

## Paracetamol and Gluten Free Prescription Survey Findings Report

August 2016

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# 1. Overview

Overall, 821 surveys were completed from local people across Leicester, Leicestershire and Rutland (LLR) and from this total not all respondents completed every survey question.

The survey comprised of 20 questions. There were no compulsory fields in the survey, which meant that respondents could answer or skip questions.

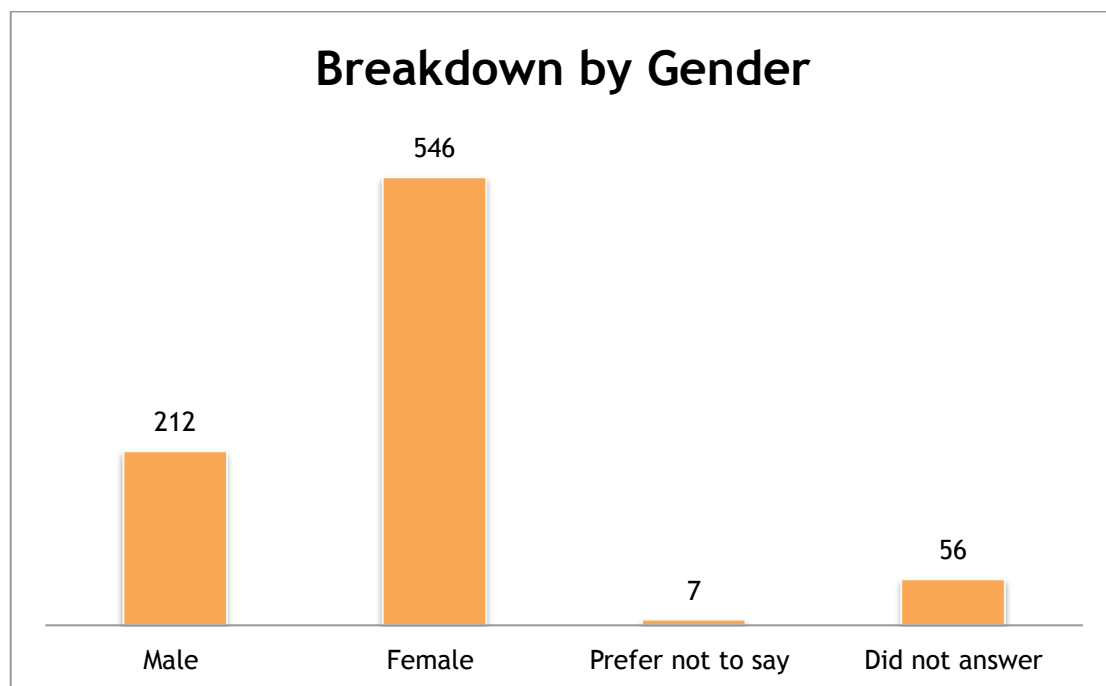
Seven of the questions were free text box questions requiring the respondent to provide a qualitative answer.

Two of the questions were multiple choice with an ‘other’ option which than required a qualitative comment.

In total, the survey received 2355 qualitative comments. In this report we present emerging themes from the feedback received however it has not been possible within the time constraints to analyse all comments in detail.

The majority of respondents were between the ages of 36-55 (284) and 66-75 (169) and more female 71% (546) than male 28% (212) respondents completed the survey (see figure 1). A small number (56) did not answer this question with a further 7 (1%) who preferred not to say.

**Figure 1.**



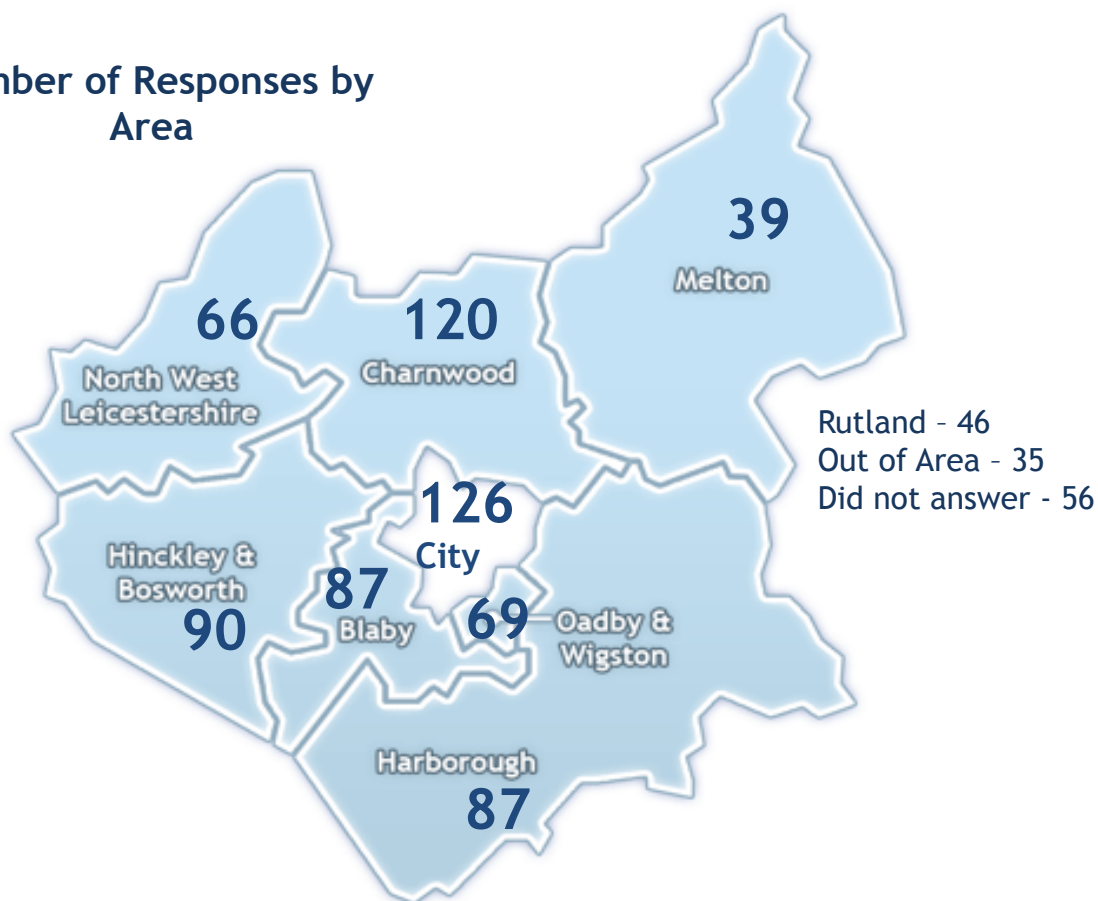
The survey has attracted a wide range of people from across the local geographical area taking the survey as shown in Figure 2.

