Informing the development of new policy	
Statutory consultation	Yes
Performance / budget monitoring report	
Cabinet request for scrutiny	
Full Council request for scrutiny	
Call-in of Cabinet decision	
Briefing paper for the Scrutiny Committee	
Other	

The Scrutiny Committee is being asked to:

Discuss the views from the engagement exercise on a potential standardisation of the NHS policy on prescribing Gluten Free products across South Yorkshire and Bassetlaw and provide the Joint Committee of CCGs with any views and comments.

To provide their views on whether any changes to the prescribing of Gluten Free bread and mixes in South Yorkshire and Bassetlaw that are drawn up utilising the principles that have been garnered from this engagement exercise, would be considered a substantial development or variation, and accordingly if they recommend that there is a formal duty to consult with the Local Authority under the s244 regulations.

Category of Report: OPEN

Report of the South Yorkshire and Bassetlaw Chief Officer Lead for Medicines Management

1. Introduction/Context

- 1.1 Information relating to gluten free prescribing, including the differences between CCGs in terms of prescribing guidelines and cost differences were presented to the South Yorkshire and Bassetlaw Joint Committee of Clinical Commissioning Groups (JCCCG) for consideration of whether all 5 CCGs should adopt the same prescribing recommendations.
- 1.2 To get an initial public viewpoint on this the South Yorkshire and Bassetlaw Citizens Panel members were asked for their thoughts. They felt that all 5 CCGs should adopt the same prescribing recommendations, i.e. that there should be equity of access across the CCGs. The Panel felt that the consideration should be one of equity rather than cost saving.
- 1.3 The JCCCG then instructed that engagement should take place with targeted members of the population, including those who might be most affected by any proposed changes (Low income groups; Mother and baby groups; Mental health patients; Young people; Older people; People with long term conditions; Coeliac and Gluten Free patients; Groups with other dietary needs). The report of this engagement is appended to this report.
- 1.4 This paper sets out the relevant issues relating to Gluten Free prescribing and seeks the views of the Joint Scrutiny Committee.

2. Background

- 2.1 Coeliac disease is a lifelong autoimmune disease caused by a reaction to gluten. When someone has coeliac disease their small intestine becomes inflamed if they eat food containing gluten. This reaction to gluten makes it difficult for them to digest food and nutrients. Symptoms include diarrhoea, constipation, vomiting, stomach cramps, mouth ulcers, fatigue and anaemia.
- 2.2 Once diagnosed, coeliac disease is treated by following a Gluten Free diet for life. A Gluten Free diet can be achieved without the need for specific manufactured products as many food items are naturally Gluten Free, e.g. meat, fish, fruit and vegetables, rice & potatoes.
- 2.3 Gluten Free (GF) foods are available on prescription to patients diagnosed with gluten sensitivity enteropathies, and have been since the late 1960s when the availability of GF foods was very limited. GF foods are now readily available in most supermarkets and a wider range of naturally GF food types are also available, so the ability of patients to obtain these foods without a prescription has greatly increased.
- 2.4 In March 2017, the Department of Health launched a consultation on the availability of Gluten Free Foods on Prescription. The outcome of the

consultation was reported in January 2018 and the overall statement was as follows:

"Following its consultation on the availability of GF foods on NHS prescription, the government has decided to restrict GF prescribing to bread and mixes only. The majority of consultation responses were in favour of this."

https://www.gov.uk/government/consultations/availability-of-gluten-free-foods-on-nhs-prescription

- 2.5 In August 2018 the Department of Health published a consultation on the changes to be made to the drug tariff for Gluten Free Items. The consultation closed on 1st October 2018; then, following amendments to the Prescribing Regulations, the Drug Tariff was amended in December 2018. NHS prescriptions issued in England from December 2018 can only be for specific GF bread or GF mixes as listed in the Drug Tariff.
- 2.6 Whilst GPs can only now prescribe GF bread and mixes CCGs can adopt local policies that may go further than the changes implemented in December 2018. There are differences across South Yorkshire and Bassetlaw between the CCGs in the prescribing of Gluten Free Products to coeliac patients.

