

## Health Scrutiny Committee

**Tuesday, 09 October 2018 at 10:30**

**County Hall, West Bridgford, Nottingham, NG2 7QP**

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### AGENDA

1	Minutes of the last meeting held on 24 July 2018	3 - 8
2	Apologies for Absence	
3	Declarations of Interests by Members and Officers:- (see note below) (a) Disclosable Pecuniary Interests (b) Private Interests (pecuniary and non-pecuniary)	
4	Dementia in Hospital	9 - 18
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### Notes

- (1) Councillors are advised to contact their Research Officer for details of any Group Meetings which are planned for this meeting.
- (2) Members of the public wishing to inspect "Background Papers" referred to in the reports on the agenda or Schedule 12A of the Local Government Act should contact:-

Customer Services Centre 0300 500 80 80

- (3) Persons making a declaration of interest should have regard to the Code of Conduct and the Council's Procedure Rules. Those declaring must indicate the nature of their interest and the reasons for the declaration.

Councillors or Officers requiring clarification on whether to make a declaration of interest are invited to contact Martin Gately (Tel. 0115 977 2826) or a colleague in Democratic Services prior to the meeting.

- (4) Councillors are reminded that Committee and Sub-Committee papers, with the exception of those which contain Exempt or Confidential Information, may be recycled.
- (5) This agenda and its associated reports are available to view online via an online calendar - <http://www.nottinghamshire.gov.uk/dms/Meetings.aspx>

## Membership

### Councillors

Keith Girling (Chair)  
Richard Butler  
Jim Creamer  
Dr John Doddy  
Kate Foale  
Kevin Greaves  
David Martin  
Liz Plant  
Kevin Rostance  
Steve Vickers  
Martin Wright

### Officers

David Ebbage	Nottinghamshire County Council
Martin Gately	Nottinghamshire County Council

### Also in attendance

Hazel Buchanan	Nottingham North and East CCG
Beth Carney	Nottingham North and East CCG
Wendy Hazard	EMAS
Dr James Hopkinson	Nottingham North and East CCG
Annette McFarland	EMAS
Michelle Livingston	Healthwatch Nottinghamshire
Dr Amanda Sullivan	Mansfield and Ashfield CCG
Dr Keith Girling	Nottingham University Hospitals
Dave Whiting	EMAS

## 1. MINUTES

The minutes of the last meeting held on 19 June 2018, having been circulated to all Members, were taken as read and were signed by the Chair.

## 2. APOLOGIES

None

Councillor Jim Creamer had replaced Councillor Michael Payne  
Councillor Kate Foale had replaced Councillor Muriel Weisz

### **3. DECLARATIONS OF INTEREST**

None

### **4. GLUTEN FREE PRESCRIBING CONSULTATION AND OTHER PRESCRIBING RESTRICTIONS**

Beth Carney, Prescribing Advisor and Medicines Management lead and Dr James Hopkinson, Nottingham North and East CCG Clinical Lead provided information about the consultation on gluten free food and over the counter medicines on prescription. The following points were raised within their briefing:-

- Health commissioners from the four Greater Nottingham Clinical Commissioning Groups consulted on whether the local NHS should restrict or stop gluten free food on prescription. The three options were:-
  - *Limit prescribing for all patients in Greater Nottingham to four units of long life bread and flour per month.*
  - *All Greater Nottingham CCGs to stop all gluten free prescribing, with the exception of children, who will be able to receive up to four units of long life bread and flour per month.*
  - *All Greater Nottingham CCGs to stop all gluten free prescribing.*
- In 2017, the Government carried out a national consultation about whether gluten free foods should be available on prescription for people with coeliac disease. The outcome of this consultation was a recommendation that gluten free prescribing should be restricted to bread and mixes only. However, there has been no decision taken about limiting quantities.
- The six week consultation ran from Thursday 14<sup>th</sup> June to Thursday 26<sup>th</sup> July 2018.
- Minor illnesses are those which can be treated with self-care and over the counter medicines, which are medicines you can buy in a supermarket, shop or pharmacy. Please note that these proposals were not about the prescribing of over the counter medicines for people with long term conditions.
- Around 20% of GP time and 40% of their total consultations are used for these common minor conditions that could be treated without seeing a GP. People that care for themselves have better health and reduced demand for services. This in turn allows more time for health professionals to see patients that require treatment for more complex conditions.

- Following the engagement analysis, the recommendation was that over the counter medicines for minor illnesses should be restricted, with the exception that GPs will be able to prescribe in other circumstances of clinical need.

During discussions, the following issues were raised:-

- Regarding gluten free products, Members felt the approach was a postcode lottery. The NHS representatives explained that the purpose of the proposals was to foster greater consistency. It was hoped that there would be no health implications in disadvantaged areas. Gluten free products are becoming more generally available in all supermarkets.
- Regarding gluten free costs, £177,000 is the predicted saving for stopping gluten free prescribing each year. Members felt to remove gluten free products from children was not acceptable.
- There have been over 500 responses from GP practices, Coeliac UK and voluntary sector: a reasonable response rate.
- Members indicated that a figure within the report stating the number of people who would be affected by this change would have been helpful, especially in relation to children

The Chair emphasised his concern also around the children in deprived areas aspect. Option two was Members preferred option.

The Chair thanked Beth Carney and Dr James Hopkinson for their attendance.

## **5. TREATMENT CENTRE PROCUREMENT UPDATE**

Hazel Buchanan provided information to Members about the procurement of services at the Treatment Centre. The following points were raised:-

- Further to the legal challenges arising regarding the procurement to award a contract for service provision from end of July 2018 onwards, a new procurement is being embarked upon from early August 2018, with the objective of awarding a contract for service provision from the end of July 2019 onwards.
- Currently Circle offers a variety of services including outpatients, surgery, termination of pregnancy and diagnostic tests. There are 60 outpatient consultation rooms, five operating theatres, three skin surgery theatres, four endoscopy rooms and dedicated diagnostic facilities such as scans and x-rays. In addition, the centre has an 11 bedded short stay ward for patients who have undergone surgery and require an inpatient stay.
- Rushcliffe CCG is the lead commissioner for the Nottingham Treatment Centre
- It is proposed that a Treatment Centre Procurement Programme Board is established with delegated authority from the Greater Nottingham Joint Committee to progress the procurement project plan and assess, approve/reject accordingly proposals from Programme team.

During discussion, the following points were made:-

- The intentions are to award the contract for July 2019 within this calendar year.
- A lot of money is spent at the Treatment Centre, within the next steps, it is planned to finalise detailed procurement programme planning and development of content, including specifications and finance modelling.
- It is challenging to attract the public to attend the focus groups. Sessions are advertised, go out to other groups including patient groups and Healthwatch.
- The quality of care which has been provided by Circle has been very high and value for money

The Chair thanked for their attendance and asked the attendees to come back in January with a further update.

## **6. EAST MIDLANDS AMBULANCE SERVICE TRANSFORMATION**

Dave Whiting, Chief Operating Officer, Annette McFarland, Service Delivery Manager for Nottinghamshire Division and Wendy Hazard, Ambulance Operations Manager informed Members about EMAS transformation plans. The following points were made:-

- EMAS has five values which underpin everything they do, including the way they deliver our services and how they all work with others. By living these values and supporting others to do the same, this will help to make sure that EMAS is an organisation they can all be proud of.
  - **Respect:** Respect for the patients and each other
  - **Integrity:** Acting with integrity by doing the right thing for the right reasons
  - **Contribution:** Respecting and valuing *everyone's contribution, and encouraging innovation*
  - **Teamwork:** Working together, supporting each other, *and collaborating with other organisations*
  - **Competence:** Continually developing and improving *our competence*
- Within the next five years, EMAS want to use technological solutions to address wider healthcare issues and drive improvement.
- Our proactive work on mental health – patients (prevention and management with partners), and staff (health and wellbeing)
- Becoming national leaders for our work on patient safety.
- Achieving equality and diversity within our workforce.
- Demonstrating international best practice for our clinical outcomes for patients with cardiac arrest.
- Developing and embedding the paramedic skillset in multi-disciplinary team approaches across wider healthcare.
- Developing a positive organisational culture that means staff want to work for EMAS and have high levels of satisfaction?
- Identifying and managing sepsis (across all geographies), building on the success of our pilot within Lincolnshire.

- EMAS plan to engage with staff and volunteers, Overview and Scrutiny Committees, Healthwatch, healthcare partners and commissioners.

During discussion, the following points were made:-

- Last winter was very concerning EMAS where all services were stretched to the limit. More in place a lot earlier on this year to prevent the same happening again. More vehicles will be on the road and 296 more frontline staff over the next two to five years. Half of that figure will hopefully be in post by this coming winter.
- Half of the emergency calls received did not need hospital care, the scheme hear and treat has was used significantly throughout last winter.

The Chairman thanked all representatives from EMAS for their attendance and to come back to us with their winter plan.

## **7. NEUROREHABILITATION UPDATE**

Dr Amanda Sullivan, Chief Officer and Sally Dore, Senior Commissioning Officer for Mansfield & Ashfield CCG updated Members in relation to the changes in Neurorehabilitation services at Chatsworth Ward, Sherwood Forest Hospitals. The following points were raised:-

- The CCGs Governing Body met on the 5<sup>th</sup> July 2018 and supported the business case to commission guaranteed Neurorehabilitation beds on the current Chatsworth ward as well as to provide a community neurorehabilitation service for patients in mid-Nottinghamshire.
- The Governing body asked for further work to be undertaken with prospective providers to ensure pathways were in place to ensure that the right level of patients (from a neurological point of view) were in the right place in the new model and that the provision was adequate for 24 hour care on the ward.
- The next steps will be to secure a provider for the service and work with them to ensure the delivery of the required service and there after a 6 month evaluation.

The Chairman thanked both for their attendance.

## **8. WORK PROGRAMME**

Members requested the following items to be added to the Work Programme:-

Hospital Parking & Charges  
Social Subscribing  
Healthwatch

To add EMAS winter plan onto the November agenda and to remove The Treatment Centre from October and add it to the January meeting.

The meeting closed at 1.05 pm.

**CHAIRMAN**





**9 October 2018****Agenda Item: 4****REPORT OF THE CHAIRMAN OF HEALTH SCRUTINY COMMITTEE****DEMENTIA IN HOSPITAL****Purpose of the Report**

1. To introduce a presentation on improving care for people with dementia, their families and carers at Nottingham University Hospital (NUH).

**Information**

2. Dementia is not a specific disease, but rather a term that refers to symptoms of mental and communicative impairment found in a variety of brain conditions and diseases, including Alzheimer's.
3. The percentage of elderly suffering from some form of dementia increases with age, with 2% of those aged 65-69, 5% of those aged 75-79, and over 20% of those aged 85-90 experiencing symptoms. One third of those 90+ have moderate to severe dementia.
4. Dementia can be caused by a variety of illnesses, some potentially very treatable (e.g., nutritional deficiency), others—like Alzheimer's— are not. Age is not the cause of dementia, but rather correlated with it. Memory loss is the earliest and most common sign. Irritability, depression, and other personality changes are also common. In more severe or worsening cases, language difficulties may occur, and spatial understanding deteriorates.
5. Delirium can be caused by fever, infection, medications, oxygen deprivation, sensory impairment, drug or alcohol abuse or withdrawal, body chemical disturbances, poor nutrition, dehydration and poisoning. It is a temporary and reversible and full recovery is common.
6. Katie Moore, Head of Patient Public Involvement at NUH will attend the Health Scrutiny Committee to brief Members on this issue and answer questions as necessary.
7. The presentation from NUH is attached as an appendix to this report.

**RECOMMENDATION**

That the Health Scrutiny Committee:

- 1) Considers and comments on the information provided.

2) Schedules further consideration as necessary.

**Councillor Keith Girling**  
**Chairman of Health Scrutiny Committee**

**For any enquiries about this report please contact: Martin Gately – 0115 977 2826**

### **Background Papers**

Nil

### **Electoral Division(s) and Member(s) Affected**

All



**Nottingham  
University Hospitals**  
NHS Trust



# Improving care for dementia patients, their families & carers

Katie Moore, Head of Patient Public Involvement

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# Alignment to national framework



# Coming into hospital

- Assess and screen for Dementia and Delirium
- Get to know as much as possible by engaging patients, healthcare professionals and carers



# Ongoing care

- Care for patients in a suitable (dementia-friendly) environment
- Eating and drinking – Memory menus, finger-foods
- Support and promote involvement and activities - #EndPJParalysis
- Carers involvement and support – About Me, Carer's Passport, Surveys



# Leaving hospital

- Planning discharge early, involving relevant professionals
- Discharge efficiently and early in the day
- Involve and support carers throughout the process



# End of life care

- Recognise end of life and provide support for patients and carers
- SWAN Initiative





# Training, education & research

- Training review
- Dementia Champions
- Research





9 October 2018

Agenda Item: 5

## **REPORT OF THE CHAIRMAN OF HEALTH SCRUTINY COMMITTEE**

### **NOTTINGHAM UNIVERSITY HOSPITAL - SYSTEM PLANS FOR WINTER AND SHARED COMMITMENT TO IMPROVING URGENT AND EMERGENCY PATIENT CARE**

#### **Purpose of the Report**

1. To consider the information provided regarding Nottingham University Hospitals (NUH) winter planning and planned developments to urgent and emergency patient care.

#### **Information**

2. The Health Scrutiny Committee takes a strong interest in acute trust's planning for the challenges of winter. Severe winter weather can mean more admissions of frail and elderly patients due to respiratory conditions, as well as fractures due to falls in icy conditions.
3. Members will see that an additional 116 beds are planned at NUH, subject to Board approval – one more ward than last winter. There will also be investment in community-based care to include 20 more enhanced care beds. In addition, there will be the provision of 48 community run beds at St Francis on the City Hospital site for patients who no longer need acute care.
4. At the Queens Medical Centre the 'front door' there will be a redesign of emergency and urgent care pathways and modernisation and expansion of A Floor via £4.5 million national funding. There will also be an increase in the number of cubicles in the 'majors' section of from 20 to 30.
5. Nikki Pownall, Programme Director, Urgent Care – Greater Nottingham CCGs and Caroline Nolan, Project Director, Urgent Care & Flow, NUH, will attend Health Scrutiny Committee to brief Members and answer questions, as necessary.

#### **RECOMMENDATION**

That the Health Scrutiny Committee:

- 1) Considers and comments on the information provided.
- 2) Schedules further consideration

**Councillor Keith Girling**  
**Chairman of Health Scrutiny Committee**

**For any enquiries about this report please contact: Martin Gately – 0115 977 2826**

**Background Papers**

Nil

**Electoral Division(s) and Member(s) Affected**

All

# System plans for Winter & our shared commitment to improving urgent and emergency patient care

Nikki Pownall, Programme Director, Urgent Care - Greater Nottingham CCGs  
Caroline Nolan, Project Director, Urgent Care & Flow - NUH

October 2018

# To cover:

- System performance
- Increase in demand
- Quality & safety monitoring
- Patient feedback/experience
- System progress
- System plan for Winter
- Ongoing challenges
- Future plan
- Questions

# System performance

- National requirement: at least 95% through ED within 4 hours
- 17/18: 81.4%
- 18/19 (YTD): 83.8%
- August 2018: 83.2%

# Increase in demand

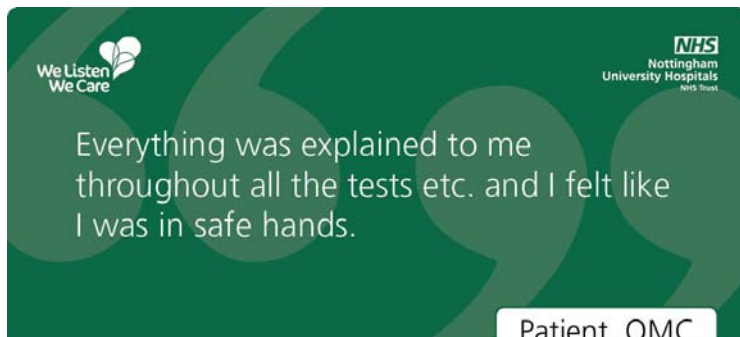
- Last winter busiest on record
- Average of 543 A&E attendances to QMC a day, a 1.3% increase on 16/17
- 4.6% overall increase in emergency admissions
- 23.1% increase in respiratory-related admissions (900 extra patients)



# Safety & quality monitoring

- 2 patients had 12 hr trolley waits in 17/18 (6 in 16/17).  
3 year-to-date (mental health)
- RCA on all waits >8hrs
- Board & Quality Assurance Committee oversight
- Consistently strong patient experience scores re: care
- A&E Delivery Board – oversees system's urgent & emergency care performance

# Patient feedback




**We Listen We Care**

Everything was explained to me throughout all the tests etc. and I felt like I was in safe hands.

Nottingham University Hospitals NHS Trust

Patient, QMC

Share **your** experiences:  
[QMCPET@nuh.nhs.uk](mailto:QMCPET@nuh.nhs.uk)



Nottingham University Hospitals NHS Trust

I felt that the staff ensured all patients received the same great treatment without delays.

Patient, QMC

Share **your** experiences:  
[QMCPET@nuh.nhs.uk](mailto:QMCPET@nuh.nhs.uk)



**NHS** choices



Nottingham University Hospitals NHS Trust

The level of care I received was exceptional especially with how busy A&E became and yet the standard remained so high.

Patient, QMC

Share **your** experiences:  
[QMCPET@nuh.nhs.uk](mailto:QMCPET@nuh.nhs.uk)



**NHS** choices

# System progress (1)

- **Discharge to Assess**
- Since 1 October 2017: ambition for no patients to be assessed for their post-hospital care needs within NUH

# System progress (2)

- Frailty hub with integrated pathways
- Integrated Discharge Team
- Best ambulance handover times in region
- EndPJParalysis/EDFit2Sit
- Red2Green and SAFER
- Respiratory service at home developments
- Home First
- System-wide discharge policy

# System winter plan

- Planning 116 extra acute beds (NUH) subject to Board approval at cost pressure – 1 more ward than last winter
- Investment in community-based care, including 20 more enhanced care beds (care home)
- 48 community-run beds at St Francis at City Hospital for patients who no longer need acute care (£1.9M national funding for capital)

# System winter plan (3)

- QMC front door – redesigning emergency and urgent care pathways and modernising and expanding A Floor (£4.5M national funding for capital works). 30 cubicles in majors (from 20)
- Expanding NUH's nationally-renowned Surgical Triage Unit model to wider specialties
- Focus on reducing long stay patients (LOS >20 days)
- Flu campaign & infection prevention
- Focus on staff health and wellbeing
- Preparing our workforce for winter
- Joined-up, system & NHS-wide public-facing comms campaign (including 'Home First' and 'Help us help you')

# Challenges

1. System Demand vs Capacity
2. Staffing - particularly medical staff (ED) and home care staff (recruitment campaign underway)
3. Environmental constraints (overcrowding)
4. Consistency of NUH processes
5. Staff morale

# Future plan

- We have previously described our ambition to develop a case for a new urgent and emergency care centre
- This will now be considered as part of a system-wide clinical services strategy part of the Sustainability and Transformation Partnership (STP)
- Care navigators supporting care outside of hospital
- System-wide demand and capacity modelling



# Questions?



9 October 2018

Agenda Item: 6

## **REPORT OF THE CHAIRMAN OF HEALTH SCRUTINY COMMITTEE**

### **RAMPTON HOSPITAL – IMPROVEMENT PLAN FOLLOWING CQC INSPECTION**

#### **Purpose of the Report**

1. To introduce a presentation on Rampton Hospital's improvement plan.

#### **Information**

2. In March 2017, an inspection by the Care Quality Commission (CQC) rated Rampton Hospital as 'requires improvement'. A subsequent follow-up visit in March of this year found that some improvements had been made and the Hospital's rating was changed to 'good' in two of the five inspection areas.
3. The hospital is still rated as requiring improvement overall. Although significant improvements have been made around staff engagement and morale, staff turnover remains a concern as does infection control (at the time of the follow-up visit staff continued to wear gel nails and use nail varnish, which contravenes infection control regulations).
4. Julie Attfield, Executive Director of Nursing at Rampton Hospital and Louise Bussell, Deputy Director of Forensic Services will attend the Health Scrutiny Committee to present progress against the improvement plan and answer questions as necessary.
5. A written briefing from Rampton Hospital is attached as an appendix to this report.