Breakdown of responses were from residents of:

Leicestershire	558 (73%)
Leicester City	126 (16%)
Rutland	46 (6%)
Out of area	35 (5%)
Did not answer	56

Figure 2.

### Number of Responses by Area



Our analysis has identified that there are no distinctive differences from respondents living in Leicester City, Leicestershire or Rutland. In the qualitative comments we give examples reflective of all three areas.

## 2. Methodology

### Survey Scope

In June 2016 Healthwatch Leicestershire (HWL) created an online survey tool using the questions provided by the Clinical Commissioning Groups (CCGs) in order to gather the views of local people with regards to potential changes to prescriptions.

The survey provided respondents with an opportunity to share how much they would be affected by changes in prescription to paracetamol and gluten free products. They were also given the opportunity to provide in-depth qualitative comments. In this report we present emerging themes some, which span across both the paracetamol and gluten free section.

The survey was divided into three sections:

- Question relating to paracetamol,
- Questions relating to gluten free foods and
- Questions relating to demographics.

Prior to the launch of the survey, HWL shared a test link with West Leicestershire CCG and invited feedback on the questions, the format, clarity and tone of the survey. This testing and sense check was important to ensure good take up of the survey.

The survey opened on 17 June 2016 and closed on 13 July 2016.

### Communications and Marketing

In order to promote the survey to a broad range of audiences, HWL invited neighbouring Healthwatch to cross promote the survey.

We also maintained a record of communication channels (targeted emails, press releases and media, website promotion, mailshots to specialist networks and cascading via GP practices) by various stakeholders.

We recorded the following channels that contributed to the unprecedented high numbers of respondents taking part in the survey:

#### Healthwatch Leicestershire

- HWL website
- HWL e-news sent out on 16 June 2016 to approximately 1700 subscribers
- HWL twitter account to 897 followers

#### West Leicestershire CCG

- WLCCG issued a press release and promoted on website
- WLCCG sent the survey out to their membership across LLR

- WLCCG sent survey to all GP practices and requested it to be forwarded on to all coeliac patients who have email. A poster was also put up in their practices.

#### East Leicestershire and Rutland CCG

- ELRCCG website

#### Healthwatch Rutland

- HW Rutland June 2016 newsletter

#### Leicester City CCG

- LCCCG website

#### Healthwatch Leicester City

- HW Leicester City Weekly News Update to members on 21 June 2016

#### Coeliac UK

- Coeliac Society wrote a letter to all their members across LLR requesting them to fill in the survey

#### Local Media

- Leicester Mercury <http://www.leicesterm Mercury.co.uk/treatments-may-soon-be-black-listed/story-29427297-detail/story.html>

## Direct contact

We received a small number of postal surveys and telephone calls relating to the survey. These have been included in the report.

We are aware that the CCGs also had a number of telephone callers that were concerned about the potential changes suggested by the survey. This report does not include these comments.

### 3. Background, Local and National Context

In this section of the report we present the background and context of the survey.

The three Clinical Commissioning Groups (CCGs) in the LLR area, who plan and pay for local services and medications, want to investigate ways that they can reduce the amount that they spend on prescribing items which are also freely available to buy in supermarkets and community pharmacies, such as paracetamol and gluten free food staples.

To help the CCGs understand the effect that reducing or stopping the prescription of some, or all of these items will have on people, a survey was designed inviting feedback on how patients and the public would be affected by any changes to how these items are prescribed.

#### Paracetamol

HWL research shows that according to The Medicines Act 1968 paracetamol can be sold by a wide range of shops, such as newsagents, convenience stores and petrol stations.<sup>1</sup> The largest pack size of paracetamol that shops without a pharmacist can sell is 16 tablets, however pharmacies can sell packs of 32 tablets. Pharmacists can also provide up to 100 tablets at their discretion for patients with chronic conditions, however for greater amounts of paracetamol a GP prescription is required.<sup>2</sup>

In January 2016, WLCCG decided to review the current position of prescribing paracetamol and said that they will engage with the public in the near future to hear their views.<sup>3</sup>

The NHS spent approximately £1.5 million pounds on prescribing paracetamol to patients in Leicester, Leicestershire and Rutland in 2015/16. Some of the prescriptions were for people with conditions, which could have got better on their own such as sore throats or headaches.

This survey states that paracetamol on prescription costs up to four times more than if it was bought over the counter in pharmacies or supermarkets. Paracetamol can be purchased for as little as 19p for a pack of 16 tablets in some supermarkets.<sup>4</sup>

#### Gluten Free foods

Currently the NHS in Leicester, Leicestershire and Rutland provide £700,000 worth of gluten-free food on prescriptions each year. In 2014, the NHS bill for gluten-free foods provided on prescription nationally was £26.8 million.<sup>5</sup> The majority of this spend was on bread and flour.

According to Coeliac UK, if an individual is diagnosed with coeliac disease they can receive gluten-free staple foods via prescription from their GP. Only gluten-free foods, which have been approved by the Advisory Committee on Borderline Substances, can be prescribed.<sup>6</sup>

Coeliac disease is a long-term autoimmune condition, where the immune system mistakenly attacks healthy tissue. The immune system mistakes substances found inside gluten as a threat to the body and attacks them, which damages the surface of the small bowel, disrupting the body's ability to absorb nutrients from food.<sup>7</sup>

Symptoms can range from mild to severe and can include bloating, diarrhoea, nausea, weight loss, headaches and osteoporosis, tiredness, hair loss and anaemia. These symptoms do not occur in all cases.<sup>8</sup>

Also, according to figures by Coeliac UK, 1 in 100 people have coeliac disease however only 24% of those who have the condition have been diagnosed. If a first-degree family member has the condition the chances increase to 1 in 10.<sup>9</sup>

Dermatitis herpetiformis is a skin condition associated with coeliac disease and gluten intolerance, which occurs as an itchy skin rash that commonly appears on the elbows, knees and buttocks. This affects around one in 3,300 people.<sup>10</sup>

Coeliac disease and dermatitis herpetiformis is usually treated by excluding foods, which contain gluten. All sources of gluten must be given up for life from a Coeliacs diet in order to prevent long-term damage to their health.

