# Medicines Management Consultation Results: views on what we prescribe in Lincolnshire

**23 November 2016** 

#### **Contents**

Page	
2	Executive Summary
3	Purpose of report
3	Introduction to the consultation
4	Equality Impact Assessment
4	Consultation process
7	Responses
10	Results
10	Background feedback
12	Proposal 1: Over the counter medication
15	Proposal 2: Gluten free food
21	Proposal 3: Specialist baby milks and infant formulae
23	Proposal 4: Oral nutritional supplements
26	Formal responses to the consultation
29	Themes from events and meetings
31	Themes from calls, letters and emails
33	Recommendations
	Appendix 1: Equality Impact Assessment
	Appendix 2: Full Health Scrutiny Committee Lincolnshire response
	Appendix 3: Healthwatch Lincolnshire feedback
	Appendix 4: Department of Nutrition & Dietetics United Lincolnshire Hospitals NHS
	Trust
	Appendix 5: Coeliac UK
	Appendix 6: British Society of Gastroenterology
	Appendix 7: British Specialist Nutrition Association
	Appendix 8: Lincolnshire Local Pharmaceutical Committee
	Appendix 9: Consultation document and Survey
	Appendix 10: Quality Impact Assessment

#### **Executive Summary**

#### **Proposal**

The Clinical Commissioning Groups in Lincolnshire (Lincolnshire East Clinical Commissioning Group, Lincolnshire West Clinical Commissioning Group, South Lincolnshire Clinical Commissioning Group) and South West Lincolnshire Clinical Commissioning Group) undertook a consultation from Tuesday 4<sup>th</sup> October until Friday 18<sup>th</sup> November 2016. This consultation proposed:

- 1. To restrict prescribing over the counter / minor ailment medicines for short term self-limiting conditions
- 2. To restrict or stop the prescription of gluten-free foods
- 3. To restrict the prescribing of baby milk including specialist infant formula
- 4. To restrict the prescribing of oral nutritional supplements in line with ACBS guidance

#### **Engagement Activities**

A comprehensive programme of communications and engagement was undertaken across Lincolnshire to enable as many people as possible to get involved in the consultation. The online survey was supported by paper copies sent to those who requested them, a social media campaign to promote the consultation and encourage involvement, attendance at community groups and arrangement of drop in sessions across the county. Links to the survey were also sent to a large number of key stakeholders and public databases. The EIA (Equality Impact Assessment) supported identification of targeted engagement.

#### Response

1,448 responses were received (1,309 via the online survey and 139 hard copy returns) with a social media reach of over 22,500, demonstrating a wide reaching, robust consultation process.

Proposal 1: to restrict prescribing over the counter medicines for short term, self-	85% agreed
limiting conditions	
Proposal 2: to limit prescribing to bread, flour and bread mixes only within Coeliac	53% agreed
UK recommended quantities	
Proposal 3: to restrict prescribing specialist baby milks and infant formulae	64% agreed
Proposal 4: to restrict prescribing of nutritional supplements	72% agreed

#### Recommendations

- 1. Implement the proposals agreed above, subject to formal endorsement at the 4 CCG Governing Body meetings on 30<sup>th</sup> November and 1<sup>st</sup> December 2016
- 2. Agree implementation for future restricting of prescriptions for over the counter medications or option to implement retrospectively
- 3. Agree implementation date of all proposals as 5<sup>th</sup> December 2016
- 4. Consider the outcomes of the Equality Impact Assessment (appendix 1) alongside these consultation findings

#### **Purpose of report**

The purpose of this report is to present the outcomes of the Medicines Management consultation in Lincolnshire to the four CCG Governing Bodies to support their decision making on the proposed approach to prescribing in Lincolnshire. The feedback will help shape the way we prescribe moving forward.

#### Introduction to the consultation

The Clinical Commissioning Groups in Lincolnshire (Lincolnshire East Clinical Commissioning Group, Lincolnshire West Clinical Commissioning Group, South Lincolnshire Clinical Commissioning Group and South West Lincolnshire Clinical Commissioning Group) undertook a consultation from Tuesday 4<sup>th</sup> October until Friday 18<sup>th</sup> November 2016 on proposals on what is prescribed in Lincolnshire.