#### **RECOMMENDATION**

That the Health Scrutiny Committee:

- 1) Considers and comments on the information provided.
- 2) Schedules further consideration as necessary.

**Councillor Keith Girling**  
**Chairman of Health Scrutiny Committee**

**For any enquiries about this report please contact: Martin Gately – 0115 977 2826**

**Background Papers**

Nil

**Electoral Division(s) and Member(s) Affected**

All

**HEALTH SCRUTINY COMMITTEE**  
**9 October 2018**  
**CQC Core Inspection of Rampton Hospital**

## 1. Introduction

Following the inspection of Rampton Hospital on the 20th – 22nd of March 2018 the inspection report was published on the 8th June 2018. The overall rating for the Hospital is 'requires improvement' and is unchanged from 2017. However; there have been improved ratings of 'good' for the effective and well led domains. A summary of the ratings is provided in the table below.

<b>2018</b>		<b>2017</b>	
Overall rating	Requires Improvement	Overall rating	Requires Improvement
Are Services Safe	Requires Improvement	Are Services Safe	Requires Improvement
Are Services Effective	Good	Are Services Effective	Requires Improvement
Are Services Caring	Good	Are Services Caring	Good
Are Services Responsive	Requires Improvement	Are Services Responsive	Requires Improvement
Are Services Well-Led	Good	Are Services Well-Led	Inadequate

The purpose of this report is to provide the Committee with the details of the progress against the nine requirement actions and four good practice actions.

The CQC made the following nine Requirement Notices in the Inspection Report

1. The provider must ensure there is adequate staffing across the hospital in order to facilitate on and off ward activities, ground leave, access to fresh air and reduce the frequent movement of staff during shifts to other wards.	2. The provider must continue to monitor incidences of lone working at night and take steps to eliminate it.
3. The provider must ensure there is a system that records the amount of activities that patients engage in are accurate and this is used by staff.	4. The provider must ensure staff feel confident and are competent to implement physical healthcare plans effectively.
5. The provider must ensure staff adhere to the trust's infection control policy.	6. The provider must ensure that all staff adheres to the trust wide observation policy when recording observations.
7. The provider must ensure recording of seclusion and long term segregation reviews are undertaken in accordance with the Mental Health Act Code of Practice.	8. The provider must ensure that nurses are aware of who is responsible for administering medication each shift and that all medication is signed for.
9. The care plans in the learning disability service must be completed in the patients' voice.	

## 2. Progress to date

To date the following actions have been taken in relation to the requirement actions;

### 1. Staffing Levels

In order to mitigate the risk of having insufficient appropriately trained staff a number of actions have been identified to address this shortfall in nursing staff in the short and medium term. Some of the work underway is detailed below:

#### Recruitment of Non-Registered and Registered Nurses

There has been a significant recruitment drive that has increased the overall number of ward based nursing staff in order to meet clinical requirements. The over-recruitment of Nursing Assistants has helped us to reach our establishment numbers across the site. Qualified nursing recruitment however remains an ongoing challenge. We are therefore pro-actively recruiting registered nursing staff with the help of an additional financial package, national recruitment campaigns, a full time Deputy Matron lead and a variety of other initiatives. This is our key priority in the short term. In the medium term we are already seconding staff to do their nurse training and Band 4 Associate Nurse training as well as building new training links with local schools and Universities.

## **Review of the ward based nursing establishment model**

Work has begun to review the ward based nursing model. This takes account of the skill mix and the introduction of new roles such as the associate nurse role. This will also take into consideration development of ward based occupational therapist roles.

Due to the increasing difficulty in recruiting Band 5 nurses we have begun to review the inpatient nursing model and have extended the number of Band 6 nursing staff within Rampton Hospital.

## **Retention of staff**

The Division are engaged with the NHSI retention programme recognising that retaining staff in a climate where there is a reduced pool to draw from is critical.

The NHS improvement (NHSI) Recruitment and Retention plan focuses on Rampton Hospital – covering orientation, induction preceptorship. It is agreed not to move new starters for 3 months.

The issue of retention has become a key area of focus for the Trust. The Trust is therefore engaged in the NHS Improvement 90 day retention cohort. Following the retention summit which was held with matrons from across the Trust on 24<sup>th</sup> May in order to engage senior nurses in analysing the data and to begin to determine the key actions which will enable a critical reduction in turnover, the Retention Plan has been formulated and submitted to NHS Improvement. Agreement reached that this will focus on Rampton Hospital. The implementation phase will be followed by a period of 12 months NHSI support and monitoring.

## **2. Lone Working at Night**

A strategic staffing review has been undertaken which resulted in a significant further investment in ward establishments at Rampton Hospital in order to provide 3 staff per ward at night.

The additional investment has been included in ward budgets and the lone working figures have reduced dramatically with no lone working being reported at the time of writing this report for the month of September. It has been acknowledged however that this will continue to be a challenge when there are unplanned medical emergencies requiring high numbers of escorting staff.

## **3. Activity Monitoring**

The existing electronic activity monitoring system (AMS) is currently being updated in order for the system to be easier for staff to input patient activity data, ensuring that reliable, valid data is produced. It is expected that this will be live by the end of November 2018. A substantially improved paper version has also been approved and is currently being piloted with agreement reached that this will be live from 1 October 2018 across all wards at Rampton Hospital.

## **4. Physical Healthcare plans**

All patients have physical healthcare plans for chronic conditions that evidence patient involvement. Designated physical healthcare ward champions are in place to ensure that these plans are regularly updated with the support of the physical healthcare team and are reviewed and remain person centred. Further work is underway to ensure all patients on the complex case register also have a co-produced care plan in place relevant to their condition.

## **5. Adherence to the Trust's infection control policy**

Monthly ward audits and exception reporting arrangements have been established specifically in respect of the agreed bare below the elbows principles. Significant improvements have been made in this area.

## **6. Adherence to the Trust wide observation policy when recording observations.**

Monitoring and reporting arrangements have been strengthened which include monthly ward audit, CCTV sampling and ward night visits.

Exception reporting has also been established where practice is found to deviate from the procedure.

#### **7. Recording of seclusion and long term segregation reviews**

Practice has been audited in relation to the long term segregation and seclusion procedure. Progress is still required in relation to ensuring improvements with the undertaking and recording of reviews. A different approach in terms of reporting the data has been utilised which included reporting the results per individual medical staff member involved in the reviews. It is expected that the revised approach will demonstrate significant improvements following the re-audit.

#### **8. Nurse awareness of who is responsible for administering medication**

A mechanism has been established via rostering arrangements to identify the nurse in charge (IC) and the nurse responsible for the administration of medication. An audit is currently being undertaken and following the production of the audit results an updated protocol for the role of the IC clinic nurse will be sent round to all wards.

#### **9. Completion of Care Plans in the Learning Disability Service**

A substantial amount of work has been undertaken in relation to ensuring all the patients in the Learning Disability Service have comprehensive person centred care plans. These are being formulated in-line with the individual positive behavioural support plans and the functional assessments of challenging behaviour. A plan has been formulated identifying the current position and timeframe for completion of all the plans in order that this can be robustly monitored. The Trust has utilised an external advisor to provide additional independent scrutiny and support to ensure we are achieving national standards.

#### **Good Practice Recommendations**

The CQC also issued 4 good practice actions which related to:

- Ensuring all staff have physical healthcare training and a good understanding of sepsis.
- Ensuring to improve consistency regards to record keeping
- Undertaking a review of the price of goods sold in the patients shop
- Continue to take actions to improve medical engagement in management decision making.

Actions are being taken to address all the good practice recommendations and include scrutiny of the Trustwide sepsis plan at the Infection, Prevention and Control Committee; additional physical healthcare training being made available to all nursing staff and a specific physical healthcare training prospectus to be produced; a quality improvement project being commissioned which involves the scoping of patient records; a review being undertaken of the price of goods which is currently being shared with the patients and their carers. The Hospital has also seen a vast increase in terms of medical engagement which is being further consolidated by the appointment of a new temporary Associate Medical Director.

We are committed to achieving and sustaining high standards of quality care provision for our patients. This is in relation to the CQC requirements and our ambition for excellence in all areas of safe and effective clinical care.

Dr Julie Attfield  
Executive Director of Nursing

Louise Bussell  
Deputy Director: Forensic Services

14 September 2018





**9 October 2018****Agenda Item: 7**

## **REPORT OF THE CHAIRMAN OF HEALTH SCRUTINY COMMITTEE**

### **GLUTEN FREE PRESCRIBING**

#### **Purpose of the Report**

1. To consider the decision taken by commissioners on restricting gluten free products.

#### **Information**

2. Members will recall that Beth Carney and Dr James Hopkinson attended the last meeting of the Health Scrutiny Committee to provide information about the consultation to restrict or stop the prescribing of gluten free products. The proposals were as follows:
  - *Limit prescribing for all patients in Greater Nottingham to four units of long life bread and flour per month.*
  - *All Greater Nottingham CCGs to stop all gluten free prescribing, with the exception of children, who will be able to receive up to four units of long life bread and flour per month.*
  - *All Greater Nottingham CCGs to stop all gluten free prescribing.*
3. The consultation ran from Thursday 14<sup>th</sup> June to Thursday 26<sup>th</sup> July 2018, and over 500 responses had been received.
4. Members registered concerns about children in deprived areas not receiving gluten free products, and therefore preferred the second option.
5. The NHS Greater Nottingham Clinical Commissioning Partnership's Joint Commissioning Committee has made the decision to stop the prescribing of gluten free food. Senior representatives of the commissioners (Dr James Hopkinson, Cheryl Gresham and Beth Carney) will attend the Health Scrutiny Committee to brief Members and answer questions as necessary.
6. A written briefing from the commissioners and accompanying Equality Impact Assessment and consultation document are attached as appendices to this report.

## **RECOMMENDATION**

That the Health Scrutiny Committee:

- 1) Determine if the proposed change is in the interests of the local health service.

**Councillor Keith Girling**  
**Chairman of Health Scrutiny Committee**

**For any enquiries about this report please contact: Martin Gately – 0115 977 2826**

### **Background Papers**

Nil

### **Electoral Division(s) and Member(s) Affected**

All

## Equality Impact Assessment (EQIA) Template

### Introduction

The EQIA template has been introduced to bring together equality and quality impact considerations into a single systematic assessment process.

An EQIA should be completed whenever the initial screening process on each scheme in the Financial Recovery Plan indicates that one is required.

The EQIA Panel will oversee the development and quality assurance of EQIAs.

To support understanding and completion of the EQIA process, this document is hyperlinked to a glossary of key terms.

### Purpose

The EQIA is designed to:

- Enable details of supporting [evidence](#) to be recorded
- Assess the impact of proposed changes in line with the CCGs' duty to reduce [health inequalities](#) in access to health services and in health outcomes achieved
- Assess the impact of proposed changes to services in line with the CCGs' duty to maintain and improve the three elements of [quality](#) ([patient safety](#), [patient experience](#) and [clinical effectiveness](#))
- Assess whether proposed changes could have a positive, negative or neutral impact, depending on people's different protected characteristics defined by the [Equality Act 2010](#)
- Identify any unlawful discrimination or negative effect on equality for patients/service users, carers and the general public
- Consider the impacts on people from relevant inclusion health groups (e.g. carers, homeless people, people experiencing economic or social deprivation)
- Identify where any information to inform the assessment is not available, which may indicate that patient [engagement](#) is required
- Provide a streamlined process and prevent equality and quality risks from being considered in isolation
- Determine whether a scheme can proceed, proceed with identified action, or not be progressed.

Decisions on whether schemes will be implemented, amended or stopped will be based on a combination of EQIAs, engagement findings and consultation outcomes.

**EQIAs are 'live' documents, and as such, are required to be revisited at key stages of scheme development and implementation, particularly following the conclusion of any engagement and consultation activities to inform decision-making.**

<b>Scheme title:</b> Restriction of, or stopping Gluten Free Prescribing in Greater Nottingham
<b>Assessor name:</b> Cheryl Gresham
<b>Date of assessment:</b> 9 <sup>th</sup> April 2018

## Summary description of QIPP scheme being assessed:

### Background

#### National

Staple gluten free (GF) foods have been available on prescription to patients diagnosed with gluten sensitivity enteropathies since the late 1960s when the availability of GF foods was limited. GF foods are now more widely available in supermarkets, although stock can be variable, with a wider range of naturally GF food types available, meaning that the ability of patients to obtain these foods without a prescription has greatly increased. Adherence to a GF diet is the only way to manage the condition and prevent further ill health related to coeliac disease.

Many Clinical Commissioning Groups (CCGs) now have limited types or units of GF foods available on prescription. A number of CCGs provide only bread and flour; several have stopped prescribing all GF foods. CCGs were set up to ensure that their local populations receive the medicines and treatments they require, with locally managed resources. Differing approaches to the availability of GF foods is creating regional variation across England. Many CCGs have made changes to local prescribing formularies and have restricted or ended GF food (Coeliac UK, 2018b). The prescribing position in CCGs in England (July 2017) is shown below:

<b>CCG Prescribing Status Prescribing Arrangements (July 2017)</b>	<b>Number of CCGs</b>
Following Coeliac UK guidelines	78
Ended all GF foods on prescription (all patients)	25
No restrictions	4
Other restrictions; product type, quantities, or patient status	102

The Department of Health (DH) conducted a national consultation and sought views from the general public as to the availability of gluten free (GF) Foods on prescription in Primary Care (Department of Health, 2017). Changes to the prescribing of GF foods could save NHS resources and reduce the primary care prescription drugs bill by up to £22.7 million in year one following changes (based on Net Ingredient Cost (NIC) and dispensing fees).

This consultation ended on 22nd June 2017, having received 7941 responses. The response to the consultation was published in February 2018 (Department of Health and Social Care, 2018).

Summary of responses from national consultation:

Points of common agreement

- Coeliac Disease (CD) is a disease state and that food is like a medicine for those patients and adherence to a GF diet is the only way of managing the condition and preventing further ill health related to CD.
- The cost to purchase formulated GF food from retail outlets is more expensive than non-formulated GF food. This is especially the case for bread products where the gap between these products is more significant.
- The quality of prescription products when compared to shop bought products can differ. Some prescription products are fortified to provide additional nutrients to patients to avoid malnutrition or vitamin deficiency.
- The availability of GF foods is not always consistent and many smaller/local shops do not always stock a range of GF food. GF food is not routinely available in food banks or budget supermarkets. For patients/parents/carers that rely on food banks, they will need to select foods that are naturally GF such as meat, fish, rice, fruit and vegetables to ensure they adhere to a GF diet.
- Patients in rural areas may depend on pharmacy deliveries for their GF foods, and may have difficulty in obtaining GF supplies from local shops.

- The shelf life of fresh bread products can lead to waste if not collected from the pharmacy in a timely manner. The patient has to rely on freezing surplus fresh bread to avoid waste as pack sizes can often contain 6 - 8 loaves.
- The local changes made by CCGs have led to inconsistencies for patients in England and this is causing inequality in access to GF food on prescription. There are also many different approaches between CCGs which have led to inequality of access to ranges, types or quantities of GF food available on prescription.
- Some CCGs have made changes without consultation, this has excluded patients, their representatives and others from having a say in how their local services are delivered.
- Pharmacies are set up and managed to issue medicines and medical supplies and are not equipped to deal with holding large stocks of foods which often have a short shelf life, or are bulky.
- Out of pocket expenses (OOPE) can be significant on some GF products, especially on fresh bread. Some CCGs have managed these out of the system through alternative GF supply models.
- All GF food products listed in the Drug Tariff are "branded" products, whilst some retail outlets supply generic/own brand GF products.
- The ACBS "recommended" list contains staple GF products, yet prescribing data<sup>6</sup> shows that luxury products such as cakes, pastries and sweet biscuits are prescribed. The majority of respondents agreed that only staple products should be available at NHS expense.

#### Main issues raised:

GF foods are not consistently available in local shops or budget supermarkets. There is often unreliable stock and/or limited range in larger supermarkets, products may also have short expiry or "use by" dates. Certain brands of GF food are not available to buy in supermarkets, limiting patient choice.

The majority of respondents requested bread and mixes to remain on prescription due to inconsistencies in availability, taste differences between prescription only products and those available in supermarkets, the price differences (especially bread), and accessibility, especially those who relied on pharmacy deliveries. Patients stated that GF mixes offered a more flexible option as they could be used at home to make a variety of foods.

Many respondents stated that the money spent on GF food could be better utilised across the NHS, and as GF food is not a medicine it should not be provided by the NHS. It was also stated that patients with other food intolerances or allergies do not get their food on prescription.

Parents or carers of children have requested that GF staples, especially bread, remain on prescription to prevent children feeling "different" to their peers, for example, the ability to take a packed lunch (sandwiches) to school. Some CCGs have retained GF prescribing for those under 18. Additionally this group are less likely to make their own dietary choices; this is especially the case for young children, as they rely on a parent/carer to purchase and prepare their meals. Information provided through the consultation stated that the lack of adherence to a GF diet could impact on the growth rate of children, delay puberty and make them susceptible to other auto immune conditions.

#### Outcome

The Government has decided to restrict gluten-free prescribing to bread and mixes only (note – there has been no recommendation made about limiting volume of prescribing, which is expressed as number of units). The timescale to implement restriction of all gluten free products, with the exception of some bread and mix products has not yet been announced.

In Nottinghamshire at present the CCGs have different recommendations for restricting prescribing of GF foods.

#### NHS Rushcliffe, Nottingham West and Nottingham North & East CCGs

A three month consultation was undertaken in 2015 to gather the views of patients, clinicians, partners and the wider public in these CCGs, 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 1016 responses were received.

The formal consultation report was published in March 2016 (NHS Nottingham West, Nottingham North and East and Rushcliffe CCGs, 2016).

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.

#### **Outcome**

In May, 2016, following feedback from the consultation and recommendations from clinical, patient cabinets and governing bodies NHS Rushcliffe, Nottingham West and Nottingham North & East made changes to Gluten Free products available on prescription. As of May 2016 all practices within the three CCGs were requested to ensure no more than four units in total of long life bread and/or flour per month were prescribed for patients with a diagnosed condition of coeliac disease or dermatitis herpetiformis. The medicines management teams work with GP practices to monitor adherence to recommendations.

#### NHS Nottingham City CCG

In June 2015 the NHS Nottingham City CCG Executive Management Team decided that the City population needs were different from those in the County and the proposed County options were not in line with these needs, so NHS Nottingham City CCG did not enter in to the consultation about changes to prescribing of gluten free foods alongside NHS Rushcliffe, Nottingham West and Nottingham North & East.

Clinicians in NHS Nottingham City CCG prescribe staple gluten free products, in line with the Nottinghamshire Area Prescribing Committee position statement (Nottinghamshire Area Prescribing Committee, 2014) and currently there is no CCG policy about further restricting quantities or items. The medicines management teams work with GP practices to align quantities with those recommended by Coeliac UK (Coeliac UK, 2018a)

#### NHS Mansfield & Ashfield and Newark & Sherwood CCGs (Mid Notts)

In January 2017 Mid Notts CCGs undertook a month's engagement. 550 responses were received in response to the following questions:

- Stop all prescribing of gluten-free foods
- Limit to 8 units of bread and/or flour each month

- Continue as now and prescribe staple gluten free foods (non-staple foods are no longer prescribed) and continue to follow the Coeliac Society's recommendations for number of units prescribed

53% of responses were in favour of continuing to prescribe gluten free products as now i.e. following Coeliac U.K. guidelines

Key themes for concerns voiced during the consultation were:

- Availability of gluten free products on prescription
- The additional cost of gluten free products in supermarkets
- Need for increased support and advice to follow a gluten free diet
- There should be negotiation between NHS and manufacturers about prices
- A need to recognise the needs of children and vulnerable groups

### **Outcome**

At its meeting on the 16 February 2017, the joint Governing Body for the two CCGs reviewed comments and agreed to stop NHS prescriptions for Gluten Free foods, for all patients, unless there are special circumstances.