Historically the availability of gluten free foods was low and therefore the foods were made available from local pharmacies via prescriptions. With an increased awareness of coeliac disease and gluten intolerance gluten free foods are now more accessible in local shops and supermarkets.<sup>11</sup>

In order to maximise NHS budgets and ensure fair use of resources for all patients, the CCGs are looking at ways to make potential savings.



## 4. Main findings

In this section of the report, we present the main findings and an analysis of what respondents told us and how they will be affected of the potential changes to the prescription of paracetamol and gluten free products.

### Paracetamol and other medicines

Respondents were asked “Are you currently or have you ever been in receipt of paracetamol on prescription?” Over a quarter of respondents 26% (193) currently receive or have previously been in receipt of paracetamol on prescription. 74% (551) respondents have never received paracetamol on prescription. 76 respondents did not answer this question.

**Table 1. Responses from those currently receiving or have previously received paracetamol on prescription.**

If paracetamol was no longer available on prescription...how much would it affect you?	Not at all	It would affect me a little	It would affect me a lot
For self-limiting illnesses	80 (42%)	50 (26%)	62 (32%)
In liquid form	162 (86%)	16 (8%)	11 (6%)
For people who only need it now and again	101 (55%)	34 (19%)	47 (26%)
Other medicines on prescription (co-codamol, ibuprofen, anti-histamines)	75 (41%)	52 (28%)	57 (31%)

The above table shows that respondents who currently receive paracetamol on prescription are more likely to be affected if it was no longer available for self-limiting illnesses, for those who need it now and again and if other medicines were no longer prescribed. The majority however would not be affected at all if Calpol or paracetamol in liquid form was no longer available.

Table 2. Responses from those who do not and never have received paracetamol on prescription			
If paracetamol was no longer available on prescription for...	Not at all	It would affect me a little	It would affect me a lot
Self-limiting illnesses	507 (93%)	30 (6%)	7 (1%)
Liquid form	488 (92%)	24 (5%)	17 (3%)
People who only need it now and again	474 (90%)	45 (9%)	6 (1%)
Other medicines on prescription (co-codamol, ibuprofen, anti-histamines)	359 (68%)	104 (20%)	63 (12%)

The overwhelming majority of respondents answered that they would not be affected at all if paracetamol for self-limiting illnesses, paracetamol in liquid form and for those who only need it now and again was no longer available on prescription. This was also the case for other medicines such as co-codamol, ibuprofen and anti-histamines being prescribed.

Respondents explained that because paracetamol can be bought at low cost in the shops and supermarkets that the NHS should stop prescribing paracetamol.

Some Respondents also said that because it is ‘*so cheap*’ they buy it from the shops as and when needed.

Below are the reasons provided by respondents who said they would be affected a little or a lot from Tables 1 and 2. In total there were 386 qualitative comments, which were analysed and grouped into 4 main areas:

- The cost of buying paracetamol, Calpol and other medicines over the counter would be too much
- Some individuals use paracetamol and other medicines for long term conditions and need it for pain management
- Cannot buy paracetamol in large quantities
- Strength of prescribed paracetamol/ medicines is stronger from GP

## Qualitative feedback - Paracetamol and other medicines

This section of the report presents a selection of qualitative comments on how respondents may be affected by any changes to prescriptions. We present the emerging themes from the qualitative comments under each question. The question is denoted in a box before each section.

### **Paracetamol tablets**

*If paracetamol was no longer available on prescription for self-limiting illnesses such as headaches, migraines, sore throat and aches and pains how much would it affect you? Please let us know any detail about this change would affect you.*

There were a total of 171 qualitative comments provided for the above question, 650 respondents skipped the question. Below are some examples that reflect the concerns people have expressed which were identified previously.

### **Cost can be prohibitive**

*"I have free prescriptions, so would have to pay for paracetamol; which I take regularly. Apart from the cost, I have a small pension I am only able to purchase a small amount, which would mean having to go to the shops more often. I do not have any local shops I can get to easily." (66-75, Female, North West Leicestershire)*

*"I am now retired with a fixed income and the additional/ increasing costs would affect me, much more so than people who are working." (Male, 66-75, Blaby)*

*"I have had Paramax and paracetamol as regular pain killers whilst on State Benefit and the extra cost would be noticed as money is tight." (Female, 66-75, Leicester City)*

*"I would be in a great deal of pain due my conditions. I can't work and not able to claim help with medical costs hence I was bought a one-year medical certificate for Christmas. I would more then likely with having this removed probably end up doing away with myself as I need this medication and have no spare money at all to buy anything the Drs won't prescribe as they are not allowed to give me." (36-55, Harborough)*

*"Having two children who qualify for NHS prescriptions, if they were to become ill and require paracetamol then it would have financial implications for me, when at present it does not - other than my tax contributions towards to cost of the NHS." (Male, 36-55, Charnwood)*

## Medication vital to support Pain management

*"I am on long-term pain relief for injuries from a car crash & an industrial accident. I'm on a maximum dose of paracetamol & a cocktail of other painkillers. As I'm a pensioner, on a fixed income & in receipt of free prescriptions it would be a modest but long-term increase in my expenses." (66-75, Male, Hinckley & Bosworth)*

*"My daughter takes Paracetamol nearly everyday for her illness. Having to buy this would cost a lot." (36-55, Female, North West Leicestershire)*

*"I have an HC2 certificate & use paracetamol for pain relief for osteoarthritis I get it on prescription so every little way of reducing my costs makes a massive difference as I am on a low income." (Female, 36-55, Harborough)*

*"If not taking paracetamol the pain would become unbearable and would have to revert to stronger pain management meds." (Unknown)*

*"I suffer from fibromyalgia and polymyalgia rheumatica. The only painkiller I can take is paracetamol. I have to take the full dose of 8 a day to help my symptoms. 56 a week." (Unknown)*

*"Due to sciatica to reduce the pain I live on paracetamol with tramadol 4 times a day for pain management. Also need it to reduces my arthritis pain." (Female, 56-65, Leicester City)*

## Quantity based on need

*"Can't buy in a large enough quantity." (56-65, Male, Charnwood)*

*"Restrictions on amount of tablets individuals can purchase." (56-65, Male, Hinckley and Bosworth)*