The challenge faced by all organisations across the NHS is how to spend the available budget in ways that most benefit the health of the whole population and delivers good value for money. The CCGs evaluate all services to ensure that each service offers good quality, the best possible outcomes for patients and good value for money. Resources must be allocated in an effective and equitable way for the benefit of the whole population to achieve the best possible outcomes for the most number of patients. A number of planned savings will come from the transformation of services to reduce complexity, waste and duplication, but in order to meet the challenging financial targets the CCGs have also had to look at reprioritising services.

#### This consultation proposed:

- To restrict prescribing over the counter / minor ailment medicines for short term self-limiting conditions
- 2. To restrict or stop the prescription of gluten-free foods
- 3. To restrict the prescribing of baby milk including specialist infant formula
- 4. To restrict the prescribing of oral nutritional supplements in line with ACBS guidance

The consultation provided an overview of the proposed service changes to ensure the health budget for Lincolnshire is spent as effectively as possible, whilst minimising waste and promoting self-care to its population. The consultation document reiterated that these items will still be available for some patients on clinical assessment.

#### **Equality Impact Assessment**

An Equality Impact Assessment was undertaken to assess the potential impact on the nine protected characteristics covered under the Equality Act 2010. From this assessment activity we undertook focused engagement with these groups, as well as the population as a whole. The full EIA is available as Appendix 1.

#### **Consultation process**

The CCGs undertook a wide reaching and robust consultation process, implementing a number of different communication and engagement methods to ensure involvement from as many people and a wide variety of stakeholders as possible. As part of the consultation, the following was produced:

- Full consultation document with survey with options to request the document in other languages and formats
- Online survey with supporting information from the consultation document
- Poster promoting the consultation
- Briefing for staff and organisations

This was distributed to the following stakeholders:

- Lincolnshire Health Scrutiny Committee
- Lincolnshire Health and Wellbeing Board
- Healthwatch Lincolnshire
- Lincolnshire County Council Adult and Children's Services
- MPs
- NHS England
- GPs and Lincolnshire Local Medical Committee
- Pharmacies and Lincolnshire Local Pharmaceutical Committee
- Lincolnshire and neighbouring NHS Provider organisations requesting circulation to relevant clinics and services
- Public Health
- District Councils
- East Midlands Ambulance Service

- Coeliac UK
- Dieticians
- Membership / patient panels for ULHT, LCHS (590 members), LPFT
- Staff in NHS Provider Organisations, CCGs
- Patient Participation Group representatives
- Children's Centres
- Care Homes
- Community groups such as Age UK, Carers Support Groups, homeless organisations, disability groups, St Barnabas, Mental Health Forum, Age Concern, British Red Cross, LCVS, Citizens Advice Bureau, Job Centres, Colleges, Social Exclusion Group, Pre – schools and many more.

#### Drop in sessions and events were held in:

Date	Time	Location
1 November 2016	2pm-4pm	St Swithin's Community Centre
2 November 2016	2pm – 4pm	John Coupland Hospital
3 November 2016	10 am – 12pm	Skegness Hospital   Main Reception
10 November 2016	2pm - 4pm	County Hospital Louth
17 November 2016	10 am – 12 pm	Parkside Medical Centre

#### Attendance at events

- Spalding COPD Group
- PPG cluster Group
- Evergreen Support Group (Stamford, Bourne and Deepings)
- South Holland Health and Wellbeing Network Meeting
- Munro PPG meeting
- Little Explorers
- Let's Get Active
- Family Fun
- Learning together tweenies
- Learning together babies
- Baby & Child Clinic Antenatal clinic
- Learning Together Toddlers
- LPFT involvement strategy event, Skegness