### **Next step for Greater Nottingham (GN) CCGs**

The GN Turnaround Director, having taken the views of the CCG Governing Bodies (GB) in Greater Nottingham, has advised to progress with patient engagement and consultation, across City and County, with the following options:

1. City CCG to align their recommendations with the current arrangements in the other Greater Nottingham CCGs (4 units per month of GF long life bread or flour)\*
2. All CCGs in Greater Nottingham to adopt the national recommendations (prescribing of GF bread and mixes, no recommended number of units)
3. All Greater Nottingham CCGs to stop all GF prescribing
4. All Greater Nottingham CCGs to stop all GF prescribing, except for defined patient groups e.g. children, where national recommendations will apply

\*NOTE – If County status is adopted across GN subsequent national changes will stop prescribing of GF flour, and there may be a need to consider whether prescribing of GF mixes is allowed instead of GF flour.

### **Context**

Coeliac disease is an autoimmune condition associated with chronic inflammation of the small intestine, which can lead to malabsorption of nutrients, triggered by the protein gluten. 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. People with confirmed coeliac disease must give up eating all sources of gluten for life. If someone with coeliac disease is exposed to gluten (found in wheat, barley and rye) they may experience



a range of symptoms and adverse effects. The symptoms from and consequences of not following gluten free (GF) diets may be mild or very severe and can include;

- Abdominal pain, diarrhoea, nausea, bloating, vomiting
- Weight loss in adults or failure to grow at the expected rate in children
- Malnutrition, iron, vitamin B12 and folic acid deficiencies
- Tiredness, headaches
- Skin rash, mouth ulcers, tooth enamel problems
- Osteoporosis, ulcerative jejunitis
- Malignancy (intestinal lymphoma)

Gluten is not necessary for a healthy diet and patients can safely exclude it from their diet and still eat healthily without purchasing special foods. Patients can safely eat meat, fish, vegetables, fruit, rice and most dairy products as these do not contain gluten.

However, the report on the national consultation states that:

- Some prescription products are fortified to provide additional nutrients to patients to avoid malnutrition or vitamin deficiency
- GF formulated prescription food is often fortified with additional nutrients that may be lacking in a coeliac patient's diet, whereas commercially formulated GF foods are less likely to be fortified than their prescription counterparts

Studies have demonstrated that gluten free diet products are poor sources of minerals (such as iron), vitamins (such as folate, thiamine niacin and riboflavin) and fibre (Thompson, 1999; Thompson, 2000). However, Lee et al. (2009) demonstrated that the adding of three servings of gluten-free alternative grains, for example oats, quinoa, buckwheat (pseudo and minor cereals) positively impacts the nutrient profile (fibre, thiamine, riboflavin, niacin, folate and iron) of the grain portion of the gluten-free diet.

Penagini et al., (2013) highlight that the inclusion of pseudo cereals and minor cereals that do not contain gluten in to the diet could offer a less expensive alternative with respect to standard gluten-free choices and could help increase dietary compliance by reducing the economic burden of the diet.

Fry, Madden and Fallaize,(2017) found that more GF foods than regular foods are classified as containing high and medium fat, saturated fat, salt and sugar and have lower fibre and protein content.

Penagini et al., (2013) also highlight other research that there is a need for early education on following a GF diet, as the diet is complicated and can be overwhelming if not presented using a thorough and proactive approach. Studies focusing on compliance to a GF diet indicate that adherence is compromised by a number of factors, including a lack of education and continued support by a physician and dietitian. The National Institute for Health and Care Excellence (2016) recommend that an annual review should be offered to people with coeliac disease so that adherence to a gluten-free diet and symptoms can be reviewed, information and advice about the condition and diet can be refreshed, and any further support needs can be identified.

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. People with conditions such as type 1 diabetes, autoimmune thyroid disease, Down's syndrome and Turner syndrome are at a higher risk than the general population of having coeliac disease. First-degree relatives of a person with coeliac disease also have an increased likelihood of having the condition. It can be diagnosed at any age.

**Supporting evidence and references:**

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Fry, L., Madden, A. and Fallaize, R. (2017). An investigation into the nutritional composition and cost of gluten-free versus regular food products in the UK. *Journal of Human Nutrition and Dietetics*, 31(1), pp.108-120.

Jsna.nottinghamcity.gov.uk. (2018). *Insight web family - Demography (2017)*. Available at: [http://jsna.nottinghamcity.gov.uk/insight/Strategic-Framework/Nottingham-JSNA/Related-documents/Demography-2016.aspx#sect\\_5](http://jsna.nottinghamcity.gov.uk/insight/Strategic-Framework/Nottingham-JSNA/Related-documents/Demography-2016.aspx#sect_5) [Accessed 9 Apr. 2018].

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National Institute for Health and Care Excellence (2016). *Coeliac Disease: Quality Standard 134*. London: National Institute for Health and Care Excellence. Available at: <https://www.nice.org.uk/guidance/qs134> [Accessed 9 Apr. 2018].

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Nottinghamshire Area Prescribing Committee (2014). *Prescribing of Non Staple Gluten free foods*. Nottinghamshire Area Prescribing Committee. Available at: <http://www.nottsapc.nhs.uk/media/1083/gluten-free-non-staple-foods-position-statement.pdf> [Accessed 6 Apr. 2018].

Nottinghamshireinsight.org.uk. (2018). *Nottinghamshire Insight*. Available at: <http://www.nottinghamshireinsight.org.uk/research-areas/jsna/summaries-and-overviews/people-of-nottinghamshire-2017/> [Accessed 9 Apr. 2018].

Penagini, F., Dilillo, D., Meneghin, F., Mameli, C., Fabiano, V. and Zuccotti, G. (2013). Gluten-Free Diet in Children: An Approach to a Nutritionally Adequate and Balanced Diet. *Nutrients*, 5(11), pp.4553-4565.

Saccone, G., Berghella, V., Sarno, L., Maruotti, G., Cetin, I., Greco, L., Khashan, A., McCarthy, F., Martinelli, D., Fortunato, F. and Martinelli, P. (2016). Celiac disease and obstetric complications: a systematic review and metaanalysis. *American Journal of Obstetrics and Gynecology*, 214(2), pp.225-234.

Thompson, T. (1999). Thiamin, Riboflavin, and Niacin Contents of the Gluten-Free Diet. *Journal of the American Dietetic Association*, 99(7), pp.858-862.

Thompson, T. (2000). Folate, Iron, and Dietary Fiber Contents of the Gluten-free Diet. *Journal of the American Dietetic Association*, 100(11), pp.1389-1396.

**If you have been unable to find evidence, please describe what you have based this scheme on instead (e.g. activity data, population data, patient experience or public engagement intelligence, clinical opinion etc.):**

#### Health inequalities:

**What will be the effect of the scheme in terms of reducing [health inequalities](#) in outcomes and in access?**

☐ Positive impact    ☒ Negative impact    ☐ No impact    ☐ N/A

**Comments/rationale:**

Nottingham City:

The level of deprivation is significantly higher in areas of Nottingham City than in most other parts of Greater Nottingham.

Nottingham is ranked 8 th most deprived district in England in the 2015 Index of Multiple Deprivation (IMD), a relative decline on 20th in the 2010 IMD.

About a third of super output areas in the City are in the worst 10% nationally (IMD 2015).

34% of children and 25% of people aged 60 and over live in areas affected by income deprivation (Jsna.nottinghamcity.gov.uk, 2018)

Nottinghamshire County:

Deprivation levels for Nottinghamshire are comparable with England. However, within Nottinghamshire there are communities with both some of the highest levels of deprivation in the country and some of the lowest levels of deprivation. In Nottinghamshire (excluding Nottingham City) there are 25 lower super output areas (LSOAs) in the 10% most deprived LSOAs in England. The most deprived LSOAs are concentrated in the districts of Ashfield, Mansfield, Bassetlaw and Newark & Sherwood (Nottinghamshireinsight.org.uk, 2018).

People living within the more deprived areas of Nottinghamshire have less healthy lifestyle choices and poorer health and wellbeing outcomes. Restriction of all gluten free foods, or partial restriction will impact residents with lower incomes.

- The cost to purchase formulated GF food from retail outlets is more expensive than non-formulated GF food. This is especially the case for bread products where the gap between these products is more significant.
- The quality of prescription products when compared to shop bought products can differ. Some prescription products are fortified to provide additional nutrients to patients to avoid malnutrition or vitamin deficiency.
- The availability of GF foods is not always consistent and many smaller/local shops do not always stock a range of GF food. GF food is not routinely available in food banks or budget supermarkets. For patients/parents/carers that rely on food banks, they will need to select foods that are naturally GF such as meat, fish, rice, fruit and vegetables to ensure they adhere to a GF diet. Patients with lower incomes may not have access to transport and so only have access to local shops.
- Patients in rural areas may depend on pharmacy deliveries for their GF foods, and may have difficulty in obtaining GF supplies from local shops.

**Protected characteristics and inclusion health groups:**

**Impact on the protected characteristic of [Age](#):**

☒ Positive impact    ☒ Negative impact    ☐ No impact    ☐ N/A

**Comments/rationale:**

These changes will affect all patients with a diagnosis of Coeliac disease. Coeliac disease can be diagnosed at any age, although the most frequently diagnosed age range is 40 to 60. A higher proportion of people aged 16-64 in Nottingham City claim some form of benefit than regionally and nationally. To that end a large proportion of the patients in Nottingham City may receive free prescriptions and may not otherwise be able to afford to buy gluten free foods.

The negative impact will be experienced by those who are in receipt of free prescriptions (including children). Nottingham City GB members highlighted that children do not have a choice in making decisions about their diet. In the national consultation parents or carers of children have requested that GF staples, especially bread, remain on prescription to prevent children feeling "different" to their peers, for example, the ability to take a packed lunch (sandwiches) to school. Some CCGs have retained GF prescribing for those under 18. Additionally this group are less likely to make their own dietary choices; this is especially the case for young children, as they rely on a parent/carer to purchase and prepare their meals. Information provided through the consultation stated that the lack of adherence to a GF diet could impact on the growth rate of children, delay puberty and make them susceptible to other auto immune conditions.

**Impact on the protected characteristic of [Disability](#):**

☐ Positive impact   ☒ Negative impact   ☐ No impact   ☐ N/A

**Comments/rationale:**

People in this protected characteristic group may be diagnosed with coeliac disease. Patients experiencing one or more mobility, sensory or intellectual impairments may not be able to access and shop at outlets that stock gluten-free products and products that contain gluten may be purchased in error. The availability of GF foods is not always consistent and many smaller/local shops do not always stock a range of GF food. Patients in rural areas may depend on pharmacy deliveries for their GF foods, and may have difficulty in obtaining GF supplies from local shops.

The health of people with coeliac disease who also have other long term conditions – eg diabetes – may be adversely affected if they do not carefully adhere to a gluten free diet and ability to achieve nutritional adequacy, as discussed previously, may affect patients in this group.

**Impact on the protected characteristic of [Gender re-assignment](#):**

☐ Positive impact   ☐ Negative impact   ☒ No impact   ☐ N/A

**Comments/rationale:**

People in this protected characteristic group may be diagnosed with coeliac disease and these changes should have no impact as a result of that characteristic.

**Impact on the protected characteristic of [Pregnancy and maternity](#):**

☐ Positive impact   ☒ Negative impact   ☐ No impact   ☐ N/A

**Comments/rationale:**

People in this protected characteristic group may be diagnosed with coeliac disease.

A metanalysis by Saccone et al., (2016) showed that untreated coeliac disease, or poor adherence to a GF diet has a higher risk of poorer pregnancy outcomes. Prescribing within the Coeliac UK quantity guidance addresses increased nutritional needs of different groups (ie additional allowance for pregnancy, breastfeeding).

**Impact on the protected characteristic of Race:**

☐ Positive impact   ☐ Negative impact   ☒ No impact   ☐ N/A

**Comments/rationale:**

People in this protected characteristic group may be diagnosed with coeliac disease and these changes should have no impact as a result of that characteristic. However, some populations shop at culturally specific local stores and not supermarkets where GF foods are located.

**Impact on the protected characteristic of Religion or belief:**

☐ Positive impact   ☐ Negative impact   ☒ No impact   ☐ N/A

**Comments/rationale:**

People in this protected characteristic group may be diagnosed with coeliac disease but no evidence has been identified to suggest that their religion or belief would in itself mean that they were adversely or positively affected by prescribing changes.

**Impact on the protected characteristic of Sex:**

☐ Positive impact   ☒ Negative impact   ☐ No impact   ☐ N/A

**Comments/rationale:**

Reported cases of coeliac disease are two to three times higher in women than men, so more women than men may be affected by prescribing changes.

People with conditions such as type 1 diabetes, autoimmune thyroid disease, Down's syndrome and Turner syndrome are at a higher risk than the general population of having coeliac disease. Incidence of these conditions vary between males and females, for example, more women than men develop autoimmune hypothyroidism. Turner syndrome is a condition that is only present in females.

**Impact on the protected characteristic of Sexual orientation:**

☐ Positive impact   ☐ Negative impact   ☐ No impact   ☐ N/A

**Comments/rationale:**

People in this protected characteristic group may be diagnosed with coeliac disease, but no evidence has been identified to suggest that their sexual orientation would in itself mean that they were adversely or positively affected by prescribing changes.

**Impact on people in any of the following Inclusion Health Groups:**

Carers, Homeless people, People who misuse drugs, New and emerging communities, including refugees and asylum seekers, People experiencing economic or social deprivation, Gypsies, Roma and Travellers

Reduction or discontinuation of the gluten free food prescribing may mean that any of the people in these health groups may not be able to obtain gluten free foods because of limitations in access or cost. It may limit the choices of the types of food they can prepare as they may also not have the skills, facilities or time to be able to use flour/mixes to make any foods.

Due to the reduction or discontinuation of gluten free food prescribing, patients in this group:

- may be unable to afford or be unable to easily obtain gluten free foods
- may not have the facilities, time or skills to make food with the flour/mixes provided
- may put their long term health at risk by choosing cheaper food containing gluten.

☒ Positive impact    ☒ Negative impact    ☐ No impact    ☐ N/A

**Impact Assessment Outcome:****Details of any risks identified and overall comments:****Recommendation:**

☒ Proceed    ☒ Proceed with action\*    ☐ Stop

\*Please provide details of action required:



**GLOSSARY** *The descriptions for the following terms are worded specifically for this EQIA.*

Term	Description
Access	Access includes the ability of patients to obtain and understand information about their health and health services, as well as being able to access clinical advice and treatment. Patients' access may be limited by a range of factors such as mobility limitations, cognitive function and language barriers.
Age	The protected characteristic of Age refers to being of a specific age or belonging to a particular age range.
Carers	Carers may be socially excluded and vulnerable, causing them to experience specific disadvantages, leading them to have poorer predicted health outcomes and a shorter life expectancy than the average population.
Clinical effectiveness	Clinical effectiveness is a component of quality in the NHS. It is the application of the best knowledge, derived from research, clinical experience and patient preferences to achieve optimum processes and outcomes of care for patients. The process involves a framework of informing, changing and monitoring practice.
Dignity and Respect	This is one of the values incorporated in the NHS Constitution: "We value every person - whether patient, their families or carers, or staff - as an individual, respect their aspirations and commitments in life, and seek to understand their priorities, needs, abilities and limits. We take what others have to say seriously. We are honest and open about our point of view and what we can and cannot do." Respect, dignity, compassion and care should be at the core of how patients and staff are treated - not only because that is the right thing to do, but because patient safety, experience and outcomes are all improved when staff are valued, empowered and supported.
Disability	<p>The protected characteristic of Disability includes people with physical or mental impairments or illnesses that have a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.</p> <p>'Substantial' is more than minor or trivial – e.g. it takes much longer than it usually would to complete a daily task like getting dressed.</p> <p>'Long-term' means 12 months or more – e.g. a breathing condition that develops as a result of a lung infection.</p> <p>Someone automatically meets the disability definition under the Equality Act 2010 from the day they are diagnosed with HIV infection, cancer or multiple sclerosis, even if they are currently able to carry out normal day to day activities.</p> <p>A disability can arise from a wide range of impairments which can be:</p> <ul style="list-style-type: none"> <li>• Sensory impairments, such as those affecting sight or hearing</li> <li>• Mental health conditions</li> <li>• Mental illnesses</li> <li>• Learning disabilities</li> <li>• Organ specific – e.g. respiratory conditions, cardiovascular diseases, stroke</li> <li>• Developmental – e.g. autistic spectrum disorders</li> </ul>



Term	Description
	<ul style="list-style-type: none"> <li>• Produced by injury to the body, including to the brain</li> <li>• Impairments with fluctuating or recurring effects – e.g. rheumatoid arthritis</li> <li>• Progressive* – e.g. motor neurone disease, muscular dystrophy, and forms of dementia</li> <li>• Auto-immune conditions, such as systemic lupus erythematosus (SLE).</li> </ul> <p>*A progressive condition is one that gets worse over time.</p> <p>The Equality Act 2010 covers people who have had a disability in the past – e.g. if a person had a mental health condition in the past which lasted for over 12 months, but has now recovered, they are still protected from discrimination because of that disability.</p> <p>For further information see <a href="#">Equality Act 2010-disability definition.pdf</a></p>
Engagement	<p>The range of activities designed and deployed by CCGs to:</p> <ul style="list-style-type: none"> <li>• Gain the views of patients, service users and carers on commissioning and service delivery</li> <li>• Include patients, service users and carers in considering their own health, care and treatment.</li> </ul>
Equality Act 2010	<p>A single piece of legislation that replaced previous anti-discrimination Acts. It simplified the law, removing inconsistencies and making it easier for people to understand and comply with. The Act outlaws direct and indirect discrimination, harassment and victimisation of people with relevant protected characteristics in relevant circumstances and requires that reasonable adjustments be made for disabled people. The Equality Act includes a public sector equality duty (PSED), which applies to public bodies and others carrying out public functions. It supports good decision-making by ensuring public bodies consider how different people will be affected by their activities, helping them to deliver policies and services that are efficient and effective, accessible to all, and which meet different people's needs.</p>
Evidence	<p>Information from research and other sources e.g. activity data, population data, patient experience or public engagement intelligence, clinical opinion, NICE, national strategies, policy documents and reports, evaluation, clinical audit, etc.</p> <p>Evidence-based practice is the integration of clinical expertise, patient values, and the best research evidence into the decision making process for patient care. Clinical expertise refers to the clinician's cumulated experience, education and clinical skills. The patient brings to the encounter his or her own personal preferences and unique concerns, expectations, and values.</p>
Gender re-assignment	<p>A person has the protected characteristic of gender reassignment if s/he is proposing to undergo, is undergoing or has undergone a process (or part of a process) for the purpose of reassigning her/his sex by changing physiological, behavioural or other attributes of sex.</p>

Term	Description
Gypsies Roma and Travellers	A group of people who may be socially excluded and vulnerable, causing them to experience specific disadvantages, leading them to have poorer predicted health outcomes and a shorter life expectancy than the average population. See also Inclusion Health groups.
Health inequalities	Preventable and unjust differences in health status experienced by certain population groups. People in lower socio-economic groups are more likely to experience chronic ill-health and die earlier than those who are more advantaged.
Homeless people	A group of people who may be socially excluded and vulnerable, causing them to experience specific disadvantages, leading them to have poorer predicted health outcomes and a shorter life expectancy than the average population. See also Inclusion Health groups.
Inclusion health groups	Groups of people who may be socially excluded and vulnerable, causing them to experience specific disadvantages, leading them to have poorer predicted health outcomes and a shorter life expectancy than the average population. These include carers, homeless people, people who misuse drugs, asylum seekers and refugees, Gypsies and Travellers, sex workers, people experiencing economic and social deprivation, people who are long-term unemployed, people who have limited family or social networks and people who are geographically isolated.
Negative impact	<p>An effect that could, for example:</p> <ul style="list-style-type: none"> <li>• Decrease or exclude access to a service or activity</li> <li>• Be detrimental to treatment outcomes</li> <li>• Have an adverse impact on patient experience.</li> </ul>
New and emerging communities, including refugees and asylum seekers	A group of people who may be socially excluded and vulnerable, causing them to experience specific disadvantages, leading them to have poorer predicted health outcomes and a shorter life expectancy than the average population. See also Inclusion Health groups.
Patient choice	Informed decision-making by patients over where/how they receive health care.
Patient experience	Patient experience is one of the three components of quality in the NHS. Experience of care, clinical effectiveness and patient safety together make the three key components of quality in the NHS. Good care is linked to positive outcomes for the patient and is also associated with high levels of staff satisfaction. Patient experience means putting the patient and their experience at the heart of quality improvement.