*"The packs available to buy only contain a limited number of tablets. It would mean several visits to several shops to buy the amount I require per month and the costs would add up for a pensioner." (56-65, Female, Hinckley and Bosworth)*

*"I would prefer to pay the cost but buy larger quantity, currently limited to buying packet of 16." (Female, 56-65, Hinckley and Bosworth)*

*"You can only buy 2 packs of 16 from any one shop and I cannot always get to shops, which would make things very difficult for me." (Unknown)*

*"It would not affect me at all. Furthermore, it is difficult to justify an NHS prescription for small quantities of mild painkillers. However, retailers are not allowed to sell more than 32 paracetamol tablets at a time, so an exception should be made for anyone whose GP considers long term usage is necessary." (Female, 66-75, Blaby)*

*"I have rheumatoid arthritis and take 100mg tramadol twice a day with paracetamol, or even three times as this helps to boost the painkillers This would mean that I would have to go to the chemist every week (as you can only get 32 tablets). This would mean if I cannot go somebody else would have to get them for me." (Female, 56-65, Blaby)*

*"I don't mind paying for paracetamol but it would be helpful if I could buy a larger quantity at a time rather than the small amount allowed. At times when my arthritis is extremely painful I need more medication." (Female, 66-75, Blaby)*

*"I have a life long condition which causes constant chronic pain but also causes multiple dislocations daily and have limited mobility, and so need medication in larger quantities, as I am unable to make journeys to the supermarket every couple of days to purchase in restricted quantities." (Female, 18-35, Leicester City)*

*"I am prescribed paracetamol for the relief of arthritic and neuropathy pain. I take these on a regular basis and have had to do this for years. I am well aware that paracetamol is widely available to buy over the counter, but you are only allowed to buy a minimum number of tablets with each purchase. I am prescribed 100 at a time so to get this amount I would have to visit the chemist or supermarket numerous times. I am elderly and have other problems with mobility etc. However I do understand the need to reduce the amount spent on drugs by the NHS for medication that can be bought more cheaply over the counter." (Female, 75+, Harborough)*

### **Lower strength is counter productive**

*"If I was in a lot of pain and I had a fever the paracetamol that you can buy over the counter doesn't seem as good as the ones the doctor has prescribed for me." (Female, 56-65, Harborough)*

*"The strong dose is not available over counter." (Male, 66-75)*

*"Never found over the counter tablets effective on any type of pain." (Male, 56-65, Leicester City)*

*"The cheap ones from supermarkets have a different make up and are less easy to digest than the ones on prescription." (Prefer not to say, 36-55, Leicester City)*

### **Purchase own paracetamol**

*"It would not. If I need paracetamol even if advised by my GP I buy it for myself and my children." (36-55, Female, Melton)*

*"I can afford to pay for paracetamol and would be happy to do so." (75+, Female, Harborough)*

*"Like most people, I keep some in my medicine cabinet, along with thermometer, cough syrup and other things that may be needed. As long as the expiry date is*

*checked occasionally, most things are there if/ when I need them.” (56-65, Female, Leicester City)*

*“Only had it prescribed as part of a hospital discharge. It's 16p in the shops- no one should need that prescribing!” (36-55, Female, Rutland)*

*“I am able to buy this at the supermarket very cheaply.” (Female, 36-55, Harborough)*

*“I'd just buy it myself. It's only 19p in asda!” (Female, 36-55, Blaby)*

#### **Paracetamol in liquid form**

***Paracetamol is also sold over the counter in liquid form for example under the brand name Calpol and used for children to help with teething and fever.***

***If paracetamol in liquid form was no longer available on prescription how much would it affect you? Please let us know any detail about this change would affect you.***

There were a total of 100 qualitative comments provided for the above question, 720 respondents skipped it. Below are some examples that reflect the concerns people have expressed which were identified previously.

#### **Cost can be prohibitive**

*“My children need it regularly and the prices in supermarkets are pricey. Especially for good brands.” (36-55, Female, Harborough)*

*“My family's medical and financial circumstances are difficult and we have purchased pre-payment prescription certificates. Having to get these drugs on top of having to pay for the annual certificate would make our circumstances more difficult.” (36-55, Male, Blaby)*

*“Having two children who qualify for NHS prescriptions, if they were to become ill and require paracetamol then it would have financial implications for me, when at present it does not - other than my tax contributions towards to cost of the NHS.” (36-55, Male, Charnwood)*

*“I don't see why the NHS should pay a premium for a brand name. It would concern me however if parents with inadequate incomes would have to let their children suffer pain or use an excessive dose of the cheaper adult product on account of the cost.” (Male, 66-75, Oadby and Wigston)*

*“I am concerned about the cost of liquid paracetamol for children of poor families who would be eligible for free prescriptions.” (Female, 56-65, Leicester City)*

*“Have needed paediatric suspension, as an adult, due to swallowing difficulties after gastric surgery and the cost to purchase this in the volume required would be extortionate.” (Female, 36-55, North West Leicestershire)*

*“In a liquid form it is expensive for children, as they need it more frequently. If they were to lesser the costs then it may be more affordable for some families.” (Female, 36-55, North West Leicestershire)*

## **Long-term conditions**

*“My son has Downs Syndrome and finds it impossible to swallow medicine in tablet form.” (36-55, Female, Leicester City)*

*“My daughter also has the same chronic condition and suffers with multiple dislocations daily and often cries due to her pain. She is unable to swallow tablet medication so needs it in liquid form. Also she reacts to most of the over the counter ones and is unable to tolerate ibuprofen due to gastro issues.” (Female, 18-35, Leicester City)*

*“Have needed paediatric suspension, as an adult, due to swallowing difficulties after gastric surgery and the cost to purchase this in the volume required would be extortionate” (Female, 36-55, North West Leicestershire)*

## **Happy to purchase it over the counter**

**26 respondents provided supportive comments about buying calpol over the counter.**

*“If my children need paracetamol liquid I buy it rather than expect my GP to provide it.” (36-55, Female, Melton)*

*“If I need it for my Son I buy it.” (Female, 18-35, Charnwood)*

*“I have never received calpol or equivalent on prescription, buying it over the counter when needed.” (Female, 36-55, Charnwood)*

*“I have two children under 6 years old and Calpol has never been offered by a GP on prescription, we have always had to buy it.” (Female, 36-55, Charnwood)*

*“I would continue to be happy to buy it for my children.” (Male, 36-55, Melton)*

*“Items like this should not be on prescription at all. You can buy generic paracetamol liquid if you ask at the pharmacy which is much cheaper than Calpol.” (Female, 66-75, Hinckley and Bosworth)*



**Paracetamol for people who only need it now and again**

***Paracetamol can be prescribed to people who do not need it every day, but take it now and again for on-going pain management of certain conditions such as arthritis.***

***If paracetamol was no longer available for people who only need it now and again how much would it affect you? Please let us know any detail about this change would affect you.***

There were a total of 118 qualitative comments provided for the above question, 703 respondents skipped it. Below are some examples that reflect the concerns people have expressed which were identified previously.

