

Formal Consultation Report

**The future of gluten-free foods on NHS prescription
across South Nottinghamshire**

March 2016

Final Version

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1. Introduction

The purpose of this report is to provide feedback on the formal public consultation which ran from 3 August to 30 October 2015 on the future of gluten-free foods on prescription across South Nottinghamshire. The 12 week consultation was led jointly by the three South Nottinghamshire Clinical Commissioning Groups (CCGs) Nottingham North & East (NNE) population 150,299, Nottingham West (NW) population 94,656 and Rushcliffe CCGs population 124,379.

The aim was to gather the views of patients, clinicians, partners and the wider public to understand the potential impact of the following proposals:

1. Stop all prescribing of gluten-free foods
2. Limit to 8 units of bread and/or flour each month (*NNE CCG has had this unit reduction in place since January 2015*)
3. Limit the products available to flour only (maximum of 4 units per month)
4. Other.

A total of **1,016** responses were received during the consultation period. This included:

- 976 direct responses to the survey
- 34 enquiries taken over the telephone
- 1 MP letter (sent to Department of Health on behalf of constituent and cc'd to NNE CCG)
- A letter from Coeliac UK to the three CCGs
- A letter from clinicians at the Department of Dietetics and Nutrition at Nottingham University Hospitals NHS Trust
- A letter from British Specialist Nutrition Association Ltd.

As part of the pre-engagement process, the CCGs liaised with Nottinghamshire County Council's Health Overview and Scrutiny Committee in July 2015 and an equality impact assessment was carried out. Consultation documents were distributed widely across South Nottinghamshire to gather views from a wide range of audiences. This included working with GP Practices to write to coeliac patients affected by the consultation as well as distribution to libraries, children's centres and community events, such as Rushcliffe's Sunday Funday and Stapleford Carnival. Websites and social media channels were utilised including Facebook and Twitter. To further engage with coeliac and non-coeliac patients, and to give wider members of the public the opportunity to discuss the proposals, 11 drop-in sessions were held across the geography covered by the CCGs.

Respondents to the survey fed back through an online survey, a freepost postal address or over the telephone. All responses were inputted into Survey Monkey to help with the data analysis. Key themes from stakeholders, social media and the drop-in sessions can be found later in the report. It is worth noting that approximately 30% of survey responses were received from people who either lived out of area (20.4%) or did not tell us their GP Practice (9.4%). It is assumed that this was a direct result of the national media coverage received (see Appendix 3).

2. Background

Coeliac disease is a common digestive condition, triggered by the protein gluten which is found in wheat, barley and rye. Symptoms range from being mild to severe and can include abdominal pain, diarrhoea, nausea, weight loss, headaches and osteoporosis. The disease affects approximately 1 in 100 people in the UK where women are two to three times more likely to develop coeliac disease than men. It can be diagnosed at any age. Symptoms are controlled by excluding foods that contain gluten from the diet. There are no medicines available to treat the condition and it cannot be cured.

The NHS is facing financial challenges as never before. The [Five Year Forward View](#) sets out a clear direction for the NHS – why change is needed and how and what it could look like. Questions have been raised around how we will manage the £30bn gap between patient need and resources, and how we will address the needs of an ever growing elderly population. Locally, as part of the Quality, Innovation, Productivity and Prevention (QIPP) programme, NHS prescriptions of gluten-free foods were identified as an area for review.

Nationally the NHS spends £25m on providing gluten-free products on prescription such as bread, flour, pasta and cereal (prescribing data April – June 2014). The total annual spend across South Nottinghamshire is £245,000. Patients with other health conditions that require adherence to special diets do not have access to foods on prescription. Over the past few years gluten-free foods have become widely available in supermarkets compared to 30 years ago when choice was limited. Yet, in some supermarkets gluten-free foods can be more expensive than the gluten containing equivalents. However, the price paid by the NHS for gluten-free foods on prescription is much higher than supermarket prices and in some cases it may be two to three times more expensive, see table 1 below.