Term	Description
Patient safety	The NHS is expected to treat patients in a safe environment and protect them from avoidable harm. Patient safety is one of the three components of quality in the NHS and is defined as the prevention of errors and adverse effects to patients associated with health care. While health care has become more effective it has also become more complex, with greater use of new technologies, medicines and treatments. Patient safety issues are the avoidable errors in healthcare that can cause harm (injury, suffering, disability or death) to patients.
People experiencing economic and social deprivation	A group of people who may be socially excluded and vulnerable, causing them to experience specific disadvantages, leading them to have poorer predicted health outcomes and a shorter life expectancy than the average population. It includes people who are long-term unemployed, or who have limited family or social networks. To comply with the Equality Act 2010, CCGs are required to consider how their strategic decisions might help to reduce the inequalities associated with socio-economic disadvantage, such as inequalities in employment, education, health, housing and crime rates. It is for individual CCGs to consider which socio-economic disadvantages it is able to influence.
People who misuse drugs	A group of people who may be socially excluded and vulnerable, causing them to experience specific disadvantages, leading them to have poorer predicted health outcomes and a shorter life expectancy than the average population. See also Inclusion Health groups.
Person-centred care	Person-centred care is the principle of 'shared-decision making' – enabling people to make joint decisions about their care with their clinicians. It involves putting patients, and their families and carers, at the heart of deciding what is most valuable for individuals with a range of health conditions, rather than clinicians or other health professionals independently deciding what is best.
Positive impact	<p>An effect that could, for example:</p> <ul style="list-style-type: none"> <li>• Increase access to a service or activity</li> <li>• Improve treatment outcomes</li> <li>• Enhance patient experience.</li> </ul>
Pregnancy and maternity	Pregnancy is the condition of being pregnant or expecting a baby. Maternity refers to the period after the birth, and is linked to maternity leave in the employment context. In the non-work context, protection against maternity discrimination is for 26 weeks after giving birth, and this includes treating a woman unfavourably because she is breastfeeding.
Privacy	Interpreted most broadly, privacy is about the integrity of the individual. It therefore encompasses many aspects of the individual's social needs – privacy of the person, personal information, personal behaviour and personal communications.

Term	Description
Protected characteristics	<p>The Equality Act 2010 outlines nine protected characteristics - Age, Disability, Gender re-assignment, Marriage and civil partnership, Pregnancy and maternity, Race, Religion or belief (including no religion or belief), Sex and Sexual orientation. The Equality Act outlaws direct and indirect discrimination, harassment and victimisation of people with relevant* protected characteristics.</p> <p>*Marriage and civil partnership is not a 'relevant' protected characteristic. (This distinction applies only in relation to work, not to any other part of the Equality Act 2010) We all have at least five of the nine protected characteristics - age, race, religion or belief/no religion or belief, a sex and a sexual orientation.</p>
Quality	<p>The definition of quality in health care, enshrined in law, includes three key components: patient safety, clinical effectiveness and patient experience. The NHS aspires to the highest standards of excellence and professionalism in the provision of high quality care – ie care that is safe, clinically effective and focused on providing as positive an experience to service users as possible.</p>
Race	<p>This protected characteristic refers to groups of people defined by their colour, nationality (including citizenship), ethnic or national origins.</p>
Religion or belief	<p>This protected characteristic includes any religion and any religious or philosophical belief. It also includes a lack of any such religion or belief. A religion need not be mainstream or well-known but it must be identifiable and have a clear structure and belief system. Denominations or sects within religions may be considered a religion. Cults and new religious movements may also be considered religions or beliefs.</p> <p>Belief means any religious or philosophical belief and includes a lack of belief. Religious belief goes beyond beliefs about and adherence to a religion or its central articles of faith and may vary from person to person within the same religion. A belief need not include faith or worship of a god or gods, but must affect how a person lives their life or perceives the world.</p>
Safeguarding adults	<p>The Care Act 2014 defines adult safeguarding as protecting an adult's right to live in safety, free from abuse and neglect with people and organisations working together to prevent and stop both the risks and experience of abuse or neglect. Safeguarding balances the adults right to be safe with their right to make informed choices, whilst at the same time making sure that their wellbeing is promoted including, taking into consideration their views, wishes, feelings and beliefs in deciding on any action (s). The Care Act 2014 defines an adult at risk of harm as: 'someone who has needs for care and support, and is experiencing, or at risk of, abuse or neglect and is unable to protect themselves'.</p>

Term	Description
Safeguarding children	Safeguarding children and young people means the actions that are taken to promote their welfare and protect them from harm, abuse and maltreatment. This includes preventing harm to their health or development, ensuring that they experience safe and effective care as they grow up and enabling them to have the best outcomes. Child protection is part of the safeguarding process and focuses on protecting individual children identified as suffering or likely to suffer significant harm. Safeguarding children and child protection guidance and legislation applies to all children up to the age of 18.
Self-care	Also known as self-management. Refers to the key role that individual people have in protecting and managing their own health, choosing appropriate treatments and managing long-term conditions. They may do this independently or in partnership with the healthcare system.
Sex	This protected characteristic refers to whether a person considers that they are a man or a woman.
Sexual orientation	This protected characteristic refers to whether a person's sexual orientation is towards their own sex, the opposite sex or to both sexes.
Shared decision-making	Shared decision-making is a process in which patients, when they reach a decision crossroads in their health care, can review all the treatment options available to them and participate actively with their healthcare professional in making that decision.







# Gluten free prescribing consultation report

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This report is an analysis of all the feedback received as part of a consultation around gluten free prescribing that the Greater Nottingham Clinical Commissioning Partnership ran for a six week period from Thursday 14 June to Thursday 26 July 2018.

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## 1. Introduction

The purpose of this report is to provide feedback on the formal public consultation on the future of gluten-free foods on prescription across Greater Nottingham, which ran for a six week period from Thursday 14 June to Thursday 26 June 2018. The six week consultation was led by the Greater Nottingham Clinical Commissioning Partnership.

The Greater Nottingham Clinical Commissioning Partnership (CCP) is made up of four Clinical Commissioning Groups (Greater Nottingham CCGs) - NHS Nottingham City, NHS Nottingham North and East, NHS Nottingham West and NHS Rushcliffe and covers the areas of Nottingham City, Rushcliffe, Broxtowe, Gedling and Hucknall and Lowdham.

The aim of the six-week consultation was to gain feedback on the following options:

- Limit prescribing for all patients in Greater Nottingham to four units of long life bread and flour per month.
- All Greater Nottingham CCGs to stop all gluten free prescribing, with the exception of children, who will be able to receive up to four units of long life bread and flour per month
- All Greater Nottingham CCGs to stop all gluten free prescribing
- Other (patients invited to have alternative suggestions)

## 2. Background to gluten free prescribing

Like other areas in the country, the local NHS is under increasing financial pressure. The demand on NHS services and the costs of new treatments and medicines is more than the money available. To make sure that we are making the best use of NHS money, we are reviewing some of the services we provide and this means sometimes we need to make difficult decisions about what services can be funded.

We are committed to working with patients, carers and local people to make sure that we consider people's views when making decisions about the services that are most needed.

Where we are looking at making a big change to services, we will always engage or consult with the people affected and the wider public about what we want to do.

In Greater Nottingham, we have a dedicated patient engagement campaign designed to start the conversation with patients about the challenges the NHS faces. The campaign is the Big Health Debate. This consultation around the future of gluten free food on prescription forms part of the Big Health Debate.

### **The Greater Nottingham gluten free food on prescription current situation**

Across Greater Nottingham, the NHS spent £176,488 last year on gluten free foods such as bread, flour, pasta and cereal.

Gluten free foods are prescribed for people suffering from coeliac disease and/ or confirmed dermatitis herpetiformis. 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. Dermatitis herpetiformis (DH) is a skin condition linked to coeliac disease. Gluten is found in foods that contain wheat, barley and rye (such as bread, pasta, cakes and some breakfast cereals).

Over the past few years, gluten free foods have become widely available in supermarkets at more competitive prices as compared to 30 years ago when choice was limited. The increased availability and choice means that it's much easier for patients get these foods without a prescription than it was 30 years ago. The NHS does not provide food on prescription for any other patients, such as diabetics or those with allergies.

Currently, across Greater Nottingham and Mid-Nottinghamshire, there are differences in how much gluten free food is prescribed to people living with coeliac disease.

### **Nottingham City**

Nottingham City currently follow the prescribing guidelines in the table below.

Age and gender	Number of units
Child (1-3 years)	10
Child (4-6 years)	11
Child (7-10 years)	13
Child (11-14 years)	15
Child (15-18 years)	18
Male 19-59 years	18
Male 60-74 years	16
Male 75+ years	14
Female 19-74 years	14
Female 75+ years	12
Breastfeeding	Add 4
3rd trimester pregnancy	Add 1

One unit is the same as: 400g loaf of bread or 250g of pasta

### **South Nottinghamshire (Nottingham North and East, Nottingham West and Rushcliffe)**

Four units are available in total of long life bread and/or flour each month on prescription for patients with a diagnosed condition of coeliac disease or dermatitis herpetiformis.

### **Mid Nottinghamshire (Mansfield and Ashfield and Newark and Sherwood)**

No prescribing of gluten free foods.

## **2.1 Previous national and local consultations**

### **National consultation**

The Government recently undertook a national consultation about whether gluten free foods should be available on prescription for people with coeliac disease.

Following the national consultation, they recommended that gluten free prescribing should be restricted to bread and mixes only. To date, there has been no decision taken about limiting quantities.

Government advice is while national recommendations should be considered that Commissioners can carry out their own consultation with local people and make their own decisions.

### **Previous local consultations**

The South Nottinghamshire CCGs - Nottingham North and East, Nottingham West and Rushcliffe - have already conducted a consultation around gluten free food on prescription in 2015. This was a 12 week formal consultation, which received over 1,000 responses. After the paper went to the CCG's Governing Bodies, gluten free food on prescription was restricted to four units of long-life bread and flour.

You can read the previous report here:

[www.nottinghamnortheastccg.nhs.uk/delivering-as-a-ccg/delivering-engagement/engagement-and-consultations/gluten-free/](http://www.nottinghamnortheastccg.nhs.uk/delivering-as-a-ccg/delivering-engagement/engagement-and-consultations/gluten-free/)

Nottingham City patients haven't previously been consulted with about whether gluten free food should continue on prescription.

## **3. Engagement methodology and feedback**

The aim of the six week consultation was to gain patient and public feedback on three options as follows:

- Limit prescribing for all patients in Greater Nottingham to four units of long life bread and flour per month.
- All Greater Nottingham CCGs to stop all gluten free prescribing, with the exception of children, who will be able to receive up to four units of long life bread and flour per month
- All Greater Nottingham CCGs to stop all gluten free prescribing.

- Other (an 'other' option was included so local people could provide their opinions and suggestions on the future of gluten free food on prescription.

In order to ensure relevant and robust feedback, the consultation approach was as follows:

- A full EQIA (Equalities Impact Assessment) was developed to assess the risk of the proposals.
- A consultation [document](#) and associated materials were developed that asked for feedback on the options identified, and:
  - Provided analysis and the case for/against each options
  - Summarised the engagement and consultation to date and explained how the options being proposed have been arrived at
- The approach was approved at formal Health Scrutiny Committees
- Feedback was invited from local representative groups and individuals and organisations (e.g. Councillors, MPs, PPGs)
- A series of drop-in events were promoted and delivered, supported by staff able to explain the clinical case and the financial case for proposals
- To present findings and proposed course of action to formal OSC committees.

Local people had the opportunity to have their say in a number of ways:

- To fill in a consultation document at their GP Practice and return to the Freepost Address. GP
- To complete online at: [www.surveymonkey.com/r/GN-gluten-free](http://www.surveymonkey.com/r/GN-gluten-free)
- To call: **0115 883 9594** (City patients) or **0115 883 1709** (County patients) for a printed copy or to complete over the phone
- To join us at a drop in session - see Appendix 2 or here: [www.nottinghamnortheast.nhs.uk/nhs/gluten](http://www.nottinghamnortheast.nhs.uk/nhs/gluten)

A total of 466 responses were received during the six week consultation period.

This included:

- 462 direct responses to the survey
- 1 MP enquiry on behalf of a Gedling patient
- A letter from Coeliac UK
- 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.

Prior to going out to consultation, we took views on the subject of gluten-free prescribing from our CCG clinicians, patient groups and our City and County health scrutiny boards.

We also undertook a full EQIA Equalities Impact Assessment. The EQIA highlighted that there are risks associated with restricting or stopping gluten free prescribing, particularly in Nottingham City.

The EQIA stated that the level of deprivation is significantly higher in areas of Nottingham City than in most other parts of Greater Nottingham. People living in more deprived areas have less healthy lifestyle choices and poorer health outcomes. The EQIA points out that cost, availability and accessibility may be an issue for some coeliac patients, particularly in more deprived areas.

The main route by which people were invited to comment was via a survey, but within the survey there was opportunity for people to give free text comments, which many chose to do. In addition, people were able to speak to us face-to-face at one of our drop-in events. A survey was chosen as the primary route because, via utilising our communications channels, it was the best way to ensure the most responses.

While the survey and associated communications tactics (detailed below) was designed to obtain feedback from patients across Greater Nottingham (both patients with coeliac disease and non-coeliacs) another strand to our approach was to specifically target Nottingham City patients, who haven't previously been consulted on gluten free prescribing.

To do this, we set up four [drop in events](#) across key areas in the City – Nottingham City central, St Ann's, Radford and Clifton. We added two additional dates later in the consultation - Asda in Hyson Green and Bulwell. The areas were chosen are multi-cultural areas with higher deprivation scores than for example more affluent City areas such as Wollaton or Mapperley.

This targeted approach had a positive impact on the number of respondents, with 36 per cent of local people who completed the survey having a City postcode - as seen in the responses to question 1 'Provide the first four letters and numbers of your postcode?' (see section 4)

The survey was promoted through social media, traditional media via press releases and online. It was also promoted to stakeholders, patient participation groups, and community groups as well as the general public.

To target patients living with coeliac disease, we contacted Coeliac UK, who submitted and formal response and said that they would alert their local members. On Facebook, we also sent private messages to two local coeliac Facebook groups to ask them to share information about the consultation.

Moreover, we targeted GP Practices with consultation information. Over a third of respondents to the survey had coeliac disease or were completing the survey on behalf of somebody they care for who had coeliac disease as illustrated in Question 3 'Which of the following best describes the way in which you are completing this survey?' (see section four).

### **Additional awareness and engagement activities**

We provided all GP practices across Greater Nottingham with a gluten free consultation pack, which included posters and printed copies of the consultation so they could promote and display materials. We also provided them with digital assets and website information so they could share via their digital channels.

Moreover, we also asked, where possible, that they write to their patients who are living with coeliac disease about the consultation and provided them with a patient letter to facilitate this - we accept that not all practices would have had the resources to do this.

As stated above, we informed Coeliac UK of our consultation and sent all the information to their team. They have responded to the consultation and confirmed that they will email all their local members, which gives us an additional channel to reach people with coeliac disease.

We invited local patients, partners, organisations and local clinicians to tell us their views on the options by completing the questionnaire online or via their GP Practice.

Notice of the consultation was given by direct stakeholder information statement to a wide range of statutory and voluntary sector stakeholders, including Healthwatch.

We raised awareness of the consultation by sending out information to stakeholders, partners and community groups and asked them to share the information with their staff, groups and the wider public. Attached to this briefing were copies of the consultation document and promotional posters and digital asset.

We have also been heavily promoting the consultation via social media and via community groups. The social media channels we concentrated our efforts on the most were Nottingham City's Twitter page (with over 10,000 followers) and NHS South Notts Facebook page, which covers all four CCG areas.

Our engagement teams used a number of community events over the six weeks to talk to people - you can see a list of these in Appendix 2. These events were to help to increase the response rate but also promoted as a place people could come and talk through the options and the issues.

#### **4. Full survey results and analysis**

The feedback was collated from the survey. Other responses to the questions were analysed by a Greater Nottingham Clinical Commissioning Partnership Analyst.

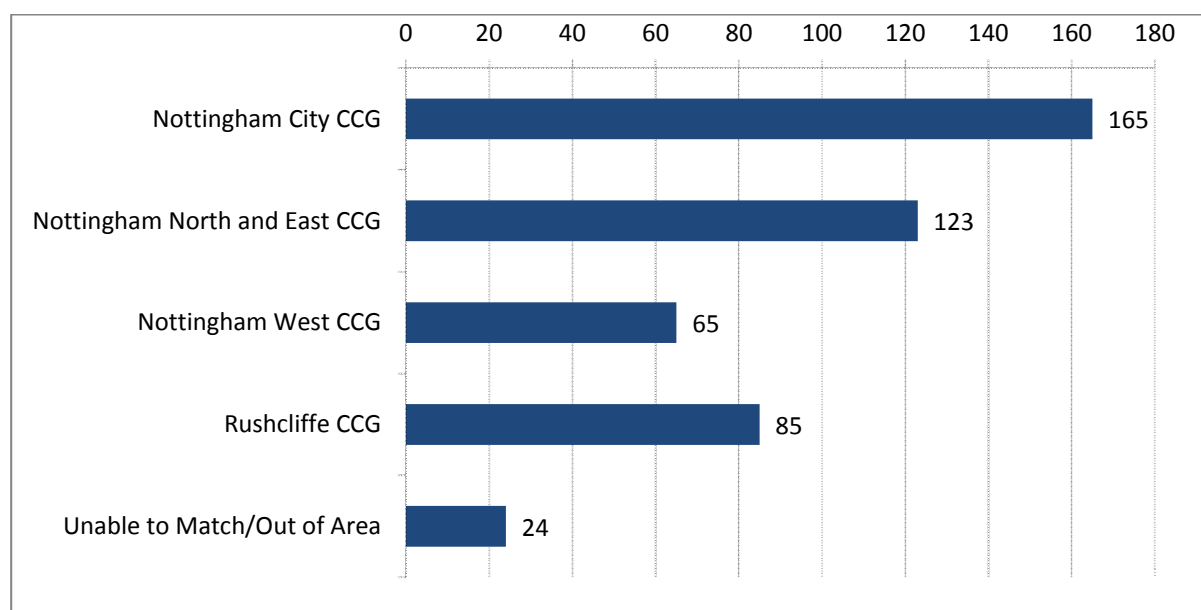
The full survey is below, it includes analysis of the themes in individual question's 'other comments' sections.

In section six of this consultation report, we have themed the responses to Question 11 'Would you like to make any more comments in relation to gluten free prescribing?'