### **Cost can be prohibitive**

*“It costs about £4 at the chemist, but only 19p at Aldi??????? I cannot always get to Aldi, so why does the chemist not bring their prices down?” (Female, 66-75, Harborough)*

*“I know people that have on-going pain and need paracetamol to manage the pain, it is one financial outlay they could do without.” (Female, 36-55, Charnwood)*

*“It is wrong that the NHS are charged so much for the items when they are so cheap over the counter. This may affect people who genuinely have no money to spare but should not cost greater to the NHS than it does in the supermarkets.” (Female, 36-55, Leicester City)*

*“It would concern me that people with inadequate incomes might be deterred from getting the pain relief they need, or that a more expensive drug might be prescribed simply because it continues to be on prescription.” (Male, 66-75, Oadby and Wigston)*

*“As a pensioner if I had to pay for it in a chemist to help with pain for arthritis I would not be able to afford it and would suffer with pain.” (Female, 75+, Melton)*

### **Purchase over the counter**

*“If one only needs it now and again, it can be bought when needed. Would not affect me; I am happy to buy it occasionally.” (Female, 66-75, Rutland)*

*“I would be happy to buy it. Need to be able to buy more than 32 at a time.” (Male, 36-55, Melton)*

*“If you only need it now and again, purchase it from Aldi for 20p.” (Male, 18-35, North West Leicestershire)*



*"It is so cheap that it would not cause hardship if purchased." (Female, 66-75, Hinckley and Bosworth)*

*"I have used paracetamol for many years to manage a pain condition and whilst I am entitled to free prescriptions, have never had this on prescription as it is easily and cheaply available over the counter." (Female, 36-55, Charnwood)*

*"More than willing to pay the asking price I would try and use it sensibly and only when needed." (Female, 66-75, Charnwood)*

### **Lower strength is counter productive**

*"The make up of the cheaper over the counter tablets is different and less easy to digest than the ones from the GP." (Prefer not to say, 36-55, Leicester City)*

*"Am nearly 70 and receive "free medicine" would need to purchase with confidence the right strength." (Female, 66-75, Oadby and Wigston)*

### **Medication vital to support Pain management**

*"I need it for back pain and arthritis." (Female, 56-65, Hinckley and Bosworth)*

*"I would have to pay for paracetamol for chronic back pain used daily." (Female, 66-75, Charnwood)*

*"It would be more difficult to effectively manage my arthritic pain." (Female, 66-75, Oadby and Wigston)*

*"Pain management would be difficult." (Female, 75+, Charnwood)*

*"I use it daily every 4-6 hours to manage my pain." (Female, 36-55, Harborough)*

*"I do have arthritis, but this is not the only reason why I take the drug. I have another long-term pain condition that causes pain 24/7, for severe pain. (Female, 36-55, North West Leicestershire)*

*"I use it every day as back up to strong pain medication I take for back pain and arthritis. So I need it all day." (Female, 56-65, Harborough)*

### **Quantity based on need**

*"However for those who do need it regularly the current restriction on the amount that can be purchased would create a significant difficulty. Paracetamol can be a safe and effective drug and we should not be discouraging use. Has any consideration been given to the possibility that patients will ask for 'stronger' analgesics simply so that they can get them more easily/ cheaply on a prescription? However I do agree that paracetamol should not be prescribed to children for acute minor illness." (Male, 56-65, North West Leicestershire)*

*“The limit of 36 tablets purchased at one time over the counter is an important hindrance.” (Unknown)*

*“It is very difficult to buy paracetamol in large amount with out a prescription and because I have long term pain I may take paracetamol a lot if I could not get it on prescription I would be having to go to the shops all the time. If I am in pain I am unable to get out to the shops.” (Female, 36-55, Charnwood)*

*“I have to take paracetamol in conjunction with codeine four times a day for pain relief I would not be able to buy to quantity of paracetamol needed without daily trips to the chemist. This is not practical!” (Female, 56-65, Leicester City)*

*“Because you can only buy in limited quantities it is better to get it on prescription when you need it regularly.” (Female, 56-65, Leicester City)*

*“I would be happy to buy it. Need to be able to buy more than 32 at a time.” (Male, 36-55, Melton)*

### Anti-histamines, co-codamol, ibuprofen and verruca treatments on prescription

*There are many other medicines currently available on prescription which can also be bought over the counter from community pharmacists, including anti-histamines, thread worm, verruca treatments, dandruff, and other pain killers such as co-codamol and ibuprofen.*

*If some or all of these medications were no longer available on prescription, how much would this affect you?*

There were a total of 211 qualitative comments provided for the above question, 601 respondents skipped it. Below are some examples that reflect the concerns people have expressed which were identified previously.

### **Cost is prohibitive**

*“Pensioner with hay fever - could not afford some of these.” (Female, 66-75, Harborough)*

*“The anti-histamine the work for me is very expensive, I have hay fever from March to October so the cost would be considerable.” (Female, 36-55, Charnwood)*

*“I have lupus and need to use high strength sun cream every day. I get this on prescription as it prevents lupus flares, which would cost the NHS much more. If this was no longer available it would affect me as the sun sense brand is £20 a bottle. The treatments mentioned above are much cheaper and not used daily and therefore there is much less justification to prescribe them.” (Female, 36-55, Rutland)*

*“Currently it would not affect me, but if my requirements change then it would be whether over the counter was cheaper than the prescription charge.” (Male, 56-65, Hinckley and Bosworth)*

*“I have and need regular prescriptions of some of these medicines and it would cost me a lot have to purchase them every month. It would be prohibitive and my health would then be affected.” (Prefer not to say, 36-55, Leicester City)*