Table 1: An example of the comparative costs to provide gluten-free foods for an adult male per month*:

On NHS prescription	£75
Purchased from supermarket	£32
Equivalent gluten containing food	£18

It is worth noting; see table 2, a significant proportion of patients diagnosed with coeliac disease do not order any gluten free products on prescription.

Table 2: Number of patients diagnosed with coeliac disease compared to number of patients diagnosed with coeliac disease who **do not** have gluten free products on prescription:

CCG	Number of patients diagnosed with coeliac disease	Number of patients who do not have gluten free products on prescription	Percentage of those who are diagnosed with coeliac disease and do not have gluten free products on prescription
Rushcliffe	509	219	43%
NNE	490	188	38%
NW	359	158	44%

**NHS Prescrip, Bulletin 69. Guidance on the prescribing of gluten free foods, Feb 2015.*

The National NICE guidance on management of coeliac disease can be found here - <https://www.nice.org.uk/guidance/ng20>

Coeliac UK's prescribing guidance can be found here - <https://www.coeliac.org.uk/gluten-free-diet-and-lifestyle/prescriptions/national-prescribing-guidelines/>

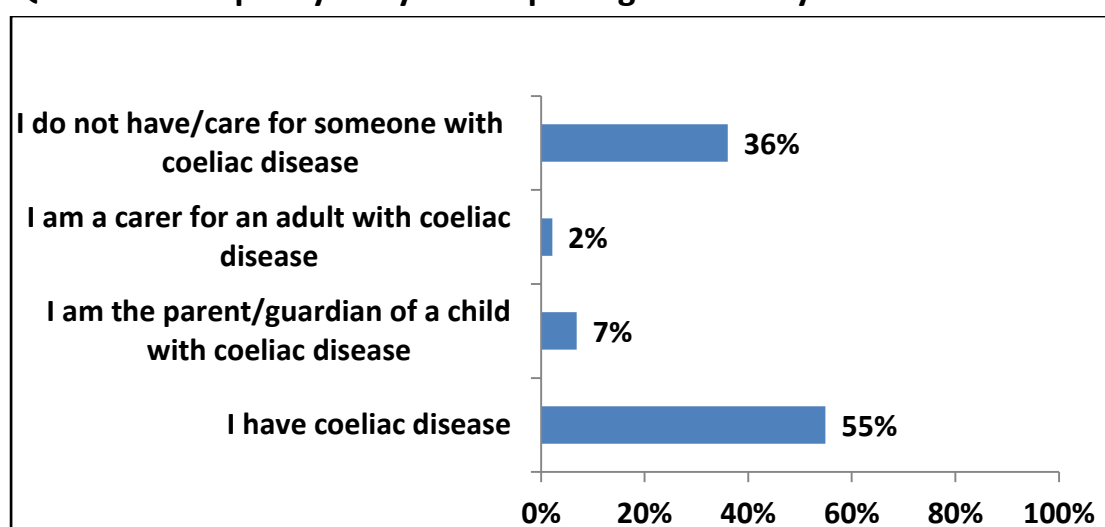
Nottinghamshire's Area Prescribing Committee guidance can be found here - <http://www.nottsapc.nhs.uk/attachments/article/3/gluten%20free%20non%20staple%20foods%20position%20statement.pdf>