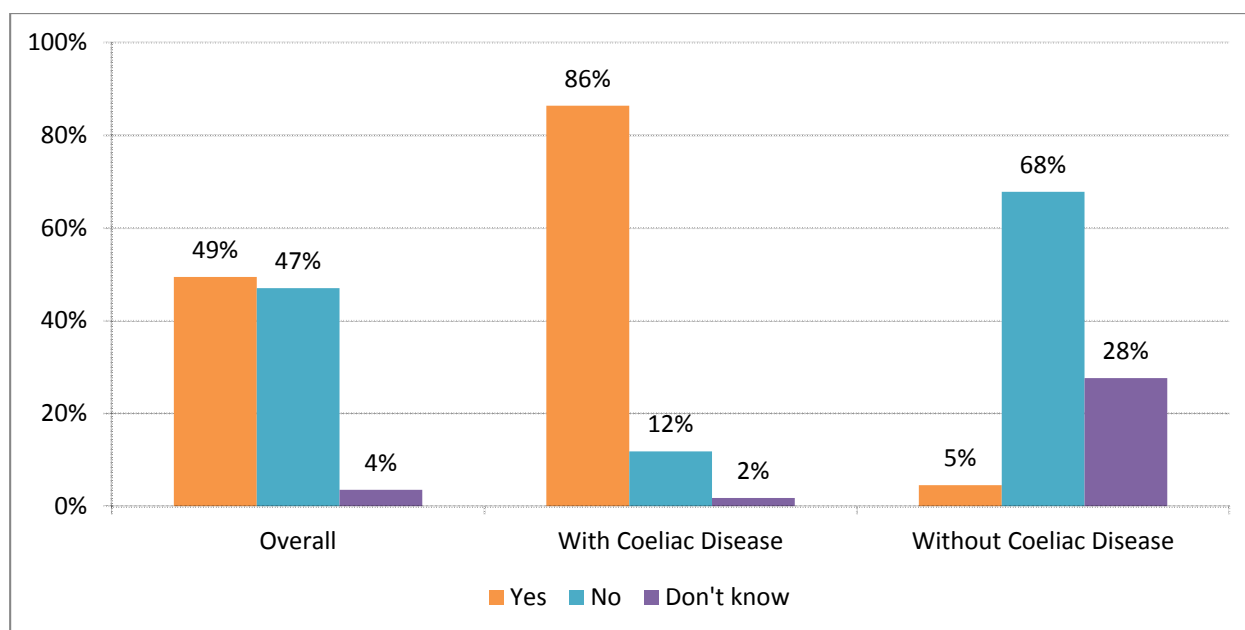
The thematic analysis was completed through multiple passes of the data. Initial familiarisation was used to define themes which were added to and expanded during later passes. A final pass was used for scoring and assignment to each of the defined themes.

Detailed thematic analysis was only undertaken for Question 11. The 'Other' responses to questions were handled independently of Question 11 and are detailed in the full survey results section below.

#### Q1. Provide the first four letters and numbers of your postcode?



## Q2. Do you think gluten free products should be available on prescription?



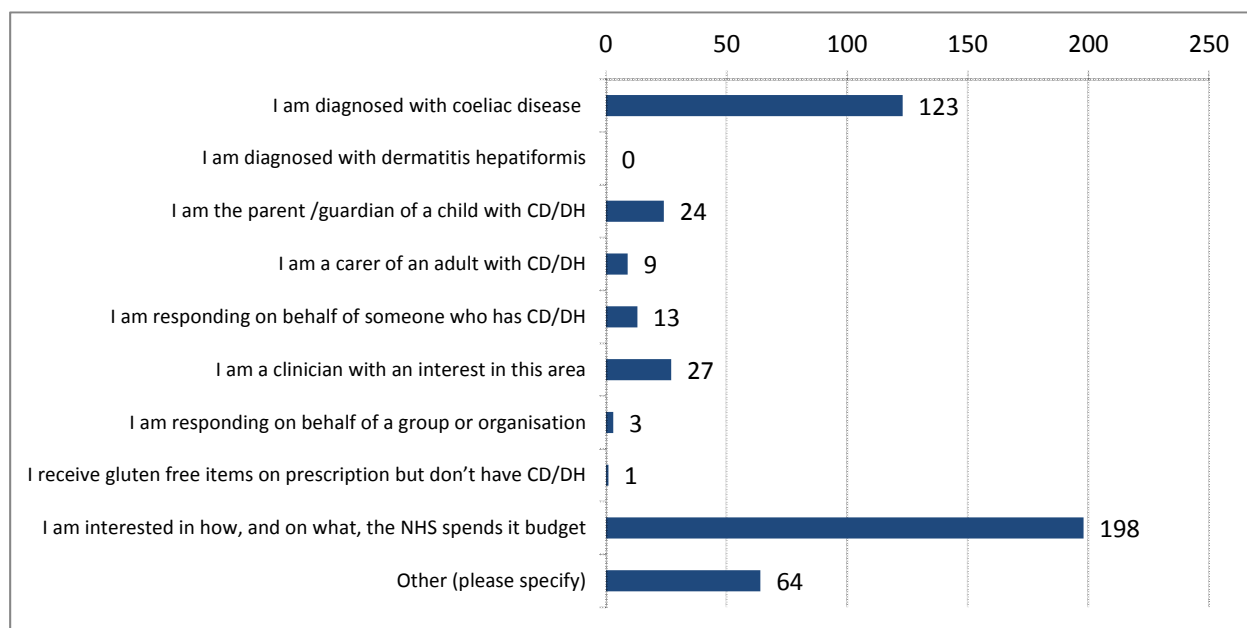
Overall, 49 per cent of patients think some gluten free food should be available on prescription. And, as we can see from the above, 86 per cent of people with coeliac disease think that gluten free food should be available on prescription.

People with coeliac disease are categorised as also including people with coeliac disease and people responding on the behalf of people with coeliac disease.

Conversely, across those without coeliac disease, which includes clinical staff, people responding on behalf of a group, people interested in how the NHS spends its budget and others only 5 per cent thought that gluten free foods should be available on prescription.



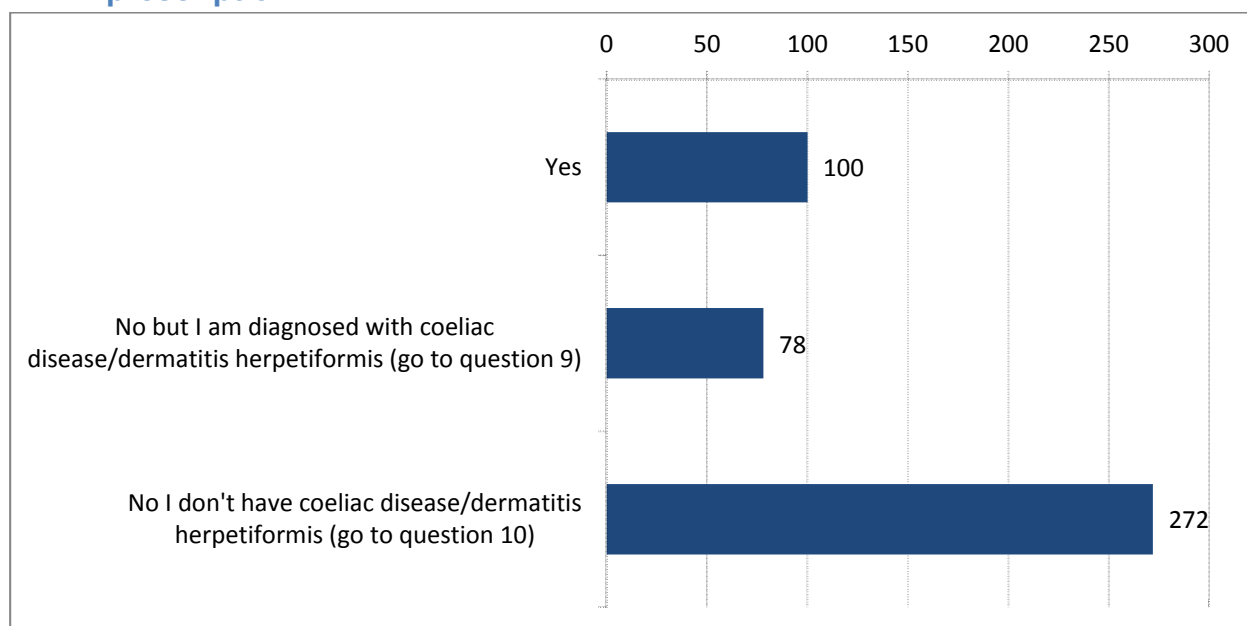
**Q3. Which of the following best describes the way in which you are completing this survey?**



From the 64 other responses, people mainly fell into the following categories:

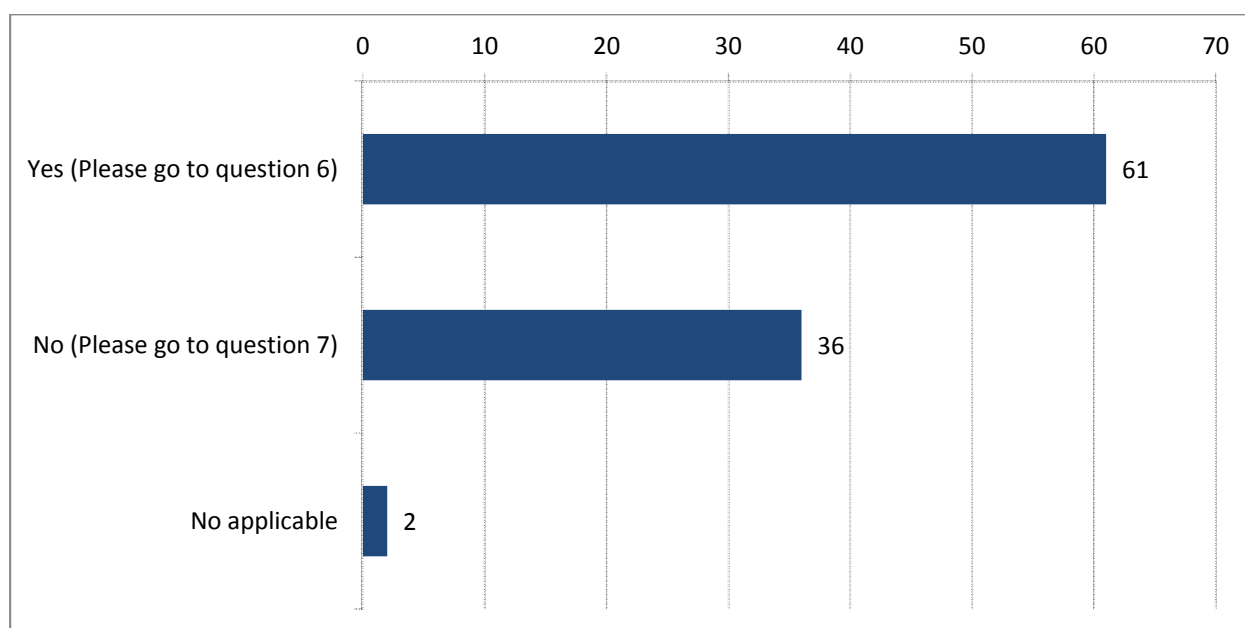
- Friends or family have coeliac disease
- Patient representatives
- People with gluten intolerance
- Providing support for people with coeliac disease

**Q4. Do you (or the person you care for) receive gluten-free foods on NHS prescription?**

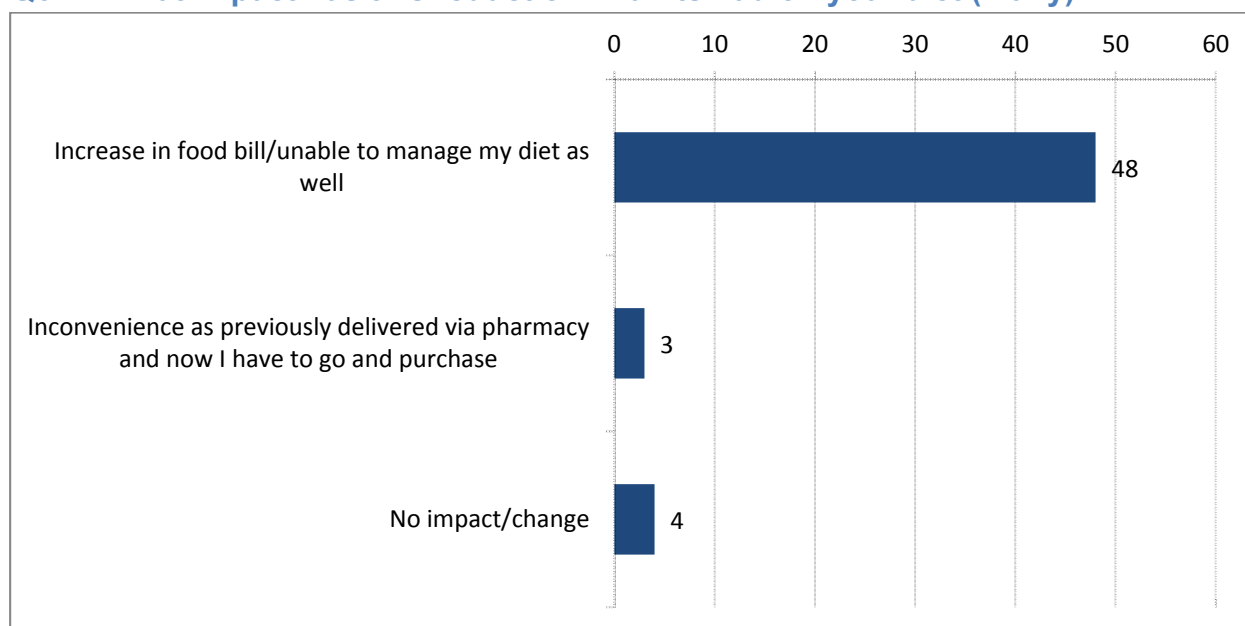


What the above chart tells us is that 78 of the respondents to this question have coeliac disease but do not receive gluten free food on prescriptions. For more details about why this is the case see question 9.

**Q5. Has your gluten-free prescription been reduced following previous consultations?**



**Q6. What impact has this reduction in units had on your diet (if any)?**

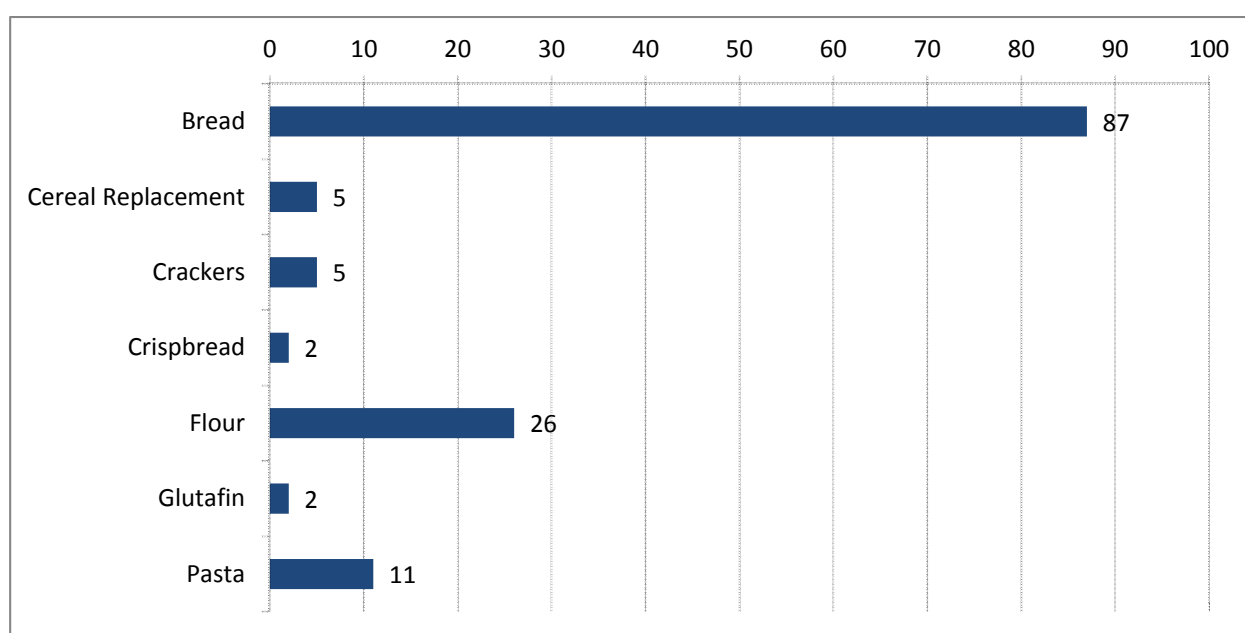


Question five and six were included to look at the impact of previous changes to gluten free prescribing following the South County CCGs' consultation in 2015. Of the 61 people who have seen their allowance changes, 48 of them have seen an increase in their food bill meaning they are unable to manage their diet as well.

There were 27 comments on this question, the main themes are:

- Affordability of gluten free food
- Accessibility 'I have to rely on others to get more bread and it's not always available'
- Inconvenience

#### Q7. Which gluten-free products do you receive on prescription?

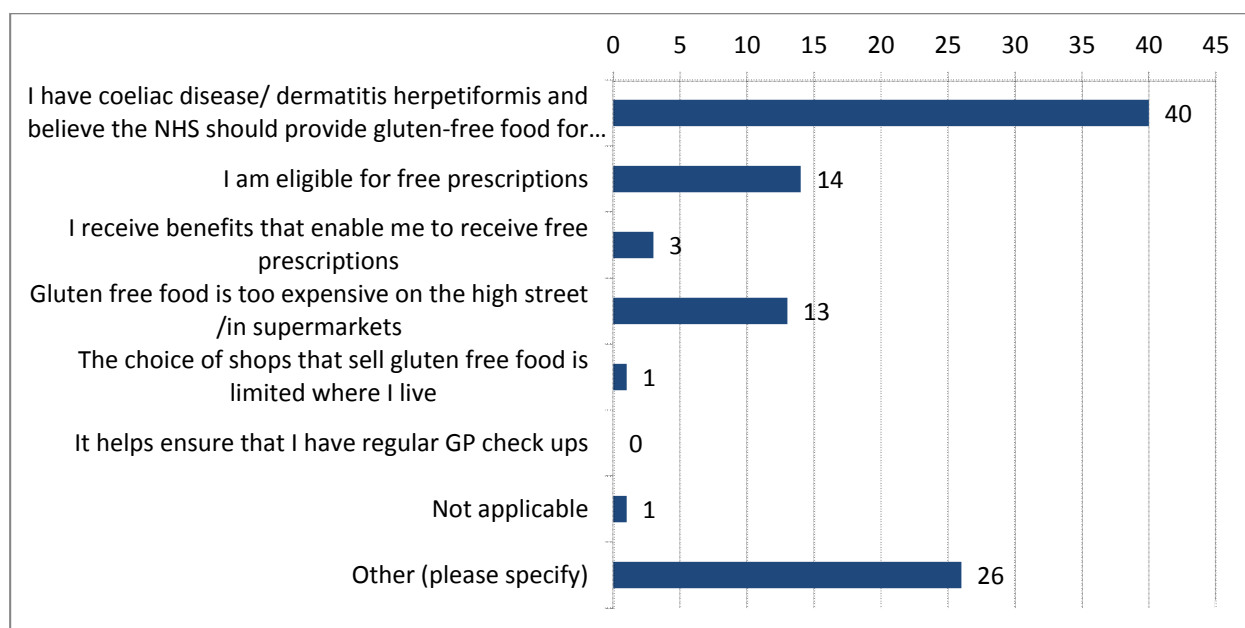


Of the answers grouped under 'Bread' - seven specified long life bread and one fresh bread.

Two people specifically mentioned Glutafin so that has been included on the table but it's important to note that Glutafin is a brand so we don't know what actual products the respondents received.

It's important to note that the only products currently available to County patients are four units of bread and flour/ mix.

**Q8. If you or the person you care for receive gluten-free food on prescription, please tell us why?**



There were 28 free text comments on this question, the main themes are:

- Affordability of gluten free food
- Accessibility - the choice in shops is limited.
- Also a number of people with coeliac disease stated that they were also eligible for free prescriptions.