*“Some of this medication can be quite costly for example threadworm treatment if buying for the whole family, although this is currently what I do in most cases as it is also less hassle than visiting the GP unnecessarily.” (Female, 36-55, Harborough)*

### **Long-term condition**

*“As a disabled person with a long-term illness, I am in constant pain and paracetamol along with other painkillers, is a daily relief. Without these, I would be always in pain.” (Male, 75+, Leicester City)*

*"I take the antihistamine acrivastine in the form of benadryl allergy relief every day, two or three times a day. Without it my nose is blocked, I can have ear ache and my asthma symptoms are made worse and as a result it can make my breathing worse."* (Female, 18-35, Hinckley & Bosworth)

*"I have hay fever throughout the year and drugs like co-codamol are used for chronic long term conditions like arthritis. co-codamol cannot be bought over the counter in the quantities he is prescribed due to limitations on the number you are allowed to purchase at one time. Anyway the costs would be prohibitive and it is likely that patients would stop taking them and instead rely on the NHS to look after them when they inevitably relapse with severe pain and ill health!"* (Female, 56-65, Blaby)

*"I take co-codamol for rheumatoid arthritis in my knee and osteoporosis in my spine."* (Female)

*"As a disabled person with a long-term illness, I am in constant pain and paracetamol along with other painkillers, is a daily relief. Without these, I would be always in pain."* (Male, 75+, Leicester City)

*"I have suffered with extreme pain for 10 years, and rely on 30/500 co codamol to be able to function. As I am on disability benefits, this would cause huge difficulties for me."* (Female, 36-55, Leicester City)

*"I have a chronic skin condition - chronic idiopathic urticaria for which I require daily anti-histamines treatment."* (Female, 36-55, Hinckley and Bosworth)

*"I am 81 years old and take ibuprofen to control inflammation of my joints due to osteoarthritis. Sometimes, I am unable to move my joints (particularly hand joints and knee joints) without having access to this medication."* (Female, 75+, Leicester City)

## **Lower strength is counter productive**

*"I take 30/500 co-codamol everyday as part of my arsenal for pain management. I do not believe this strength is available over the counter."* (Male, 66-75, Charnwood)

*"Co-codamol cannot be bought at 30/500 strength over the counter for 8 tablets a day."* (Female, 66-75, Oadby and Wigston)

*"I take co codamol you can only get low dose over the counter which are not strong enough for the pain."* (Female, 56-65, North West Leicestershire)

*"Some co codamol is stronger than can be purchased over the counter, I would need to know that I was still able to get this. Also my son recently had a verruca and after the treatment the pharmacist recommended didn't work we had to get something from the GP."* (Female, 36-55, Blaby)

## Quantity based on need

*“I get prescribed codeine and paracetamol a box of 32 tablets to purchase over the counter would only last me 4 days then I would have to go chemist for more and pharmacists do not like selling these to you if you have taken them for 3 days running, also I have difficulty getting out because of health problems.” (Female, 36-55, Blaby)*

*“I have sensitivities to a range of everyday products and been to take them daily. Pharmacist will only sell enough for two weeks then say you need to see your GP. Also on a low wage I would not afford to cover the cost every month”(Male, 18-35, Leicester City)*

*“I regularly take 400mg Ibuprofen 3 times daily for Arthritis & Spinal Stenosis. I also depend on Chlorphenamine every day as I react to various stimuli. I already buy any co-codamol I require, as I cannot tolerate a higher dose on prescription. As a pensioner I could not afford to buy the quantity of Ibuprofen & Chlorphenamine I would need to maintain my independence.” (Female, 66-75, Oadby & Wigston)*

## Gluten free foods

In this section we present the findings and qualitative feedback for the gluten free part of the survey. In total 762 individuals answered this question and 59 skipped it. Respondents were allowed to select all that apply from the list below and therefore some may have selected more than one option.

Table 3 shows that over half of survey respondents (60%) said they have Coeliac Disease. It is interesting to see that 28% (210) of respondents do not have Coeliac Disease or Dermatitis Herpetiformis, however they still answered questions in this section of the survey.

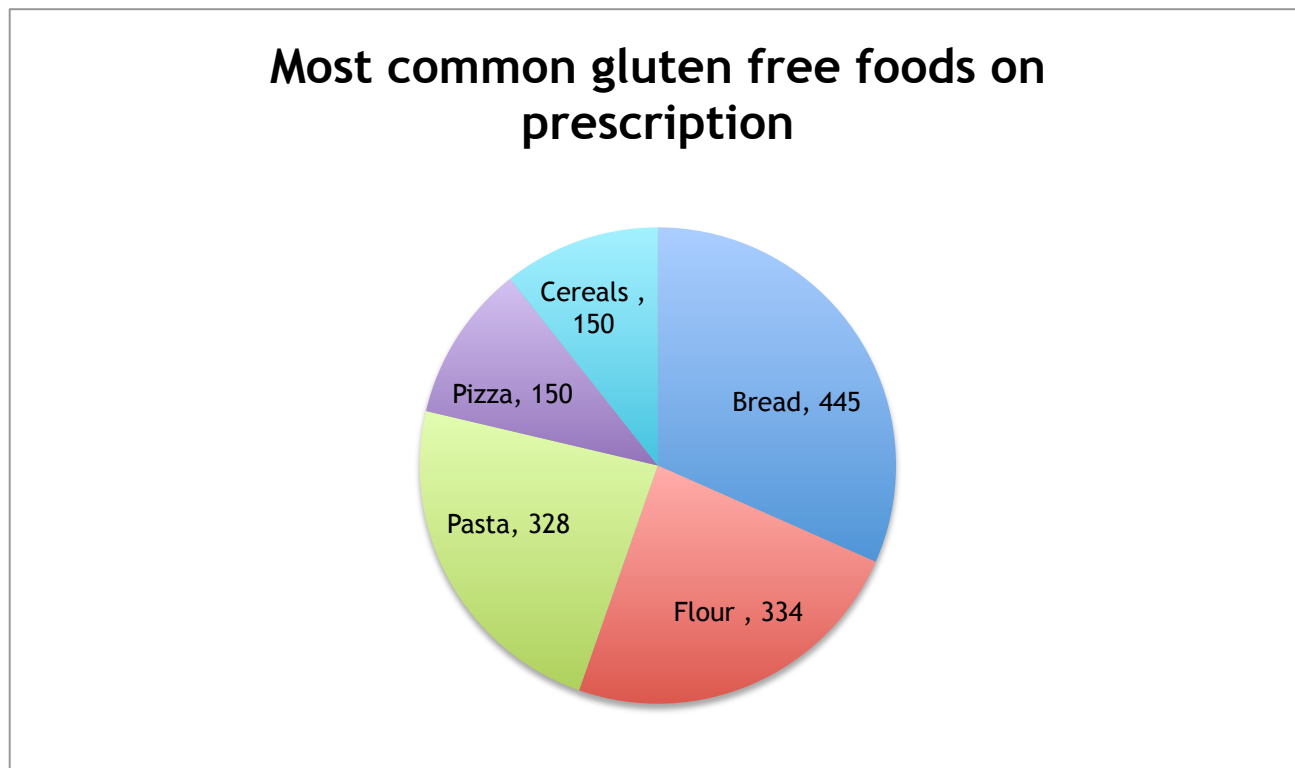
<b>Table 3. What condition do respondents have?</b>	
I have Coeliac Disease (CD)	458 (60%)
I have Dermatitis herpetiformis (DH)	40 (5%)
I am the parent/ guardian of a child with CD	95 (12%)
I am the carer of an adult with CD	20 (3%)
I do not have CD or DH	210 (28%)