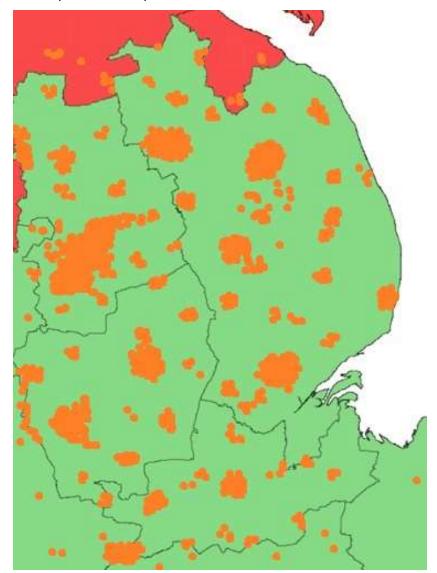
This was promoted using the following methods:

- On each of the four CCG websites with adverts pinned to the front page
- Facebook pages
- Twitter accounts
- Press releases
- Radio interview

The total social media reach across the consultation period is outlined below:

Total	22,547
Lincolnshire West	12,311
South West Lincolnshire	2,796
South Lincolnshire	3,321
Lincolnshire East	4,119

In total 1,448 surveys were completed, 1,309 via the online survey and 139 hard copy returns. The map below shows the spread of responses received across Lincolnshire.



Of the 1448 responses, 1408 indicated in what context they were responding as, as shown in the table below:

Respondent	Number	%
A member of the public	1,142	81%
A GP	48	3%
Another healthcare professional	131	9%
A pharmacist	20	1%
A representative of a group or organization	67	5%
with an interest in these proposals		

Some respondents provided additional information to express that they were patients with conditions affected by the consultation, clinical staff, a councillor, PPG member, staff from nursing homes and other professions.

<u>Age</u>	<u>e</u>	<u>Gender</u>			Sexual orientation	
<17	0%	Male	33%		Heterosexual / straight	88%
18-20	1%	Female	65%		Bisexual	1%
21-29	7%	Prefer not to say	3%		Gay man	<1%
30-39	13%				Gay woman	1%
40-49	17%	Same gender as			Prefer not to say	9%
		assigned at bi	<u>rth</u>			
50-64	35%	Yes	95%			
65-74	21%	No	<1%		Are you a carer?	I
75-84	7%	Prefer not to say	4%		Yes	14%
85+	0%				No	86%

Do you consider yourself to			<u>Do you consider</u>			Employment status		
have a disability?				yourself to have a long				
				term condition	<u>n?</u>			
Yes	18%	, D		Yes	50%		Employee in full time	39%
							work	
No	78%	, D		No	47%		Employee in part time	14%
							work	
Prefer not to say	4%			Prefer not to say	3%		Retired	32%
	I						Permanently sick /	3%
							disabled	
Nature of dis	<u>abilit</u>	<u>Y</u>		Nature of condi	tion		Full time carer	1%
Learning disability		3%		Heart condition	17%		Unemployed	1%
Long term mental 1:		15%		Diabetes	17%		Self employed	7%
health								
Physical impairmen	t	63%		COPD	5%		Looking after home	2%
			l	1			į.	•

Blind / sight impairment	5%	Chronic kidney	2%	Full time education	1%
		condition			
Deaf / hearing	14%	Cancer	5%	Part time student	<1%
impairment					
Learning disability	3%	Coeliac Disease	55%	Government supported	0%
				training	

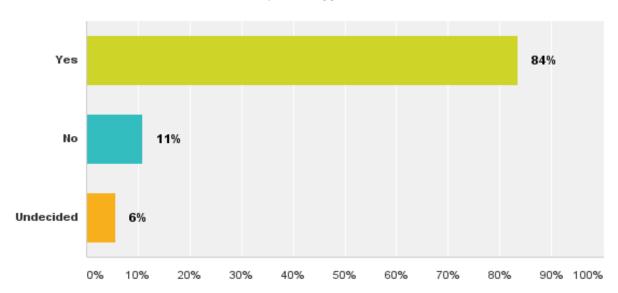
<u>Ethnicity</u>			
Asian or Asian British - Bangladeshi	<1%	White – British	89%
Asian or Asian British – Indian	<1%	White – Irish	1%
Asian or Asian British – Pakistani	<1%	White – Polish	<1%
Other Asian background	<1%	White –	<1%
		Gypsy/Traveller/Roma	
Black or Black British - African	<1%	Other white background	2%
Black or Black British - Caribbean	0%	Chinese	<1%
Mixed Heritage – White & Asian	<1%	Prefer not to say	5%
Mixed Heritage- White & Black African	0%		
Mixed Heritage- White & Black Caribbean	<1%		
Other mixed background	<1%		
	1	l .	1