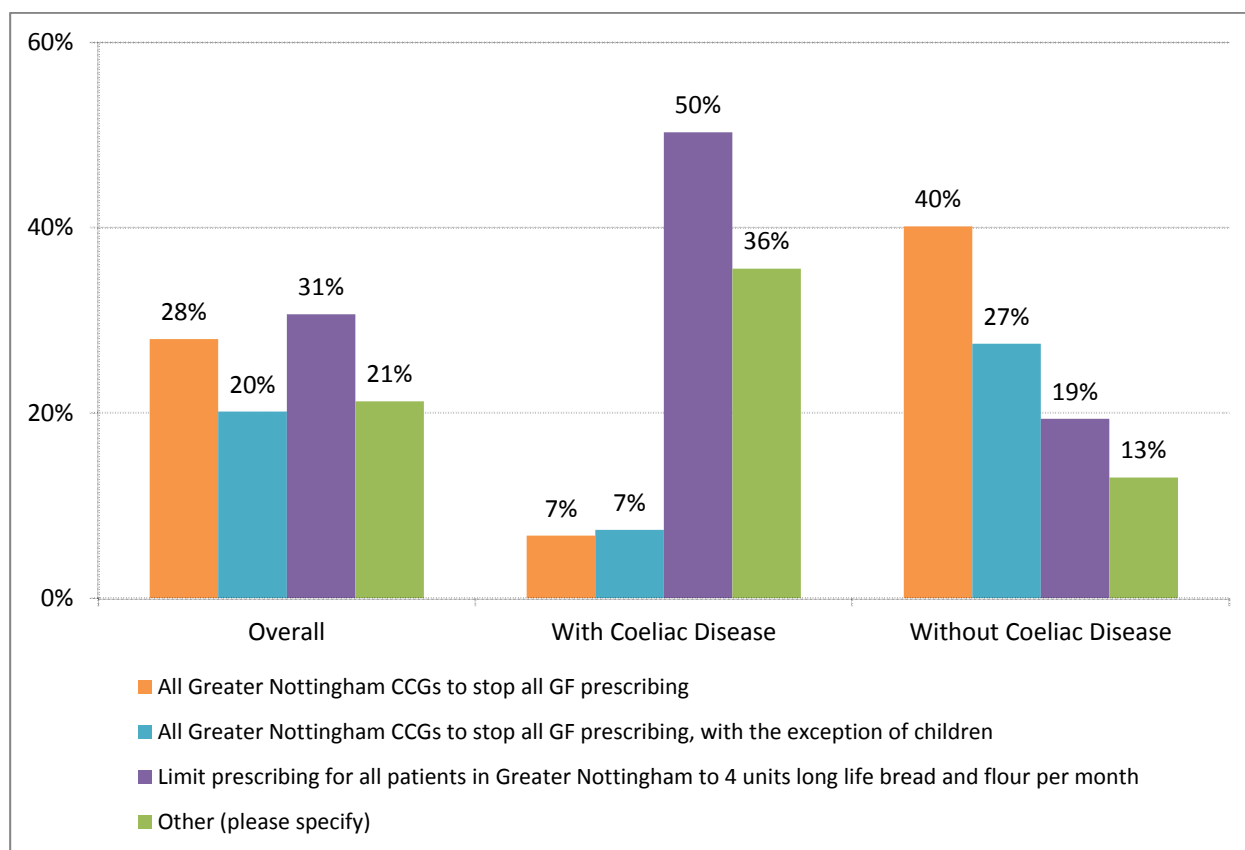
**Q9. If you or the person you care for, have coeliac disease or dermatitis herpetiformis but don't receive gluten free foods on prescription, please tell us why not below (tick all that apply)**



There were 47 free text comments on this question, the main themes are:

- Awareness - I wasn't aware you could get gluten free food on prescription/ I haven't been offered gluten free food/ My GP does not/will not prescribe
- Affordability - I can afford my own

**Q10. Please select which proposal you agree with for the future prescribing of gluten-free foods**



While the most popular option for those without coeliac disease is to stop all gluten free prescribing, overall, the preferred option across all respondents is to limit prescribing to four units.

There were 47 free text comments on this question, the main themes/ suggestions are:

- Should be available to people on low incomes/means tested
- Continue with current prescribing
- Increase limits and range of gluten free products available on prescription
- Follow national guidelines, four units is not enough.

**The equalities data can be found in Appendix two**

## 6. Key stakeholder consultation feedback

In response to the consultation, we also received three formal written responses from official bodies namely: The Coeliac Society, the Department of Dietetics and Nutrition at Nottingham University Hospitals NHS Trust and the British Specialist Nutrition Association (trade association representing nutritional product manufacturers). The consultation plans also went to both City and County Scrutiny Committee.

### Nottinghamshire County Health Scrutiny Committee

The consultation plans complete with the rationale and options were presented at the City and County Health Scrutiny Committees. The County HSC supported options two and wanted to ensure that children still had some access to gluten free food on prescription.

### Coeliac UK

This is the leading charity for people living with coeliac disease. The charity supports people with coeliac disease and dermatitis herpetiformis and has more than 60,000 members.

#### Coeliac UK's key points

- **Access to gluten free food**  
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.
- **Cost and availability of gluten free food**  
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.

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.

### Department of Dietetics and Nutrition at Nottingham University Hospitals NHS Trust

The Greater Nottingham CCP received an email with a letter attached from the Department of Dietetics and Nutrition at NUH.

#### Department of Dietetics and Nutrition key points

- **More cost to the NHS to stop prescribing**  
Coeliac disease is a long-term health condition and as such the cost of gluten-free food on prescription as treatment represents a much lower cost to the NHS than the treatment of other life-long conditions. Stopping the prescriptions or restricting them inappropriately may lead to an increase in complications which will require more expensive NHS treatments.

- **Advice and support**

The diet is complicated and food choices are limited by all these factors, people with Coeliac disease need as much help and support as possible.

- **Different prescribing models**

We are currently in a situation where the advice we provide on use of gluten free prescribable products to patients we see varies depending on the CCG of their GP practice. We would therefore welcome a consistent system across the CCP.

However, we would not wish this to be at the cost of implementing a system which would be detrimental to the dietary treatment of patients with Coeliac disease.

- **Accessibility of gluten free products**

It can be particularly difficult for patients in rural areas or with mobility issues or reliant on public transport who may use small local shops which do not stock gluten-free varieties of staples such as bread and flour.

The department provided an opinion on each of the consultation options – key points are below, the full letter can be viewed [here](#).

#### **Stop all gluten free prescribing**

- Removing gluten free foods on prescription will impact on adherence to a gluten-free diet and disproportionately disadvantage the most vulnerable groups in our population.
- Removing access to all gluten free foods on prescription is in direct contrast to the outcome of the national Department of Health consultation completed in 2017 which recommended ongoing prescription of bread and flour mixes.

#### **Stop all gluten free prescribing, with the exception of children, who will be able to receive up to four units of long life bread and flour per month**

- It is not clear what the rationale would be for children only to receive some gluten free foods on prescription. People can be newly diagnosed with Coeliac disease at any age and the challenges in adapting to a gluten free diet are different for everyone. If the reasoning is consideration of children as a vulnerable group then this does not seem equitable to other vulnerable groups such as older people or those with disabilities.

#### **Limit to four units of long life bread and flour per month**

##### **Preferred option but:**

- Since the South Nottinghamshire CCGs put this option in place in May 2016, we have experienced a number of patients who have found it very difficult to maintain a strict gluten-free diet with the restricted level of products available on prescription.



- Restricting the amounts to be the same for all patients regardless of age or gender takes no account of different nutritional requirements.
- What is the rationale behind 4 units?
- It would be helpful for patients if the system could be more flexible – for example being able to alternate prescriptions for bread and flour each month.

### **British Specialist Nutrition Association (BSNA)**

The Greater Nottingham Clinical Commissioning Partnership received a letter from the BSNA with their response to the consultation.

#### **BSNA Key points**

- BSNA welcome that Greater Nottingham CCP would like to align the various GF prescribing policies in the locality and would urge that this follows the outcome of the National consultation.
- The organisation suggests that the CCP waits to make decisions about the amount of units allowed because: 'a Task and Finish Group has been convened by the DHSC of which Coeliac UK, British Dietetic Association (BDA) and NHS Clinical Commissioners are all members. As part of their work, the group was responsible for defining which products fall within the bread and flour mixes categories, and they will also be making a recommendation regarding unit allocation.

## **7. Key themes and findings**

The themes which we have been consistent through all the 'Any other comments' feedback in questions 1-10 of the consultation, and indeed from the stakeholder feedback we received have been concerns about affordability and accessibility. There has been particular concern about how changes will affect vulnerable people across Greater Nottingham.

Question 11 was an open question, which asked 'Would you like to make any more comments in relation to gluten free prescribing?' There were 198 free text responses to this question - 47 per cent of the participants in the survey. Below we have themed the responses to Question 11 as you can see affordability and accessibility are key concerns amongst the respondents, particularly those with coeliac disease.

### **Key themes**

Theme: Cost, choice and availability of products	Responses
Gluten free foods are too expensive in the supermarket	42

Gluten free products should be free for those with low incomes	29
Can't help having coeliac disease	21
There should be more choice of gluten free products on prescription	13
Gluten free products should be free for children	10
Gluten free food is difficult to find	8
Cost savings from reducing GF prescribing will result in increased costs from complications of coeliac disease	6
Four units is not sufficient	5

Theme: it's not the job of the NHS	Responses
Gluten free products/alternatives are now easy to buy	36
Gluten free products shouldn't be paid for by the NHS	20
Other diseases don't get their food paid for (eg. Diabetes)	13
Bread isn't a necessity	3

Theme: other suggestions	Responses
Discount or voucher scheme should be provided for those with coeliac disease	8
More help should be given in terms of advice and support (eg. Dietary advice, cookbooks)	5

## Findings

- There is opposition to all the proposals from those living with coeliac disease - thirty six per cent of respondents wanted a different proposal - generally this meant keeping the same provision (City patients) or more choice and/ or more products on prescription.
- Key themes behind this opposition are that gluten free food is not consistently available, it's expensive and people who cannot afford to adhere to the diet will get ill meaning more expense for the NHS. Throughout the free text answers to questions, we can see that these themes of affordability and accessibility are consistent throughout.
- Moreover, all of the key stakeholder feedback urges caution – will the stopping of gluten free prescribing have a knock on effect on coeliac patient health, particularly in deprived communities in the City?
- The BSNA suggests that there will be further Government advice on quantities of gluten free food available on prescription and requests that the CCGs wait until this work is done.
- The Department of Dietetics and Nutrition at NUH suggest since the South Nottinghamshire CCGs reduced to four units, they have experienced a number of patients who have found it very difficult to maintain a strict gluten free diet.

**However**

- Seventy eight people who have coeliac disease did not receive gluten free food on prescription, 12 per cent of those because they didn't believe that food should be available on prescription.
- To question 2 'Do you think gluten free products should be available on prescription?' 68 per cent of non-coeliacs 12 per cent of people living with coeliac disease said No.
- When it came to choosing a preferred option, forty per cent of non-coeliac patients thought that gluten free foods on prescription should be stopped. Interestingly seven per cent of people living with coeliac disease also chose this option.
- Fifty per cent of people living with coeliac disease chose 'limit to 4 units' option as their preferred option.
- It's clear through the free text answers, that more advice and information for coeliac patients will be beneficial if gluten free prescribing is restricted or stopped.

**Overall, the outcome of the consultation is that option three 'limit to 4 units' is the preferred choice when you combine the responses of people with coeliac disease and those without.**

## **8. Next Steps**

This consultation report will be made available on all the Greater Nottingham 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.

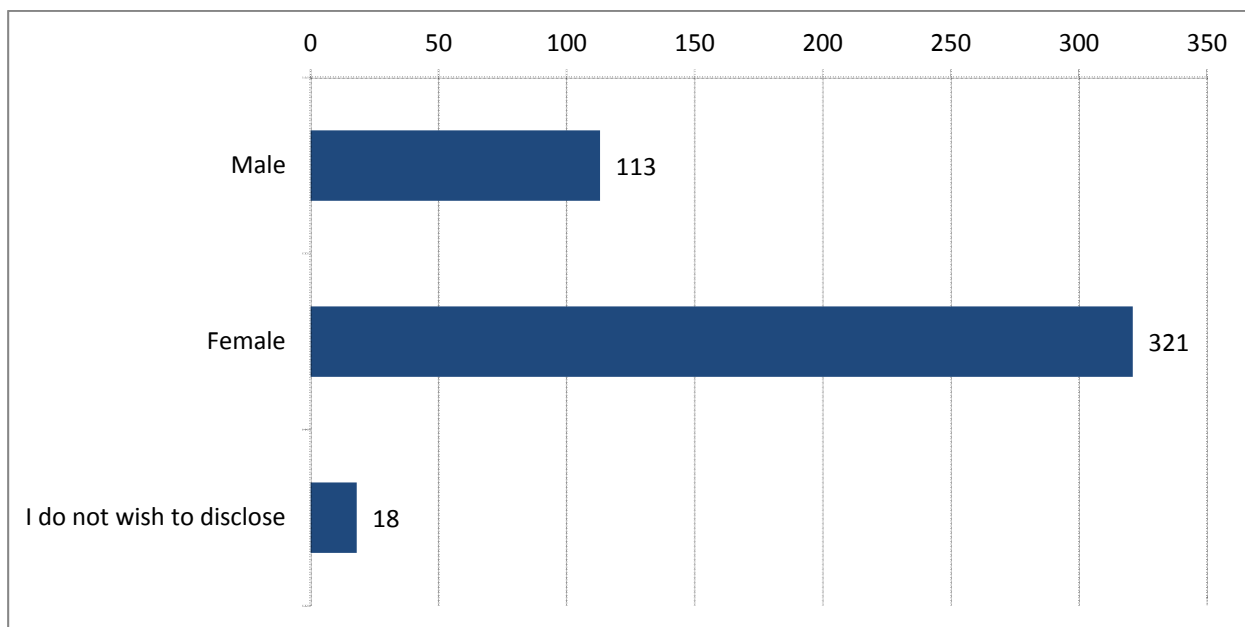
The outcome of the consultation will be used to inform the recommendation which will be presented to the Greater Nottingham Clinical Commissioning Partnership's Joint Commissioning Committee on Wednesday 26 September 2018.

Thank you to everyone who took part in this consultation.

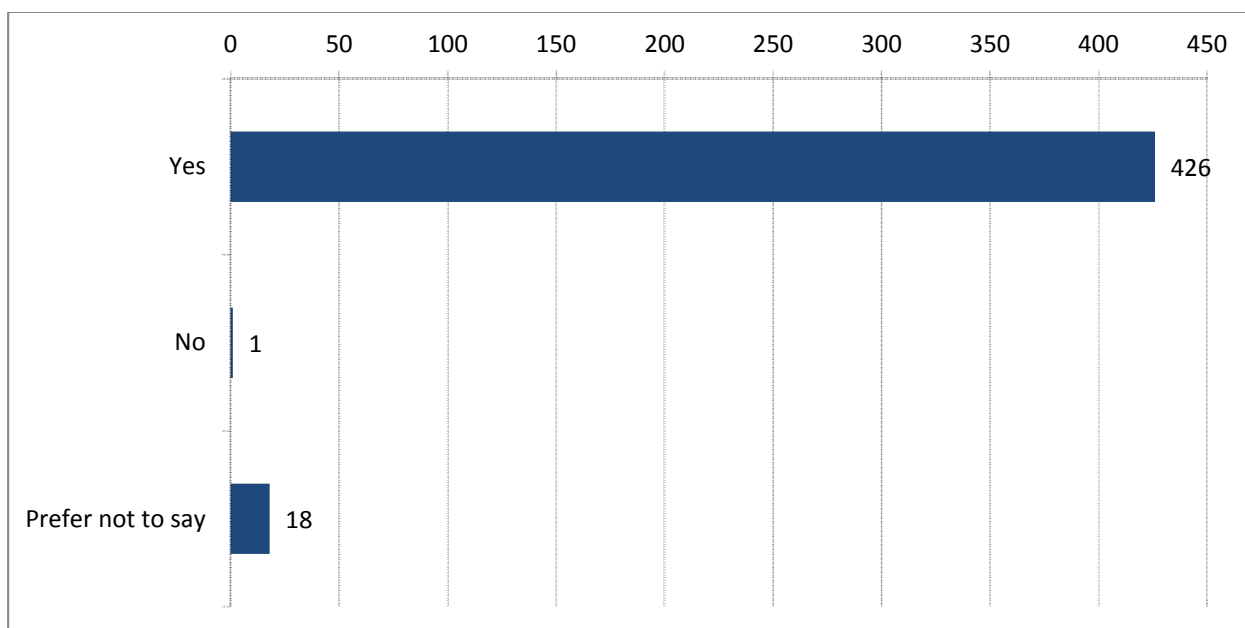
## Appendix 1

### Demographic Information

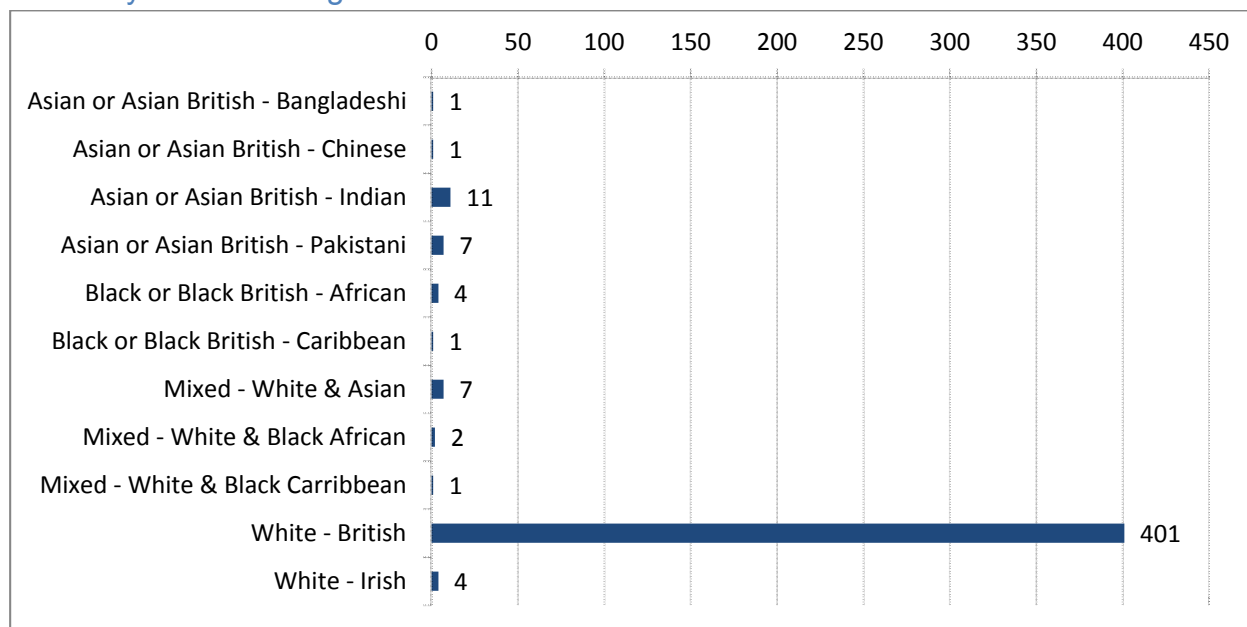
What is your gender?



Is your gender the same as the gender you were originally assigned at birth?