3. Survey Results

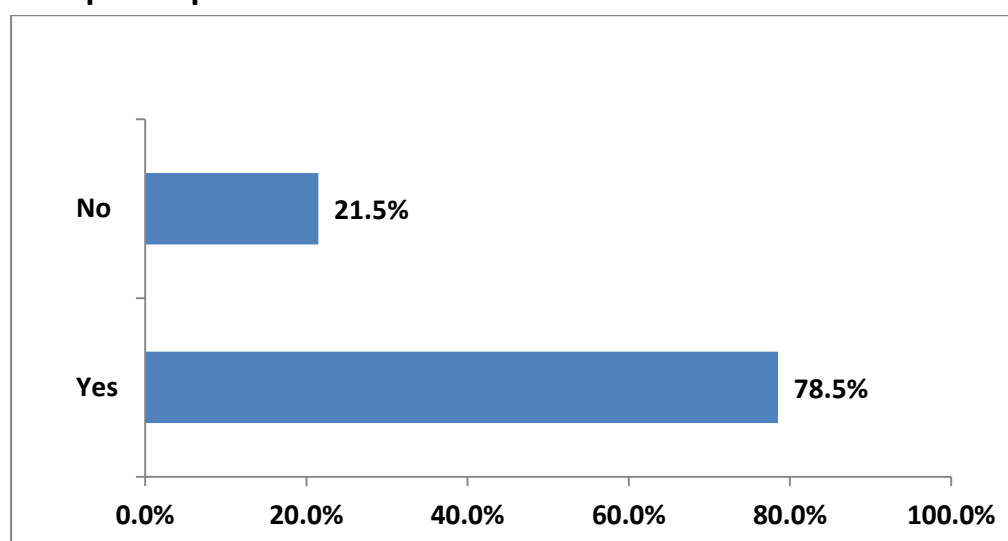
Q1. Is your GP Practice within the three South Nottinghamshire CCGs?

Answer	%	Count
Yes	70.2%	685
No	20.4%	199
Unknown	9.4%	92
Total	100%	976

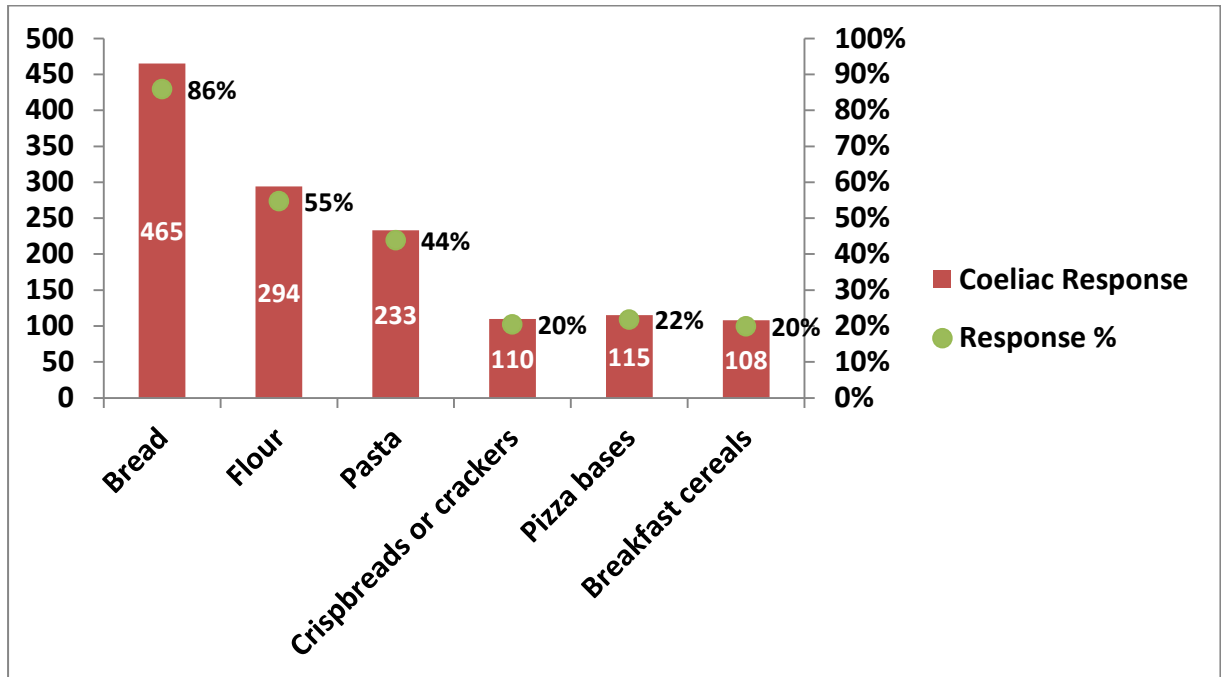
Q2. In what capacity are you completing this survey?