#### **Results**

#### **Background feedback**

# Q1 Do you understand why the Lincolnshire CCGs need to make the changes proposed in this consultation?

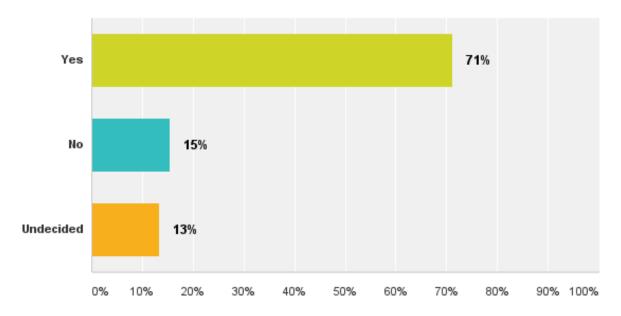
Answered: 1,437 Skipped: 11



By far the majority of respondents (84%) understood why these proposed changes need to be made. Of the 156 respondents who answered 'no' to this question, more than the average of all respondents paid for their prescriptions and have either themselves or a member of their family have been prescribed gluten free food.

# Q2 Do you agree that the money being spent on over the counter items would be better spent on maintaining and protecting other treatments and services?

Answered: 1,435 Skipped: 13



The majority of respondents (71%) agreed that money being spent on over the counter items could be better spent. 15% disagreed and 13% were undecided.

#### Q3: Please tell us what you would most prefer to spend your money on

(where 1 is the most preferred to spend money on and 6 the least preferred).

Answered: 1,381 Skipped: 67

	1	2	3	4	5	6	Total	Scor
Access to Physiotherapy Services	<b>48</b> % 596	<b>25</b> % 316	<b>11%</b> 138	<b>8</b> % 99	<b>5</b> % 61	<b>3</b> % 34	1,244	4.9
Non urgent referrals to orthopaedics for 3 months	<b>17%</b> 214	<b>39%</b> 490	<b>17%</b> 205	<b>12%</b> 151	<b>10%</b> 119	<b>5%</b> 63	1,242	4.2
Prescription of over the counter drugs	<b>11%</b> 129	<b>6%</b> 76	<b>19%</b> 226	<b>12%</b> 149	<b>17%</b> 203	<b>35%</b> 430	1,213	2.
Prescription of gluten-free food	<b>17%</b> 201	<b>7%</b> 90	<b>12%</b> 148	<b>18%</b> 222	<b>24%</b> 287	<b>22%</b> 265	1,213	3.
Prescription of baby milk and specialist infant formula	<b>11%</b> 129	<b>13%</b> 152	<b>25%</b> 299	<b>24%</b> 287	<b>18</b> % 218	<b>10%</b> 120	1,205	3.
Prescription of oral nutritional supplements	<b>4</b> % 47	<b>7</b> %	<b>17%</b> 211	<b>22%</b> 271	<b>23</b> % 283	<b>27%</b> 335	1,233	2.0

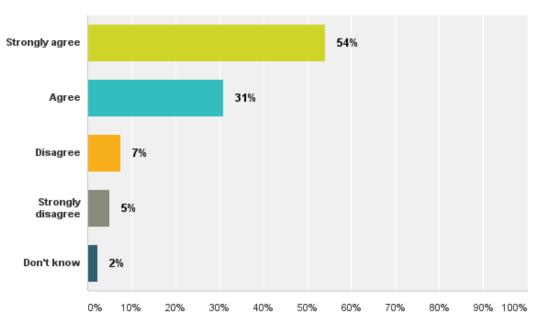
As the previous table shows, respondents ranked each service depending on which they would prefer to spend money on.