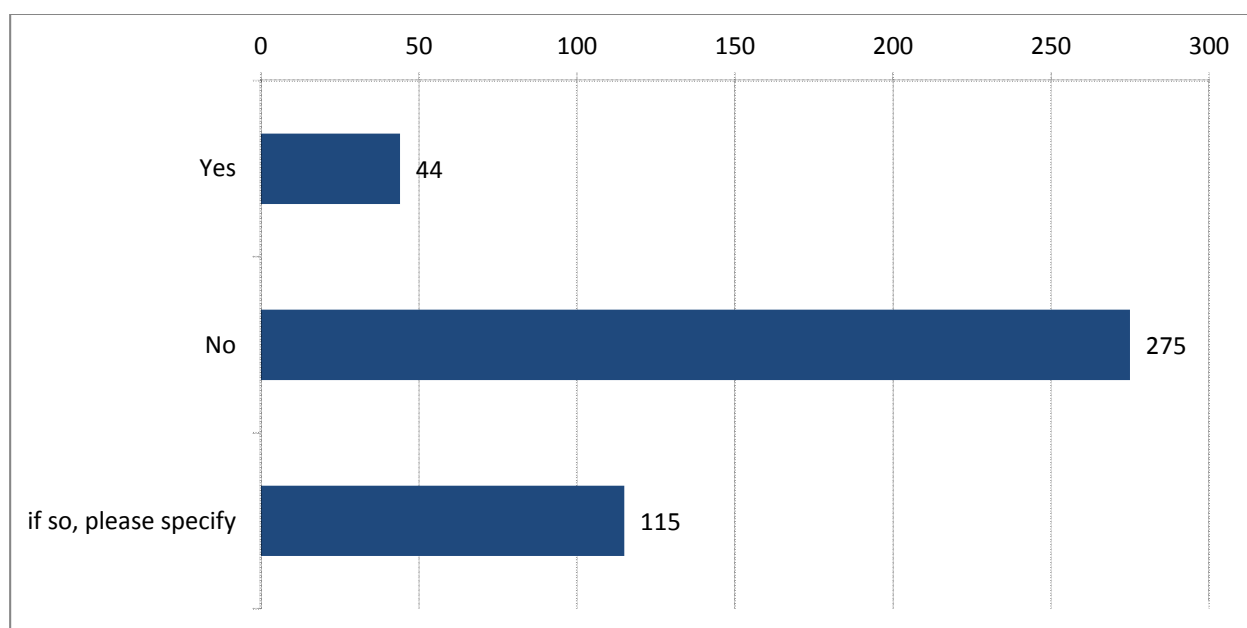
### What is your ethnic origin?



### What is your age?

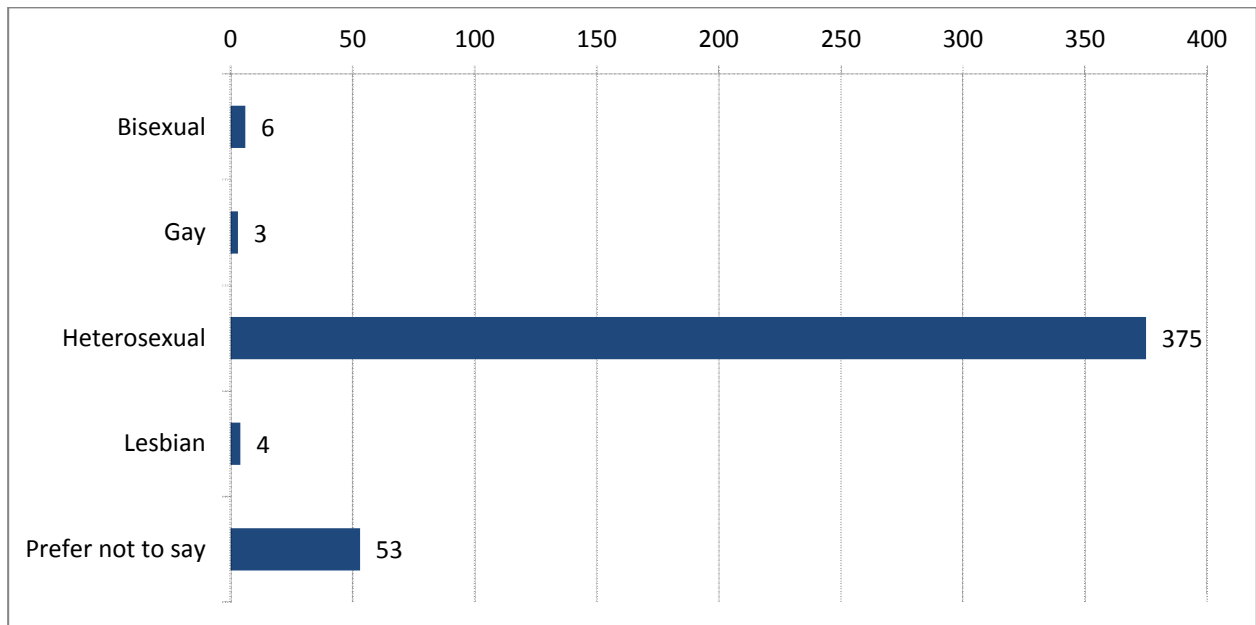
The average age of respondents was 47.13

### Do you consider yourself to have a disability or long term condition?

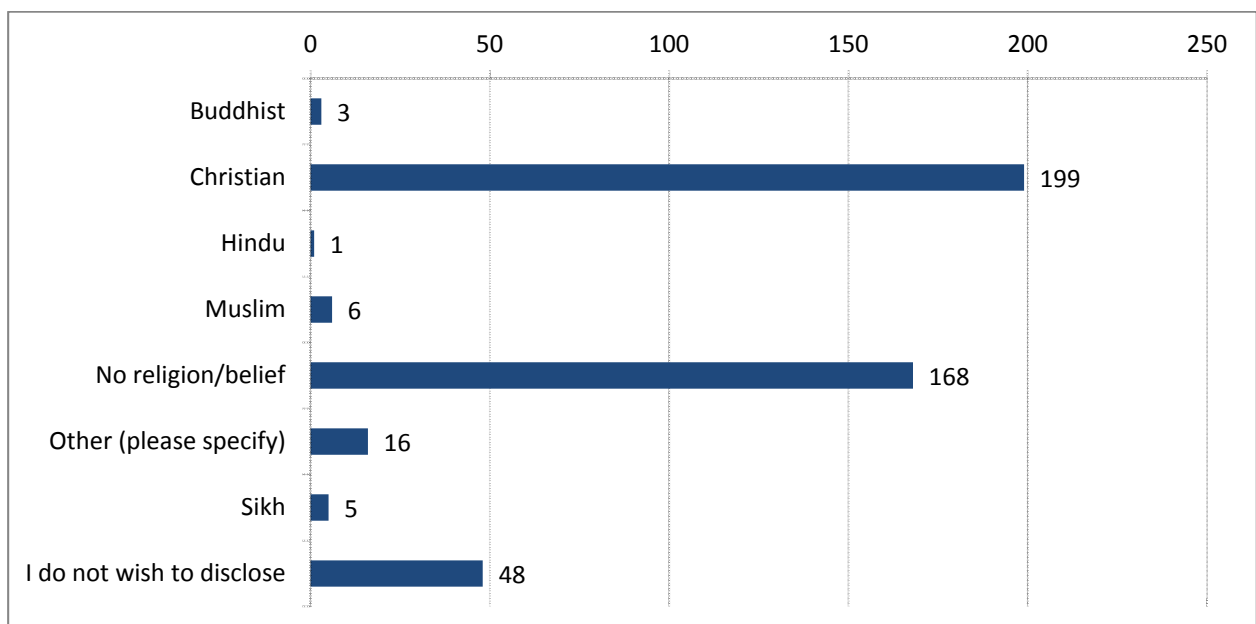


Specified: Coeliac disease, diabetes, arthritis, asthma, fibromyalgia, hypothyroidism

### What is your sexual orientation?

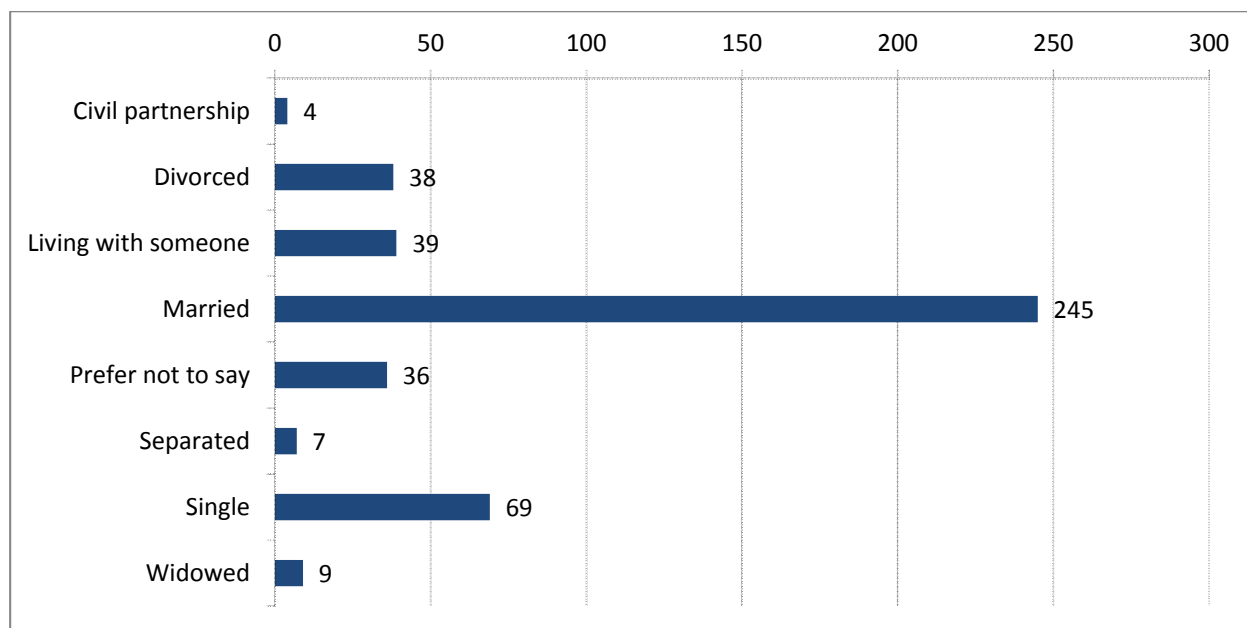


### What is your religion or belief?

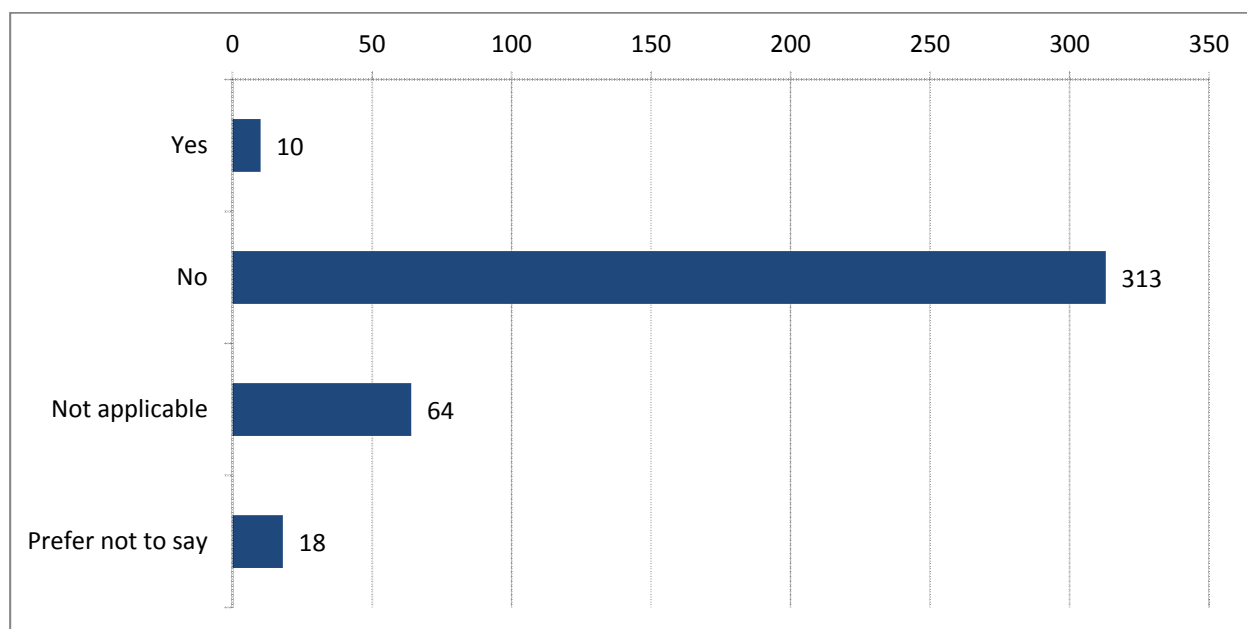


Other: Agnostic, Jehovah's Witness, Baptist, Methodist, Mormon, Paganism, Quaker, Secular Humanist, Spiritual, Taoist

### What is your marital/civil partnership status?



### Women - Pregnancy and Maternity, are you currently pregnant?





## Appendix 2

### Events



## Join us to have your say about gluten free food on prescription

We'd like to hear your views about whether gluten free foods should continue to be prescribed on the local NHS for people living with coeliac disease. We invite you to join us at one of our engagement drop-in events.

Date	Time	Venue
16/6/2018	All day	Arnold Carnival, Arnot Hill Park, Gedling NG5 6LU
16/6/2018	All day	Cotgrave Festival, Welfare Field, Woodview, Cotgrave
23/6/2018	From 4pm	East Leake Carnival, Gotham Road Playing Fields
12/7/2018	9am to 4pm	Hucknall Tesco, Ashgate Road, Hucknall, NG15 7UQ
14/7/2018	From 1pm	Radcliffe Carnival, the Grange, Radcliffe on Trent
14/7/2018	From 11	Keyworth Show, Rectory Field, Keyworth

(please note these are drop-in sessions, please drop in during the time listed)

## Can't make it? You can still have your say...

Go to: [www.surveymonkey.com/r/GN-gluten-free](http://www.surveymonkey.com/r/GN-gluten-free)

Call: **0115 883 9594** for a printed copy or complete over the phone

**This consultation will run from Thursday 14 June to Thursday 26 July 2018**



## Join us to have your say about gluten free food on prescription

We'd like to hear your views about whether gluten free foods should continue to be prescribed on the local NHS for people living with coeliac disease. We invite you to join us at one of our engagement drop-in events.

Date	Time	Venue
Thursday 28 June 2018	12pm - 2pm	St Ann's Valley Centre, 2 Livingstone Road, Nottingham NG3 3GG
Wednesday 4 July 2018	10am - 12pm	Nottingham Central Library, Angel Row, Nottingham NG1 6HP
Wednesday 4 July 2018	1pm - 3pm	Mary Potter Centre, 76 Gregory Blvd, Nottingham NG7 5HY
Wednesday 11 July 2018	1pm - 3pm	Clifton Cornerstone, Southchurch Drive, Clifton, Nottingham NG11 8EW

(please note these are drop-in sessions, please drop in during the time listed)

### Can't make it? You can still have your say...

Go to: [www.surveymonkey.com/r/GN-gluten-free](http://www.surveymonkey.com/r/GN-gluten-free)

Call: **0115 883 9594** for a printed copy or complete over the phone

**This consultation will run from Thursday 14 June to Thursday 26 July 2018**

## **Prescribing of Gluten Free foods in Greater Nottingham**

### **1. Background**

Coeliac disease is an autoimmune condition associated with chronic inflammation of the small intestine, which can lead to malabsorption of nutrients, triggered by the protein gluten. If someone with coeliac disease is exposed to gluten (found in wheat, barley and rye) they may experience a range of symptoms and adverse effects. The symptoms from and consequences of not following gluten free (GF) diets may be mild or very severe and can include;

- Abdominal pain, diarrhoea, nausea, bloating, vomiting
- Weight loss in adults or failure to grow at the expected rate in children
- Malnutrition, iron, vitamin B12 and folic acid deficiencies
- Tiredness, headaches
- Skin rash, mouth ulcers, tooth enamel problems
- Osteoporosis, ulcerative jejunitis
- Malignancy (intestinal lymphoma)

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. There are approximately 850 patients across Greater Nottingham who are prescribed a gluten free product.

People with conditions such as type 1 diabetes, autoimmune thyroid disease, Down's syndrome and Turner syndrome are at a higher risk than the general population of having coeliac disease. First-degree relatives of a person with coeliac disease also have an increased likelihood of having the condition. 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. People with confirmed coeliac disease must give up eating all sources of gluten for life.

Over twenty to thirty years ago only a small range of GF foods, if any, were available to purchase and they were relatively expensive. To enable people to manage their disease, these foods were made available on prescription. However in recent years the range of GF foods has considerably expanded and become widely available via supermarkets at a more competitive price. However, gluten is not essential for a healthy diet and there are other foods that can provide carbohydrates e.g. potato and rice.

In 2017 the Department of Health (DH) recently conducted a national consultation on the availability of Gluten Free (GF) foods on prescription in primary care.

The options considered were:

- Option 1: Make no changes to the National Health Service (General Medical Services Contracts) (Prescription of Drugs etc.) Regulations 2004.

*Under this option all types of GF foods would continue to be prescribed in primary care at National Health Service (NHS) expense.*

- Option 2: To add all GF foods to Schedule 1 of the above regulations to end the prescribing of GF foods in primary care.

*Under this option no GF foods would be available on prescription in primary care.*



- Option 3: To only allow the prescribing of certain GF foods (e.g. bread and flour) in primary care, by amending Schedule 1 of the above regulations.

*Under this option only certain GF foods would be available on prescription in primary care.*

The outcome from the national consultation was published on 1<sup>st</sup> February 2018 and the Government decided to restrict gluten-free prescribing to bread and mixes only. The majority of respondents to the consultation preferred this option.

The consultation response stated that:

“It is for CCGs to decide how they commission local services to best meet the needs of their populations”.

This statement signalled that the outcome of the consultation does not affect the statutory authority that a CCG has to determine the availability of gluten-free foods in their local area. Greater Nottingham Clinical Commissioning Partnership decided to undertake a public consultation to support decision making about prescribing of gluten free foods for their population.

## **2. Current position**

### **NHS Rushcliffe, Nottingham West and Nottingham North & East CCGs**

- May 2016 – Following feedback from a three month consultation and recommendations from clinical, patient cabinets and governing bodies NHS Rushcliffe, Nottingham West and Nottingham North & East made changes to Gluten Free products available on prescription. As of May 2016 all practices within the three CCGs were requested to ensure no more than four units in total of long life bread and/or flour per month were prescribed for patients with a diagnosed condition of coeliac disease or dermatitis herpetiformis. The medicines management teams work with GP practices to monitor adherence to recommendations.

### **NHS Nottingham City CCG**

- In June 2015 the NHS Nottingham City CCG Executive Management Team decided that the City population needs were different from those in the County and the proposed County options were not in line with these needs, so NHS Nottingham City CCG did not enter in to the consultation about changes to prescribing of gluten free foods alongside NHS Rushcliffe, Nottingham West and Nottingham North & East.
- Clinicians in NHS Nottingham City CCG prescribe staple gluten free products, in line with the Area Prescribing Committee (APC) position statement and currently there is no corporate policy about further restricting quantities or items. The medicines management teams work with GP practices to align quantities with those recommended by Coeliac UK.

### **NHS Mansfield & Ashfield and Newark & Sherwood CCGs**

- February 2017 – Following a month’s engagement in January 2017 at its meeting on the 16 February 2017, the joint Governing Body for the two CCGs reviewed comments and agreed to stop NHS prescriptions for Gluten Free foods, for all patients, unless there are special circumstances.

Prescription expenditure on GF foods (April to June 2018)

Nottingham City CCG	£26,377
Nottingham North and East CCG	£5,786
Nottingham West CCG	£3,154
Rushcliffe CCG	£3,815

Using this data to calculate a full year effect produces and anticipated expenditure of £156,528 per annum on GF foods.

### **3. Options**

The options in the public consultation were agreed following discussion at Governing Body meetings in each Greater Nottingham CCG:

**Option 1:** Limit prescribing for all patients in Greater Nottingham to four units of long life bread and flour per month.