Respondents were asked if they are currently in receipt of gluten free products on prescription. 774 respondents answered this question and 47 skipped it. Well over half (64%) of the respondents said that they are currently in receipt of gluten free prescriptions. The remainder 36% are not in receipt of gluten free products on prescription.

A list of gluten free products, which are available on prescription, was provided with the survey. Respondents were asked which items from the list they received on prescription. They were given the option to tick as many as apply. A total of 506 respondents answered this question, 315 skipped it.

Figure 3 shows the most common gluten free items received on prescription as reported by the respondents.

**Figure 3.**



The CCGs provided three proposals for the future prescribing of gluten free products. Respondents were asked to select which one they agreed with. 749 respondents answered this question and 71 skipped it.

Table 4 shows the responses from the 64% of respondents currently IN receipt of gluten free foods on prescription.

<b>Table 4. Respondents currently IN receipt of gluten free foods on prescription</b>	
Stop all prescribing of gluten-free foods	3 (1%)
Limit to 6-8 units of bread and/or flour each month	73 (15%)
No change to the current prescribing of up to 18 units per month	376 (76%)
Other	39 (8%)

It is clear that the majority of respondents do not favour any change to the current prescribing of up to 18 units per month.

However, if any changes were to be made respondents were more in favour of limiting the units each month rather than completely stopping prescriptions of gluten free foods.

Table 5 presents responses from individuals who are NOT in receipt of gluten free foods on prescription. 253 of 281 respondents who said they do not receive gluten free foods on prescription answered this question.

<b>Table 5. Respondents NOT in receipt of gluten free foods on prescription</b>	
Stop all prescribing of gluten-free foods	73 (29%)
Limit to 6-8 units of bread and/or flour each month	64 (25%)
No change to the current prescribing of up to 18 units per month	74 (29%)
Other	42 (17%)

There was no strong majority response to this question from respondents who do not receive gluten free foods on prescription.

There also appears to be a opposing views from this cohort of respondents between stopping the prescribing of gluten-free foods (29%) and those that support no changes to the current prescribing of up to 18 units per month.

A quarter of respondents however leaned towards limiting the amount of units prescribed each month.



## Qualitative feedback - Gluten Free Foods

In order to understand further, respondents were asked to explain the reason behind their choice from question 11, which asked respondents to choose which proposal they agreed with for future prescribing of gluten free foods. 656 respondents including those who do and do not receive gluten free products on prescription answered the question. 165 respondents skipped this. An analysis of the qualitative comments highlighted the following issues:

- Financial implications for low income families and pensioners without prescription
- Lack of availability in supermarkets/ shops
- Prescribed gluten-free products are better quality
- It is not a choice, gluten free products is 'our' medicine

***If gluten free foods were no longer available on prescription how much would this affect you?***

When asked how much respondents would be affected if gluten free foods were no longer available on prescription, the majority (420) said it would affect them a lot, 113 said it would affect them a little and 218 said it would not affect them at all.

***Please let us know any detail about how this change would affect you.***

Respondents were asked to provide some detail about how any change to the prescription of gluten free foods would affect them. 489 respondents answered this question and 332 skipped it. An analysis of the qualitative comments for this question highlighted the same issues which emerged previously, which were:

- Financial implications for low income families and pensioners without prescription
- Lack of availability in supermarkets/ shops
- Prescribed gluten-free products are better quality
- It is not a choice, gluten free products is 'our' medicine

The following section of the report presents the four main recurring themes, which emerged from the qualitative comments in the gluten free section.

### Cost can be prohibitive

*"It would make my weekly food bill very expensive. Based upon today's prices, the smallest gluten-free own brand loaf of bread costs £2 from a supermarket. Other brands, such as Genius and Warburtons cost £3 - £3.50. An equivalent loaf that contains gluten costs from 60p." (Female, 66-75, Blaby)*

*"This would financially affect me and would hinder my ability to ensure the person I care for gets the nutrients required for a healthy diet." (Male, 56-65, Hinckley and*

Bosworth)

*“Supermarket prices are very expensive compared to non GF items & I wouldn't be able to afford to manage a balanced diet.” (Male, 36-55, Harborough)*

*“The cost of gluten free products is considerably more than the gluten equivalent and they are not always available in the supermarkets.” (Female, 36-55, Leicester City)*

*“As a self employed individual who does not earn vast amounts of money, I simply cannot afford the cost of purchasing gluten free foods from supermarkets to live off. The cost of these foods is a great deal more than gluten containing products and there is so much less variety. I am completely at a loss as to understand why it should be acceptable for those with a life long autoimmune condition to be in a position where they have to eat food which is incredibly expensive and of little nutritional value.” (Female, 18-35, Hinckley and Bosworth)*

*“Cost would determine what food is purchased as opposed to food that is required. As well as if more than one person is coeliac then cost is multiplied. Given that this is again not a choice and genetic inherited condition it is likely this will discriminate people on health grounds.” (Male, 36-55, Blaby)*

*“It would immediately limit my intake of fortified cereals and products. I would not be able to eat the range of foods that I currently enjoy on prescription, as they are too expensive. As a single, working parent my food choices are important BUT until 'saver' or 'value' ranges of safe, gluten free foods are produced I would not be able to afford my same diet. This could have a negative impact on my health and well-being. I worry that this could lead to non- compliance with the gluten free diet.” (Female, 36-55, Melton)*