Most prefer to spend money on	Access to physiotherapy services
<b>^</b>	Non urgent referrals to orthopedics for 3 months
	Prescription of baby milk and specialist infant formula
	Prescription of gluten free food
<b>V</b>	Prescription of over the counter drugs
Least prefer to spend money on	Prescription of oral nutritional supplements

#### **Proposal 1: Over the counter medications**

Q4 When considering the prioritisation of healthcare funding due to more demand on our budget than we can meet, to what extent to do you agree with the proposal to stop prescribing over the counter / minor ailment medicines for short term, self-limiting conditions?

Answered: 1,434 Skipped: 14

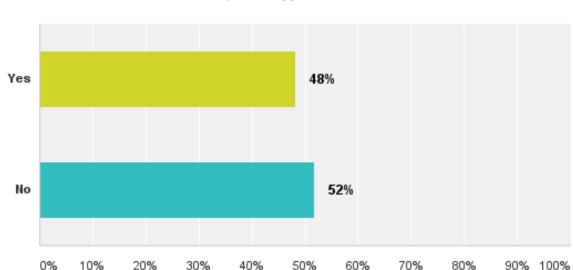


By far the majority of respondents strongly agreed or agreed (85%) with the proposal to restrict prescribing over the counter medicines for short term, self-limiting conditions. 52% of those agreeing with the proposal do not currently pay for their prescriptions whereas 48% do.

Of the 12% (180) who disagreed with this proposal, 60% still understood why the CCGs needed to make the changes proposed. 51% pay for prescriptions and 49% don't.

Comments made on this are again supportive of the proposals as they are widely available over the counter and at a much reduced price. However, the consensus was that for those with severe, life limiting illnesses, these medications should continue to be prescribed and consideration given to patient's circumstances (e.g. financial) and for children and the elderly before decisions are made using means testing and not a 'one size fits all' approach.

### Q5 Do you currently pay for your prescriptions?



Answered: 1,431 Skipped: 17

A slightly higher proportion of respondents do not pay for their prescriptions (52%) than those who do (48%). Of those who did pay for their prescriptions, 84% understood why the CCGs need to make the changes proposed and 71% agreed that the money spent on over the counter medications could be

better spent on maintaining and protecting other treatments and services with similar answers of 83% and 72% respectively for those who do not pay for prescriptions.

There is little difference in agreement or not to the proposals based on whether respondents pay for prescriptions or not as the table below shows although the difference in the options for gluten free food is larger than any other proposal:

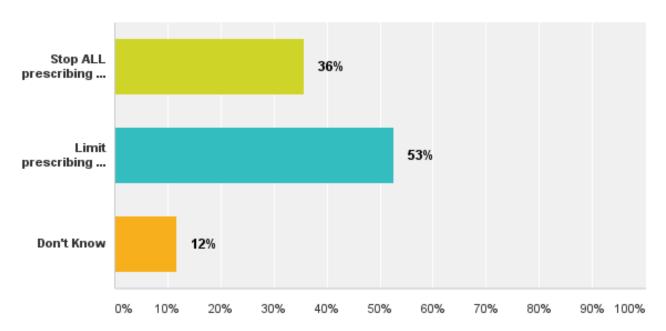
(% agree or strongly agree to the proposals):

Proposal	Pay for	Do not pay for		
	prescriptions	prescriptions		
Over the counter medication	84%	86%		
Stop all gluten free food	41%	31%		
Limit gluten free food	48%	56%		
Baby milk and formula	62%	66%		
Nutritional supplements	73%	73%		

#### Proposal 2: Gluten free food

# Q6 When considering the prioritisation of healthcare funding due to higher demands on our budget than we can meet, what is your preferred option for the future prescription of gluten-free food below

Answered: 1,420 Skipped: 28



Slightly more than half of respondents' (53%) preferred option is to limit prescribing to bread, flour and bread mixes only within Coeliac UK recommended quantities and over a third (36%) preferred to stop ALL prescribing of gluten-free foods with no replacement system. Of those who are prescribed, or a member of their family are prescribed gluten free food, 16% prefer the option to stop all prescribing and 73% prefer the option to limit prescribing.