#### **Benefits**

- This option would ensure that all patients in Greater Nottingham have GF products prescribed in line with the same guidance and will provide equitable provision for patients and clarity for prescribers. It will bring Nottingham City CCG prescribing in line with the other CCGs.
- All patients will be able to access a defined quantity of GF bread and flour to support their adherence to a GF diet
- Prescribing cost efficiencies of approximately £65K could be realised

#### **Risks**

- Patients at risk of developing signs and symptoms of gluten intolerance and subsequently potential serious complication, leading to a pull on primary and secondary care resources should they not be able to afford additional GF products to supplement the prescribed volume. Impact for patients with protected characteristics – please see EQIA (Appendix 1) for more information.
- This option is not in line with the recommendations from the national consultation and could generate considerable public and media interest, which may involve significant resource to manage and may have a detrimental CCG organisational reputational impact.

**Option 2:** All Greater Nottingham CCGs to stop all gluten free prescribing, with the exception of children, who will be able to receive up to four units of long life bread and flour per month

#### **Benefits**

- This option would ensure that all children in Greater Nottingham have GF products prescribed in line with the same guidance and will provide equity for these patients and clarity for prescribers.
- Children will be able to access a defined quantity of GF bread and flour to support their adherence to a GF diet. Information provided through the national consultation stated that the lack of adherence to a GF diet could impact on the growth rate of children, delay puberty and make them susceptible to other auto immune conditions.
- Prescribing cost efficiencies would be realised.

#### **Risks**

- Adult patients at risk of developing signs and symptoms of gluten intolerance and subsequently potential serious complication, leading to a pull on primary and secondary care resources should they not be able to afford GF products.
- This option is not in line with the recommendations from the national consultation and may generate considerable public and media interest, which may involve significant

resource to manage and may have a detrimental CCG organisational reputational impact.

**Option 3:** All Greater Nottingham CCGs to stop all gluten free prescribing

Benefits

- Prescribing cost efficiencies of approximately £156K could be realised

Risks

- Patients at risk of developing signs and symptoms of gluten intolerance and subsequently potential serious complication, leading to a pull on primary and secondary care resources should they not be able to afford GF products.
- This option is not in line with the recommendations from the national consultation and could have a detrimental reputational impact.
- Possible legal challenge - as part of the consultation process across the three south CCGs, legal advice was sought and the recommendation was not to stop all prescribing of GF products on prescription. This was based on patient access and GPs and CCGs responsibility to provide patients with adequate products/medication to prevent harm.
- Impact on patients with certain protected characteristics – please see EQIA (Appendix 1) for more information.

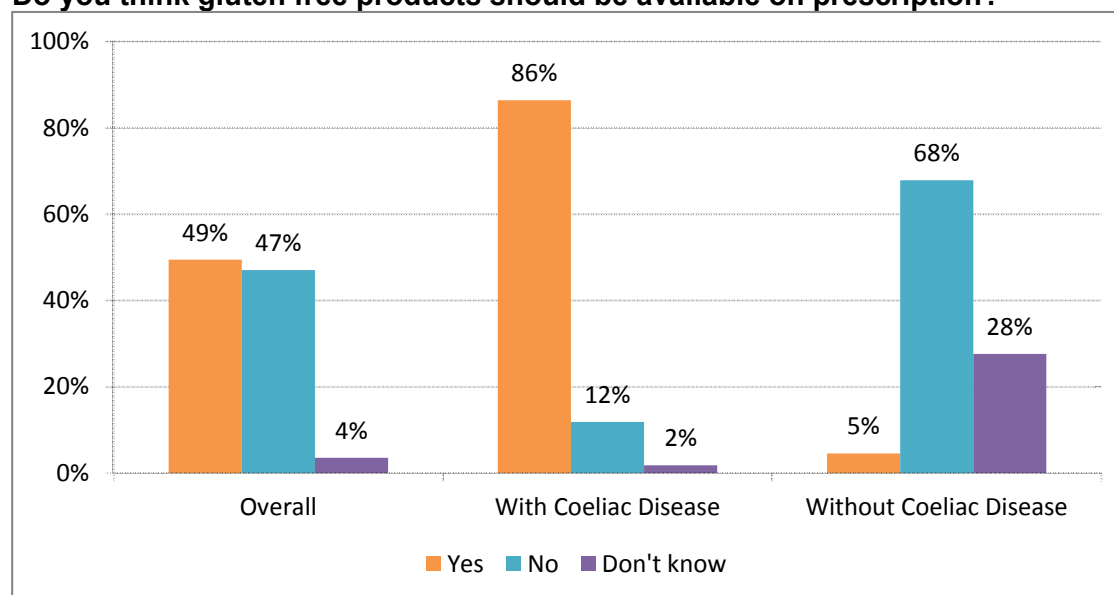
#### **4. Public Consultation**

The results from the public consultation on the options outlined above are given in Appendix 2. There were 462 responses to the consultation. 169 responses were from people who have diagnosed coeliac disease/ dermatitis herpetiformis, or who are caring for or responding on behalf of people who have diagnosed coeliac disease/ dermatitis herpetiformis.

Overall, the outcome of the consultation is that the option to 'limit to 4 units' (option 1 above) is the preferred choice when the responses of people with coeliac disease and those without were combined.

However, 49% of respondents chose this option, and 47% said that GF items should not be available on prescription; this is illustrated below:

## Do you think gluten free products should be available on prescription?



## 5. Recommendation

This scheme was considered at the Clinical Commissioning Executive Group (CCEG) on 19 September 2018. The following were considered in reaching a recommendation for JCC:

- The outcome of the consultation which identified that whilst 86% of respondents with Coeliac Disease supported continued prescribing when all responses are considered the results are marginal (49% in favour and 47% not).
- It was noted that the Mid Nottinghamshire CCGs have already stopped GF prescribing. Greater Nottingham recognise the importance of consistency in care across Nottinghamshire.
- Equity in relation to other conditions e.g. diabetic foods are not provided on prescription.
- The clinical risk for patients with coeliac disease/ dermatitis herpetiformis not following a GF diet was noted.
- It is possible to have a healthy balanced diet without having gluten containing foods or gluten free alternatives.
- Gluten free foods are more widely available and whilst still more expensive have reduced in cost.
- The EQIA was considered in particular the increased impact on people with low incomes was acknowledged.
- The current financial position was noted.

Following consideration of the above factors the recommendation is to stop prescribing of GF products for all patients in Greater Nottingham.

The Joint Commissioning Committee reviewed and approved the recommendation to stop all prescribing of GF products in Greater Nottingham at their meeting on 26th September.

Greater Nottingham will support the implementation with a robust communications plan to ensure that patients who are currently receiving gluten free foods on prescription are notified of the change. The CCGs are liaising with local Dietitians to ensure that nutritional information can be provided to patients. The impact on patients will be monitored as part of the implementation.

Name of Report Author: Cheryl Gresham  
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E-mail: [c.gresham@nhs.net](mailto:c.gresham@nhs.net)  
26 September 2018



**9 October 2018****Agenda Item: 8****REPORT OF THE CHAIRMAN OF HEALTH SCRUTINY COMMITTEE****REVIEW OF HEALTH SCRUTINY WORK PROGRAMME 2017-2018****Purpose of the Report**

1. To introduce a look back at some of the work of the Health Scrutiny Committee during 2017 and 2018.

**Information**

2. There are broadly two types of item contained within the Health Scrutiny Committee work programme. Firstly, issues which are of direct concern to Members and their constituents and appear on the agenda at Members' request. Secondly, issues brought to the attention of the Chair of the Health Scrutiny Committee by the NHS. These typically involve changes to NHS services and may include substantial variations and developments of service. The role of the committee is to hold the NHS to account and ensure that changes that are being undertaken are in the interest of the local health service and have been properly consulted on.

**IN-VITRO FERTILISATION**

3. In 2017, Health Scrutiny Members registered severe concerns about changes to criteria for In-Vitro Fertilisation (Newark and Sherwood/Mansfield and Ashfield) how they had been consulted on. The reduction in age criteria for women – from 42 years maximum down to 34 - seemed unfair and created a 'post code lottery' as compared to other Clinical Commissioning Group areas. In addition, Members did not feel that the specific proposal to be implemented had been properly consulted on since it had emerged as a 'hybrid option.' The commissioners actually consulted on reducing the age range to 40. The Health Scrutiny Committee invited the commissioners to think again about this change to health services, and ultimately it was not implemented. Not only does this represent a positive outcome for patients, it also serves to demonstrate that the Health Scrutiny Committee is properly holding commissioners to account regarding consultation.

**PAEDIATRIC ADMISSIONS AT BASSETLAW HOSPITAL (A3)**

4. In January 2017, Bassetlaw Hospital closed its Paediatric Ward A3 to admissions at night due to national shortages of paediatric staff for safety reasons. This resulted in an enhanced assessment service during the day and inpatient paediatric care at Doncaster Royal Infirmary or Sheffield Children's Hospital. This arrangement was, and continues to be, of concern to Health Scrutiny Members because of the resulting additional travel which must

now be undertaken by patients and their families. This variation of service continues to be monitored by the Health Scrutiny Committee.

### **CHATSWORTH WARD NEURO-REHABILITATION**

5. In October 2017, Sherwood Forest Hospitals NHS Foundation Trust declared an intention to withdraw from the provision of specialised neuro-rehabilitation at Chatsworth Ward. This was due to reasons of clinical sustainability, and again, was not due to financial factors but reflected difficulties in recruiting clinical staff. This matter was also subject to ongoing monitoring by the Health Scrutiny Committee. In July 2018, the Health Scrutiny Committee heard that the CCG's governing body supported the business case to commission guaranteed Neuro rehabilitation beds on the current Chatsworth Ward as well as to provide a community neuro rehabilitation service for patients in mid Nottinghamshire. Further work is now taking place with prospective providers regarding this service.

### **WINTER PLANS**

6. The Health Scrutiny Committee takes a strong interest in winter planning issues. Bassetlaw Hospital attended in November 2017 to brief Members on their winter plan.

### **SUICIDE PREVENTION PLANS**

7. Further to a request from the House of Commons Health Select Committee, in early 2018 the committee received a briefing from the Director of Public Health on arrangements for suicide prevention in Nottinghamshire. This resulted in Members receiving a briefing on suicide prevention in Rampton Hospital from Dr John Wallace, Clinical Director, and then undertaking a visit to Rampton Hospital. As part of its developing focus on outcomes from CQC inspections, the committee will also be examining Rampton Hospital's improvement plan.

### **GP FORWARD VIEW - NOTTINGHAMSHIRE**

8. In April, the Health Scrutiny Committee held a special meeting solely devoted to examining the General Practice Forward View which commits an extra £2.4 billion a year to support general practice services by 2020/21. The purpose of this additional funding is to improve patient care and access.

### **NOTTINGHAM TREATMENT CENTRE PROCUREMENT**

9. Since the re-procurement of services can result in disruption of services, the Health Scrutiny Committee has taken a strong interest in the re-procurement of the Nottingham Treatment Centre, where a range of different services are currently provided by Circle. The delivery of services at the Treatment Centre is subject to ongoing monitoring. In addition, Health Scrutiny Members have a standing invitation from Circle to observe an operation taking place.

## **FARNSFIELD GP PRACTICE**

10. Councillor Laughton, the local Member for Muskham and Farnsfield, raised concerns about access to services at the general practice in Farnsfield. Councillor Laughton was able to raise the issue at March 2018's Health Scrutiny when the committee considered GP access in Mansfield and Ashfield and Newark and Sherwood. Councillor Laughton has indicated that the Health Scrutiny Committee was pivotal in providing the impetus for improvement and the development of a plan of action. In particular the committee provided a platform which enabled the Councillor to explain what was happening in this community and raise the issues directly with the commissioners. Further to the meeting over 400 residents participated in an engagement exercise – which while recognising that there is still room for improvement also allowed residents to praise doctors for their professionalism and the care they provide.

## **ASHFIELD HOMESTART**

11. Further to the decommissioning of Ashfield Homestart services in 2017, in March 2018 the Health Scrutiny Committee asked Mansfield and Ashfield/Newark and Sherwood CCG and its partners to undertake a review of the decision, properly informed by the impact of the loss of the service on the families concerned. Members were very unhappy at the decommissioning of the service and felt that there had been a fundamental misjudgment about the importance of this service.

## **SHORTAGE OF HEAD AND NECK CANCER SERVICES**

12. In June, after Members had been briefed by commissioners and the provider (NUH) on the shortage of clinical staff which had led to patients living outside the Nottingham City boundary having to be transported to other areas (e.g. Derby, Leicester and Sherwood Forest), the Health Scrutiny Committee registered strong concerns about the rationale behind this decision – i.e. levels of deprivation. Commissioners are seeking to address the shortage of staff across the East Midlands region, and once proposals are developed they will feature on the agenda of the Health Scrutiny Committee in the usual way.

## **RECOMMENDATION**

That the Health Scrutiny Committee:

- 1) Considers and comments on the information provided.

**Councillor Keith Girling**  
**Chairman of Health Scrutiny Committee**

**For any enquiries about this report please contact: Martin Gately – 0115 977 2826**

## **Background Papers**

Nil

**Electoral Division(s) and Member(s) Affected**

All

**9 October 2018****Agenda Item: 9**

## **REPORT OF THE CHAIRMAN OF HEALTH SCRUTINY COMMITTEE**

### **WORK PROGRAMME**

#### **Purpose of the Report**

1. To consider the Health Scrutiny Committee's work programme.

#### **Information**

2. The Health Scrutiny Committee is responsible for scrutinising substantial variations and developments of service made by NHS organisations, and reviewing other issues impacting on services provided by trusts which are accessed by County residents.
3. The work programme is attached at Appendix 1 for the Committee to consider, amend if necessary, and agree.
4. The work programme of the Committee continues to be developed. Emerging health service changes (such as substantial variations and developments of service) will be included as they arise.
5. Members may also wish to suggest and consider subjects which might be appropriate for scrutiny review by way of a study group or for inclusion on the agenda of the committee.

#### **RECOMMENDATION**

That the Health Scrutiny Committee:

- 1) Considers and agrees the content of the draft work programme.
- 2) Suggests and considers possible subjects for review.

**Councillor Keith Girling**  
**Chairman of Health Scrutiny Committee**

**For any enquiries about this report please contact: Martin Gately – 0115 977 2826**

**Background Papers**

Nil

**Electoral Division(s) and Member(s) Affected**

All

## HEALTH SCRUTINY COMMITTEE DRAFT WORK PROGRAMME 2018/19

Subject Title	Brief Summary of agenda item	Scrutiny/Briefing/Update	Lead Officer	External Contact/Organisation
<b>08 May 2018</b>				
Bassetlaw Children's Ward	Further consideration.	Scrutiny	Martin Gately	Richard Parker, Chief Executive DBH
Suicide and Self-Harm prevention – Rampton Hospital	An initial briefing on suicide and self-harm prevention at Rampton Hospital as part of the committee's ongoing look at suicide prevention.	Scrutiny	Martin Gately	Dr John Wallace, Clinical Director, Rampton Hospital (Nottinghamshire Healthcare Trust)
<b>19 June 2018</b>				
Ashfield Homestart	Examination of the decommissioning of the Ashfield Homestart Service	Scrutiny	Martin Gately	Dr Amanda Sullivan, Chief Officer, Mansfield and Ashfield CCG
Shortage of capacity – Head and Neck Cancer Service	Examination of the decision to direct Nottinghamshire patients to out of county services due to the shortage of capacity	Scrutiny	Martin Gately	Dr Keith Girling, NUH Medical Director
Circle	Briefing on the services provided by Circle and how Circle fits within the wider health service (and STP governance structure)	Scrutiny	Martin Gately	Claire Probert, Service Transformation Manager
<b>24 July 2018</b>				
Chatsworth Neuro-rehab Ward	Consideration of final proposals	Scrutiny	Martin Gately	Dr Amanda Sullivan, Sherwood Forest CCG
Gluten Free prescribing consultation and other	Consideration of consultation and initial evidence gathering on	Scrutiny	Martin Gately	Greater Notts CCG (TBC)

prescribing restrictions	prescribing restriction issues.			
East Midlands Ambulance Service Transformation Plans	Continuing examination of EMAS improvement plans.	Scrutiny	Martin Gately	EMAS
Treatment Centre Procurement Update	An update on the latest position with commissioning/procurement of Nottingham Treatment Centre	Scrutiny	Martin Gately	Greater Nottingham CCG representatives
<b>09 October 2018</b>				
Dementia in Hospital	Initial briefing/commencement of a review	Scrutiny	Martin Gately	TBC
Rampton Hospital – Improvement Plan following CQC inspection	Further to the recent CQC inspection, an examination of progress against the improvement plan.	Scrutiny	Martin Gately	Dr John Wallace, Clinical Director, Rampton Hospital
Gluten Free Proposals	Consideration of the proposals for gluten free prescribing	Scrutiny	Martin Gately	Hazel Buchanan, Cheryl Gresham/Toni Smith
NUH Winter Plans & A&E Modernisation	An examination of winter plans and changes to the ‘front door’ of A&E.	Scrutiny	Martin Gately	Dr Keith Girling TBC
Review of Health Scrutiny Work Programme 2017/18	A summary of the issues examined by the Health Scrutiny Committee in the last municipal year.	Scrutiny	Martin Gately	None
<b>20 November 2018</b>				
Food and Nutrition in Hospitals (Sherwood Forest Hospital and NUH)	An initial briefing on nutritional standards, including hydration.	Scrutiny	Martin Gately	Sherwood Forest Hospitals/NUH TBC
Dental Services	An initial briefing on dental services.	Scrutiny	Martin Gately	Greater Nottingham CCG
Nottinghamshire Healthcare Trust Services	An initial briefing on mental health services within Nottinghamshire	Scrutiny	Martin Gately	Senior Officer (TBC) Nottinghamshire Healthcare Trust
Child and Adolescent Mental	An initial briefing on mental health	Scrutiny	Martin	Nottinghamshire



Health Service (CAMHS)	services for children and young people		Gately	Healthcare Trust TBC
East Midlands Ambulance Service Transformation Plans and Performance	Further consideration	Scrutiny	Martin Gately	TBC
<b>08 January 2019</b>				
Rampton Hospital – Improvement Plan following CQC Inspection	A further update on progress against the improvement plan following the CQC inspection.	Scrutiny	Martin Gately	Dr John Wallace, Clinical Director, Rampton Hospital
Treatment Centre Procurement Update	A further update on procurement of services at the Nottingham Treatment Centre	Scrutiny	Martin Gately	Greater Nottingham CCG
Bassetlaw Children's Ward – Update (TBC)	Update on the current position regarding overnight closure of the Children's Ward at Bassetlaw Hospital.	Scrutiny	Martin Gately	Doncaster & Bassetlaw Hospital
<b>12 February 2019</b>				
Public Health (TBC)	Overview of the work being undertaken by the Public Health Dept.	Scrutiny	Martin Gately	Jonathan Gribbin, Director of Public Health
<b>07 May 2019</b>				
<b>18 June 2019</b>				
<b>23 July 2019</b>				
		Scrutiny	Martin Gately	
		Scrutiny	Martin Gately	
		Scrutiny	Martin Gately	

		Scrutiny	Martin Gately	
Dementia in Hospital	Initial briefing/commencement of a review	Scrutiny	Martin Gately	TBC
NUH Maternity Services	Initial Briefing	Scrutiny	Martin Gately	TBC
EMAS Transformation Plans	Continuing examination of EMAS improvement plans	Scrutiny	Martin Gately	Richard Henderson, Chief Exec.
<b>To be scheduled</b>				
Hospital Transport/Arriva				
Hospital Car Park Charging				
Social Prescribing				
Healthwatch				

### **Potential Topics for Scrutiny:**

CCG Finances

Recruitment (especially GPs)

Muscular Dystrophy

**Overview Sessions** (To be confirmed)

Nottinghamshire Healthcare Trust – autumn (TBC)

Nottingham University Hospitals (NUH) – autumn

### **VISITS**

Medium secure mental hospitals - TBC

Sherwood Forest Hospitals Trust - AutumnTBC