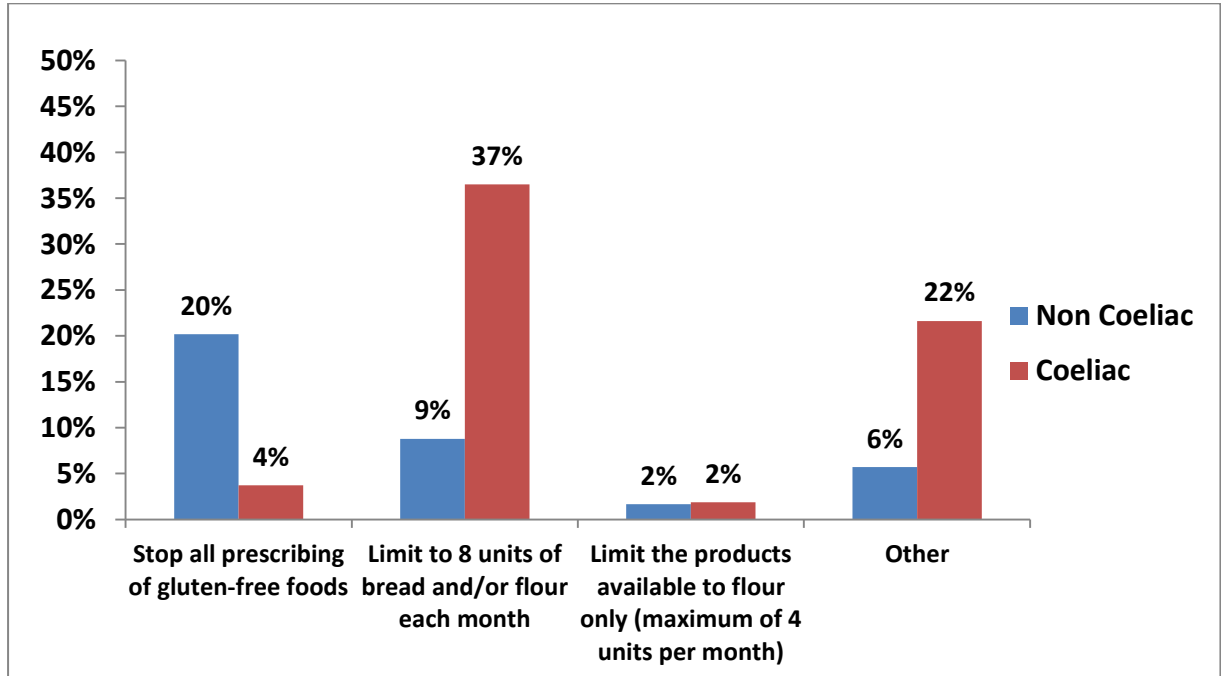
Q3. Do you (or the person you care for) receive gluten-free foods on NHS prescription?



Q4. Which gluten-free products do you receive on prescription?



Q5. Please select which proposal you agree with for the future prescribing of gluten-free products.



Q5. Key themes from 'other' comments

1	To not stop gluten free products on prescription.
2	Patients are not able to access gluten free products or products only available from specific supermarkets.
3	Patients cannot afford gluten free products as they are more expensive.
4	The options given did not suit their needs.

Q6. Is there anything else we could do to support people with coeliac disease to better manage their condition?

Key Themes

1	Patients would like to know where they can get gluten free products that are cheap, good quality, have a long use by date and are easy to cook.
2	Gluten free recipes would be helpful, along with a list of current gluten free suppliers within the CCG, diet sheet with products and recipes.
3	The CCG should work with big supermarkets to make products more affordable with clearer labelling and cheaper prices.
4	Better education and information of dietary needs for coeliac and non-coeliac people.