#### Q7: Comments on the proposal for gluten free prescriptions

1,229 comments were received to this question and have been themed and summarized in order of reference below.

#### Those who preferred the option to limit prescribing commented (747):

Most	Theme	Summarised comments
mentioned		
mentioned 1	Expense	<ul> <li>Gluten free foods are not available at "competitive prices" and cost considerably more than the gluten containing equivalents.</li> <li>Not everyone will have the resources to buy gluten free food, which usually costs a lot more and is harder to find</li> <li>"Our current shopping bill is large enough with the addition of gluten free products and I feel that if we had to buy bread as well, this would be difficult as we are a one income family"</li> <li>Gluten free food can be expensive particularly in a poor household so I would be in favour of limiting the future prescription to those that really need it</li> <li>Gluten-free prescriptions should be equated with medicine that a</li> </ul>
2	Access	<ul> <li>sufferer of another condition has</li> <li>Patients should buy treats (cakes and biscuits), but bread rolls and mixes are not affordable and the mixes are NOT available in the shops- the only place you can get these is on prescription.</li> <li>Elderly, frail, vulnerable, bed bound and disabled people do not have</li> </ul>
2	Access	<ul> <li>Elderly, frail, vulnerable, bed bound and disabled people do not have the same access to broad supermarket shopping</li> <li>Lincolnshire is a rural county and the patient may not have access to larger supermarkets who supply gluten free products</li> <li>"To shop is minimum 3hr round trip for me to get gluten free bread"</li> <li>Some low income families can't afford to buy these products</li> <li>Children and those on benefit should be catered for by NHS</li> <li>To stop prescribing of gluten-free foods with no replacement system</li> </ul>

		is wrong as it will have a huge impact on children from low income families.
3	Availability	Gluten free foods are more widely available in supermarkets
		<ul> <li>It should be prioritized- gluten free food, like over the counter</li> </ul>
		medicines can be bought at supermarkets etc
		"Personally I am gluten free and manage to obtain everything
		from supermarkets"
		There is more readily available gluten-free foods that are much
		cheaper than the cost of a prescription.
		Basics should be provided but the choice in shops has improved
		dramatically over recent years
4	Nature of	Coeliac disease can lead to serious health implications and a gluten
	the	free diet is the only treatment. Prescription items such as gluten-free
	disease	bread are fortified with important vitamins and nutrients not always
		found in shop-based items. In addition, many shop-bought gluten-free
		items are high in fat and sugar.
		"Prevention is better than cure. If you restrict all gluten free food
		people will take short cuts in their diets and will eat badly and
		cause themselves problems."
		Coeliac disease needs to be treated properly in order to prevent other
		complications for example bowel cancer and costing the NHS even
		more in treatment costs
		Not getting the right stuff for some people with gluten-related
		disorders can be fatal, it is important that they have the security of
		knowing they will always be able to access gluten-free food cheaply.
		It is too easy now for the newly diagnosed to buy poor quality 'gluten-
		free food, if they can afford it and then suffer in the years to come

#### Those who preferred the option to **stop prescribing** commented (507):

Most	Theme	Summarised comments
mentioned		
1	Availability	<ul> <li>Gluten-free foods are widely available in supermarkets</li> <li>Gluten free food is readily available in all major supermarkets.  Everyone else is responsible for buying their own food. It should not be the NHS responsibility to feed people. This food is available at a reasonable cost and therefore should be purchased if required.</li> <li>Gluten free products are now a routine product which may be purchased in our local supermarket at a similar cost to non-gluten. £6 spent on a prescription for gluten free spaghetti when the same product in Aldi is 99p.</li> <li>"Gluten food should be paid for like every other food. It is readily available in all big supermarkets. The days have gone where it was hard to find"</li> </ul>
2	Inequality	Gluten free food products are widely available and should be part of normal housekeeping. It is not right that people can get them on the NHS
	mequality	<ul> <li>This removes the inequity described in the papers. Affordable healthy options are widely available. Advice is also widely available.</li> <li>Other conditions don't have access to prescribed special foods and plenty availability of GF foods now</li> <li>"Diabetics, renal patients and others with food allergies and intolerances don't get food prescribed- why should coeliacs be any different?"</li> <li>There are not the same provisions for other allergies/intolerances. People could just avoid those foods if they can't afford to pay for the products in a supermarket.</li> <li>Other conditions don't have access to prescribed special foods. There is plenty of availability for gluten intolerant patients to buy food that will accommodate their condition</li> </ul>
		Reactions to certain foods is not confined to Coeliacs - we all have to