## **Availability and accessibility**

*“Live in a small town and it is hard to get the things I need.” (Female, 75+, Out of area)*

*“There is less availability in stores, so it would mean my food choices would be more limited.” (Female, 18-35, Blaby)*

*“Non prescription GF foods are not easy to obtain and it makes a big difference knowing that you can pick them up from a pharmacy, and the foods won't run out.” (Female, 66-75, Leicester City)*

*“As I am retired, and due to the fact that I have been diagnosed with other serious illnesses the 16 units I receive each month, helps me have the quality foods that my GP has recommended to me and it is important that the prescription free foods continue on the same basis as this is a great help financially, as not all shops or supermarkets stock gluten free products and if they do, they offer a limited amount of these products, and they are very expensive relative to non gluten free foods.” (Male, 66-75, Blaby)*

*“Even my basic requirements would be a significant extra monthly expense. Supermarkets all provide a limited range of options. I choose my prescribable products to be as free from fat, sugar and additives as possible, and there is not that free choice at supermarkets. If basic foods are no longer available on prescription it is inevitable that manufacturers will cut back on their ranges and that future choice, especially on the basis of healthy ingredients, will be more limited.” (Female, 66-75, Harborough)*

*“The additional expense, the limited choice in the area I live, freshness (bread delivered directly and frozen immediately currently).” (Female, 36-55, Melton)*

*“ I live in a small town. Only one 'supermarket', and 2 very small pharmacies, none of which stock G/F items, none of which have room to carry a range of G/F food. Bus/ car trip to nearest big town 40 mile round trip. Too tiring/ expensive for pensioners and young families. We did not cause our coeliac condition by bad life style choices, it was just the luck of the genetic draw.” (Female, 66-75, Rutland)*

*“Living in a small town choice of shopping is restricted and health does not always allow to travel 12 miles to alternative shops.” (Female, 66-75, Rutland)*

## **Quality of gluten free foods**

*“The food you can purchase in the supermarket lacks the correct nutrition for coeliac. This is why I react to it so severe. I suffer with Dermatitis Herpetiformis and sticking strictly to a gluten free diet, it keeps reappearing. Also found food purchased at the supermarket sometimes was a disclaimer in small print. To say not suitable for all coeliacs which I have found by being ill.” (Female, Unknown)*

*“The bread I receive is a life saver, bread from the supermarket is very expensive and does not last or freeze as well as Juvela which is not available to buy, and therefore I would very much miss my bread from the chemist.” (Female, 66-75, North West Leicestershire)*

*“The quality of the bead and flour available on prescription is very high, and well controlled in manufacture. The price from the supermarkets is very high, and I would struggle to cope with my financial situation. I feel I would have to go without some foods if the food was not available from on Prescription. I would have to continue my life under nourished.” (Male, 36-55, Oadby and Wigston)*

*“One of the flour mixes I use is not available in store and the flours that are available in store are not as successful when used in recipes. Therefore if I can't get access to that flour mix my quality of life would be affected.” (Male, 36-55, Charnwood)*

*“It has already affected me when my cereals were removed and caused an increase in alternative prescription costs so no saving and may even cost the CCGs more. I can trust the quality of prescribed foods to be genuinely meeting the standard for gluten free status- you cannot always guarantee contamination issues with foods claiming to*

*have no gluten in them. Prescribed foods have to meet standards for additional nutritional additives which shop brought foods do not.” (Female, 36-55, Hinckley and Bosworth)*

### **Necessity; not a choice**

*“Why take something away from people with coeliac who have no choice but to follow a gluten free diet and have relied on this prescription most of their lives to then make somebody change their routine and purchase products elsewhere where it is unclear how safe it would be to eat!” (Female, 18-35, Leicester City)*

*“If people with diabetes get free prescriptions then why don’t people with coeliac disease, as this is the only thing we can have to help our lifelong condition which can be related to other life threatening conditions such as bowel cancer?” (Male, 18-35, Melton)*

*“It would be a hardship for pensioners. Gluten free foods are a medicine to coeliacs.” (Male, 66-75, Blaby)*

*“Do NOT stop prescribing gluten free foods - this is not fair as we need this food to help us live a healthier lifestyle, you’re making cut backs in the wrong places!” (Male, 66-75, Blaby)*

*“I didn’t choose to have this disease! It would be unfair to stop all prescriptions leaving me to pay for gluten free products from the supermarket!” (Female, 18-35, Leicester City)*

In order to improve patient care and understand how this could be done, respondents were asked if there is anything else which the NHS can do to help those who suffer from Coeliac disease. This was an open-ended question, allowing respondents to give a detailed answer. 458 respondents answered this question and 363 respondents skipped it.

*Is there anything else, which the NHS can do to help those who suffer from Coeliac disease?*

An analysis of the qualitative comments given by respondents highlighted the following ways in which people feel the NHS can help those who suffer from Coeliac disease.

- Better trained Doctors/Nurses/Specialists
- Dietary advice
- Annual check ups with a specialist
- Continue to prescribe gluten free foods
- Encourage manufacturers of gluten free foods to reduce cost
- Provide a voucher/pre-paid card system to buy gluten free foods from supermarkets/shops
- Gluten free snacks/meals in hospital
- Ensure local shops/pharmacies/supermarkets stock gluten free foods
- Only prescribe staple foods
- Means-tested prescriptions
- Raise awareness of Coeliac disease
- Support for newly diagnosed patients
- Find a cure
- Better diagnosis
- More research and follow ups

## 5. Conclusion

There has been a strong response to this survey from both respondents that may be impacted by proposed changes and from the wider public whose opinions also need to be heard.

The findings from this survey allow the CCGs across Leicester, Leicestershire and Rutland to understand more fully patient and public issues, concerns and challenges with proposed changes to prescribing practices.

Our desk research has highlighted that other localities have adopted different strategies to address the challenges of choice, access, cost outlined in this report and that learning from these maybe useful to overcome barriers whilst ensuring patient and public have been listened to e.g. dispensing GP's particularly in rural areas.<sup>12</sup>

We hope that the report will shape and inform the CCG's to identify where further information is needed and from whom, what areas (geographic and thematic) require more exploration with different cohorts of the population before formal consultation on ways in which CCG's can potentially reduce the amount spent on prescriptions.

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