Q7. In January 2015, NNE CCG made changes to gluten-free prescribing by reducing the monthly unit limit to 8. What impact has this reduction in units had on your diet? (Answered by NNE CCG patients only)

Key Themes

1	Most responses stated that they experienced very little change.
2	Out of the 286 people that took part in this question, 107 responses (37%) stated that the reduction had no impact/change to their diet.
3	Comments were received about food bills increasing due to having to purchase more gluten free items from the supermarket.

Q8. Any additional comments?

Other Comments	
1	Some participants already brought their own gluten free products from the supermarket; therefore they would be fine to have no/reduced prescription.
2	Many comments suggested that patients are upset that they will have to spend more on gluten free products, especially older generations.
3	Some felt the consultation document was biased. Some felt they were being targeted and made to feel guilty that the cost is their fault.
4	Some commented that CCGs should work alongside supermarkets and restaurants to provide more gluten free products.

Equality and diversity data can be found in Appendix 1.

4. Key Findings

Along with the survey results and stakeholder feedback (see Appendix 2), 11 public drop-in sessions held during the consultation period. These took place in various venues such as libraries and supermarkets across South Nottinghamshire. Approximately 70 people attended the sessions.

Key themes from feedback included:

- Fresh bread often goes out of date quickly and leads to increased wastage.
- The buying power of the NHS needed to be addressed – why is the NHS paying such inflated prices?
- Lack of quality in supermarket products.
- More support needed for coeliac patients, including annual reviews.
- Late diagnosis of symptoms caused concern for patients.
- Concerns for vulnerable patients, i.e. children, elderly, low income.
- The introduction of a voucher scheme could benefit patients.

5. Next Steps

This consultation report will be made available on all South Nottinghamshire CCG websites and will be sent directly to respondents who requested a copy. This consultation will form part of the consideration of the CCGs when making a final decision.

Thank you to everyone who took part in this consultation.

Appendix 1

Equality & Diversity Data

The following questions were optional:

1. Gender	%	count	Coeliac	Coeliac%
Male	29.7%	278	192	20.6%
Female	68.2%	636	404	43.3%
Other (gender identity)	0.0%	0	0	0.0%
Don't want to disclose	2.2%	20	6	0.6%
Total	100%	934	602	64%

2. Age Group	%	Count	Coeliac	Coeliac %
0-17	2%	19	8	1%
18-39	20%	153	65	8%
40-59	37%	286	123	16%
60-74	31%	242	163	21%
75 and over	10%	77	65	8%
did not wish to disclose	1%	4	1	0%
Total	100%	781	425	54%

3. Disability	%	Count
Yes	15%	126
No	85%	727
Total	100.00%	853

4. Ethnicity	%	Count
White - British	96%	864
White - Irish	1%	7
Black or Black British - Caribbean	0%	2
Black or Black British - African	0%	1
Asian or Asian British - Indian	2%	15
Asian or Asian British - Pakistani	0%	4
Asian or Asian British - Bangladeshi	0%	0
Asian or Asian British - Chinese	0%	1
Mixed - White & Black Caribbean	0%	3
Mixed - White & Black African	0%	1
Mixed - White & Asian	1%	6
Total	100.00%	904

5. Religion & Belief	%	Count
Christian	57%	289
No religion/belief	30%	149
I do not wish to disclose	9%	45
Other (please specify)	2%	10
Hindu	1%	5
Buddhist	1%	3
Muslim	0%	2
Sikh	0%	2
Jewish	0%	0
Total	100.00%	505

6. Sexual Orientation	%	Count
Heterosexual	88%	444
Prefer not to say	10%	52
Gay	1%	4
Bisexual	1%	3
Lesbian	0%	2
Total	100.00%	505

7. Marital Status & Civil Partnership	%	Count
Married	63%	327
Single	10%	54
Living with someone	8%	39
Prefer not to say	8%	39
Widowed	5%	25
Divorced	4%	21
Separated	3%	13
Civil partnership	1%	4
Total	100.00%	522

