



Gluten free prescribing consultation report

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 herpeitformis. 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: <u>www.nottinghamnortheastccg.nhs.uk/delivering-as-a-ccg/delivering-</u> <u>engagement/engagement-and-consultations/gluten-free/</u>

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 <u>document</u> 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
- 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

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 dropin 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 <u>drop in events</u> 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 of 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

Greater Nottingham Clinical Commissioning Partnership



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 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...

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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