3.0 Current Policies

- 3.1 Prescribing of Gluten Free foods to adults (over the age of 18) are not recommended in Sheffield. Prescribers can however apply discretion in exceptional circumstances where they are sufficiently convinced that there is a genuine risk that a vulnerable individual is, or will become, undernourished if they do not prescribe Gluten Free products. A full public consultation with people in Sheffield was undertaken before this policy was adopted in Sheffield.
- 3.2 Barnsley CCG has restricted prescribing of bread and mixes to a volume of 8 units per month per individual.
- 3.3 Bassetlaw and Doncaster CCGs recommend to clinicians that Gluten Free bread and mixes should be prescribed to the Coeliac Society recommendations.
- 3.4 Rotherham is slightly different to Bassetlaw and Doncaster recommending that the quantity to prescribe is 2 units less than the Coeliac Society recommendations.
- 3.5 Across South Yorkshire and Bassetlaw in 2018/19 over £400,000 was spent on prescribing Gluten Free food.
- 3.6 Standardising policies on Gluten Free products would have significantly different financial impacts depending on the approach taken with a potential range of an investment of £200,000 to a saving of up to £290,000

4.0 What does this mean for the people of South Yorkshire and Bassetlaw?

- 4.1 There are approximately 1,400 adults who request prescriptions for Gluten Free bread and mixes in South Yorkshire and Bassetlaw. This is approximately 0.11% of the population a figure which has reduced significantly in recent years, largely due to the wide availability of Gluten Free products in shops.
- 4.2 Approximately 1% of the population have coeliac disease.
- 4.3 Approximately 90% of those with coeliac disease do not use prescriptions. Where prescriptions are used the volumes requested by individual patients vary from infrequent to regular.
- 4.4 Any change in policy is therefore likely to have no, or very little, impact on 99.9% of the population.
- 4.5 If any future policy recommended further removal of access to Gluten Free prescriptions the impact on some of the 0.1%, particularly those living in poverty, could be significant.

5.0 Findings from the recent engagement

- 5.1 Following a stakeholder mapping exercise, a range of groups was identified and engaged throughout February and early March across Barnsley, Bassetlaw, Doncaster, Rotherham and Sheffield. These included:
 - Low income groups
 - Mother and baby groups
 - Mental health patients
 - Young people
 - Older people
 - o People with long term conditions
 - Coeliac and GF patients
 - Groups with other dietary needs
- 5.2 In total 88 people took part in the engagement through focus groups, attendance at existing groups and meetings and in-depth interviews—either face-to-face or over the telephone.
- 5.3 It was felt that this targeted approach to engagement would ensure the views of different communities who could be impacted by any proposed changes were heard in an equitable way that didn't favour one viewpoint over another. It was also felt that this would build on and not duplicate the national and Sheffield full public consultations into GF prescribing which have already taken place.
- 5.4 The engagement was independently analysed.
- 5.5 The vast majority of participants felt that access to health and care services and medication prescribing should be the same regardless of location, not only within South Yorkshire and Bassetlaw but also nationally.
- 5.6 Overall, the vast majority of participants felt that the NHS should not be funding products that are readily available in supermarkets and that funding for clinical decisions should be the priority.

- 5.7 Overall, the vast majority of participants felt that an increase in Gluten Free prescribing was not needed, especially not at the expense of other NHS services.
- 5.8 Almost all participants stated that they would be happy with a reduced level of Gluten Free prescribing in their area as long as those in need of support were protected and that it should be looked at on an affordability basis.
- 5.9 Overall, it was felt that whatever happens next with regards to Gluten Free prescribing the changes made should make the system fairer for all and reduce waste within the NHS. The most common themes emerging from participants were that there needs to be support to access Gluten Free foods in place for those most in need and a wider package of support for recently diagnosed people.

6.0 Proposals

- **6.1** The engagement has shown us that people feel:
 - There should be uniformity of approach across SYB
 - The NHS should not be routinely funding products available in the supermarket
 - An increase in Gluten Free prescribing is not felt necessary
 - They would be happy with reduced levels of GF prescribing
 - But they would like to see support measures in place for those who are most vulnerable/ in need
- 6.2 Our proposed next step is therefore to develop a business case based on these principles.

7.0 Recommendation

- 7.1 Discuss the views from the engagement exercise on a potential standardisation of the NHS policy on prescribing Gluten Free products across South Yorkshire and Bassetlaw and provide the Joint Committee of CCGs with any views and comments.
- 7.2 The Committee is asked for their views on whether any changes to the prescribing of Gluten Free bread and mixes in South Yorkshire and Bassetlaw that are drawn up utilising the principles that have been garnered from this engagement exercise, would be considered a substantial development or variation, and accordingly if they recommend that there is a formal duty to consult with the Local Authority under the s244 regulations.