8. Pregnancy & Maternity	%	Count
Yes	2%	10
No	65%	321
Prefer not to say	3%	15
Not applicable	30%	148
Total	100.00%	494

9. Is your gender the one assigned to you at birth?	%	Count
Yes	93.60%	479
No	1.00%	5
Prefer not to say	5.50%	28
Total	100%	512

Appendix 2

Stakeholder Responses

A wide range of stakeholders were informed during the consultation period. These included GP Practices, Pharmacies, Coeliac UK, Patient Participation Groups, Local Medical Council, Healthwatch, Nottinghamshire County Council (Joint Health Overview and Scrutiny Committee), Dieticians, MPs, District Councils and Councillors. In addition to the survey responses above, eight letters of correspondence were received from stakeholders during the consultation period.



Each CCG received a letter received from Coeliac UK during the consultation period. The charity supports people with coeliac disease and dermatitis herpetiformis and has more than 60,000 members.

Key points included:

- Lack of adherence to the diet can lead to long term complications such as osteoporosis and in rare cases small bowel cancer leading to greater long term cost to the NHS.
- Research from 2015 supports earlier research showing gluten-free staple foods are not readily available to purchase in budget supermarkets and corner shops. As mentioned in previous communication, access to gluten-free food on prescription is especially vital for the most vulnerable such as the elderly or those with limited transport options. Where gluten-free staple foods are available in supermarkets, research shows that they are 3-4 times more expensive than gluten containing equivalents.
- Gluten-free staple foods on prescription help to reduce the financial burden for patients and are particularly important for people on low incomes.
- We hope you will consider alternative supply routes for gluten-free food which have been shown to produce cost savings and improve patient experience. The 'Community pharmacy supply of gluten-free foods: a toolkit for commissioning groups' provides a framework for developing pharmacy-led gluten-free prescribing and highlights the benefits of these schemes with the potential of producing significant savings due to better product control and saving GP time.



Each CCG received a letter from the British Specialist Nutrition Association (BSNA) which is the trade association which represents manufacturers of products designed to meet specialist nutritional needs.

Key points included:

- It is vital that coeliac disease is managed as a long term condition and its management and treatment is appropriately and fairly budgeted for, in order that all coeliacs can maintain good health and not become a burden to the NHS.
- For patients to properly adhere to a strict gluten-free diet, it is important that funding of a reasonable supply of staple gluten-free prescription foods linked to an appropriate care pathway is continued, particularly for those in at risk groups.
- Despite an increase in the incidence of coeliac disease, and an associated increase in demand for gluten-free foods, availability of these products from supermarkets can still be lacking or widely variable. The cost of gluten-free foods also remain significantly more expensive than gluten containing counterparts.



A letter was received from the Dietetics and Nutrition Department at Nottingham University Hospitals NHS Trust.

Key points included:

- A significant number of patients rely on their full allowance of prescribable gluten-free products to provide the backbone of their diet. This tends to be particularly bread or bread rolls for toast and sandwiches and flour for baking bread or chapatis but also can be high fibre breakfast cereals, uncontaminated oats and crackers or crispbreads; all of which are difficult to find in shops and/or expensive to buy. This patient group will contain proportionately more children, older people, those with a physical or mental disability and others on a low income.
- We believe that gluten-free food should continue to be provided on prescription because it is a fundamental part of treatment with a gluten-free diet. Removing gluten-free foods on prescription will impact on adherence to a gluten-free and disproportionately disadvantage the most vulnerable groups in our population. Patients with Coeliac Disease do not currently have access to annual review for

their condition, as recommended in the NICE 2015 guidance. Therefore, removing gluten-free products and the impact on adherence to a strict gluten-free diet will increase the risk of complications in this group.

- Two of the options being considered as part of this consultation allow continued provision of gluten-free foods on prescription but limiting this to either 8 units per month of bread and/or flour, or to 4 units per month of flour only. While either of these would be preferable to remove gluten-free foods from prescription altogether, we would have concerns. Restricting the amounts to be the same for all patients regardless of age or gender takes no account of different nutritional requirements. It also does not take into account age, lifestyle, patterns of school, college and work, religion, ethnic group, health status, shopping habits due to physical ability, mobility and financial situation. We are not aware of any evidence-base as to why certain products have been chosen and others not – as other staples may be more important to receive on prescription than bread or flour since these can be difficult to purchase.

Members of Parliament

One MP letter was sent to the Department of Health on behalf of their constituent and cc'd to Nottingham North and East CCG.

Feedback included:

- Pricing of gluten-free products in supermarkets
- Gluten-free food on prescription would help university students
- Cutbacks could be made in other areas of the NHS.

Appendix 3

Media & Social Media Coverage

Media Coverage

To raise awareness of the survey, and gather as much public feedback as possible, we embarked on a media and social media campaign to encourage people to have their say on the future of gluten free foods. Dr Paul Oliver, Clinical Lead at Nottingham North and East CCG was the key media spokesperson.

The first media release was picked up by BBC Radio Nottingham and Dr Oliver was interviewed for the breakfast show. Following this, the Daily Mail¹ ran a negative story about gluten free prescribing. The story was also covered by numerous news sources, including the Independent² and Mirror³ during mid-August. Celiac UK⁴ also issued a response to the national media coverage. As a result, the media release about our survey attracted a lot of interest.

Over the week commencing 17 August 2015, Dr Oliver was interviewed on:

- BBC Radio Nottingham - drive time show (average weekly reach of 160,000)
- BBC East Midlands Today TV (average weekly reach of 3 million)
- ITV Central (Coverage can reach up to 994,000 viewers)
- ITV ran an online poll⁵ (with more than 4,800 votes).

Media coverage was balanced. Dr Oliver was interviewed alongside a patient with coeliac disease in each broadcast. The media release was also used in Nottinghamshire Focus and Nottingham Post.

Social Media Coverage

We used the media interest to drive our social media. Through referencing national and local news, it gave us a strong hook on which to promote our survey.



We posted at regular times throughout the three month period on the NHS South Notts and NHS Nottingham North and East Facebook pages. To date, they have 1,641 followers from across South

Nottinghamshire. With shares these posts reached over 7,500 people in the three month period (please note – no paid for advertising was used). Twitter promotion

¹ www.dailymail.co.uk/news/article-3200285/Doughnuts-pizza-NHS-116million-junk-food-handed-prescription-past-year.html

² www.independent.co.uk/life-style/health-and-families/health-news/coeliac-disease-patient-groups-defend-nhs-spending-on-gluten-free-food-for-sufferers-10459575.html

³ www.mirror.co.uk/news/uk-news/gluten-free-not-nhs-shouldnt-6269398

⁴ www.coeliac.org.uk/about-us/news/coeliac-uk-letter-to-the-daily-mail-and-others-on-gluten-free/

⁵ www.itv.com/news/central/update/2015-08-18/poll-should-gluten-free-foods-be-available-on-the-nhs/

was carried out as well, however Facebook proved better for debate and relevant shares.



All three CCGs regularly posted on their Twitter pages too. Nottingham West has 2768 followers, Rushcliffe 1428 followers and Nottingham North and East has 1275 followers.

Examples of social media content

3 August

Should gluten free products, like bread and cereal, be provided free on prescription for people living with coeliac disease? We're currently running a consultation to find out what you think? Tell us at: www.surveymonkey.com/r/NHS-gluten-free

2710 people reached, 23 shares, 18 comments

17 August 2015

You might have seen gluten-free food on prescription is in the news today. In South Notts we don't prescribe items like cakes and biscuits but we are currently looking at what we do offer and what may be provided in the future. And we need to hear what you think... <http://www.surveymonkey.com/r/NHS-gluten-free>

1095 people reached, 9 shares, 6 comments

28 September

Over 750 people have shared their views about the future of gluten free food on prescription. Have you? Our consultation ends on October 31 - have your say now www.surveymonkey.com/r/NHS-gluten-free

759 people reached