		purchase food according to what suits us.
		<ul> <li>I have asthma and need daily medication to live which I am forced to</li> </ul>
		pay for, whereas if you are allergic to gluten, as limiting as it is you
		can simply not ingest it. I don't have the option of choosing not to
		breathe.
3	Nutrition	"Diet does not need to include specialist gluten-free food, in the
		past people avoided things and ate alternatives so why do we
		need a substitute? The consultation says that "Gluten free foods
		will still be prescribed in specific circumstances where a
		dependent patient could be at risk of dietary neglect." so some
		people will still be protected which is fair but the vast majority
		should be purchasing their own food".
		There are plenty of alternatives to foods containing gluten. It is a
		question of educating people as to what those alternatives are.

#### Suggestions from all of these comments included:

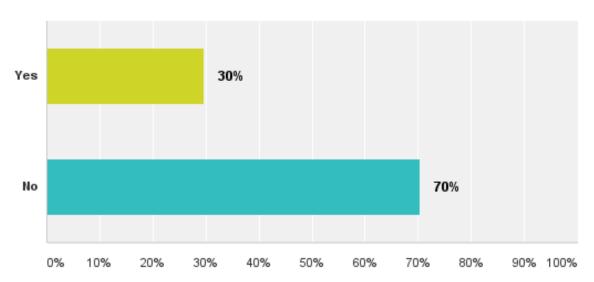
- Immediate withdrawal of these foods for some dependent on them may cause initial problems for those unable to regulate their own diet. Therefore, a fallback position in the form of these staple ingredients together with GOOD nutritional advice should lessen this potential problem before an eventual stop to all prescribing of such foods is introduced.
- Provide vouchers to coeliac patients who have to eat gluten free food
- Reviewing the current gluten free prescription list to consider supporting the healthy food choices of wholemeal / whole grain / seeded and high fibre products rather than the processed white flour and high sugar items allowed onto that list at present
- Stop prescribing but allow patients to access coeliac society approved quantities via a coeliac society outlet, i.e. the coeliac society acts for and helps support its members to behave responsibly in accessing appropriate levels of gluten free products.
- Phased approach to eventual withdrawal would be more appropriate
- > Benefits agency to provide the extra money to finance gluten free food
- > Commission pharmacies to operate a token service- cut out the GP on-costs plus Pharmacies are VAT exempt so service delivery costs and supply costs are outside of the scope of VAT
- > A limited service, or means-tested service might work better

- ➤ There will, of course, be cries of hardship, but mainly from people who do not want to prepare food and expect everything to be delivered ready to eat. The NHS cannot afford to provide this service. Quantities will need to be assessed so that people can prepare other foods.
- > Campaign nationally and locally to negotiate reduced prices with the suppliers
- My prescription of 8 loaves every time is too much and some is wasted

A small number of comments were made relating to the survey itself regarding frustration that an option wasn't provided to continue prescribing gluten free products in the current way using the points based system.

## Q8 Have you, or a member of your family, been prescribed gluten-free food?





70% of respondents or a member of their family have not been prescribed gluten free food whereas 30% have. Of the 30% who have themselves or a member of their family been prescribed gluten free food, 29% didn't agree that the money being spent on over the counter items would be better spent on maintaining and protecting other treatments and services which is nearly twice the proportion of the rest of the respondents.

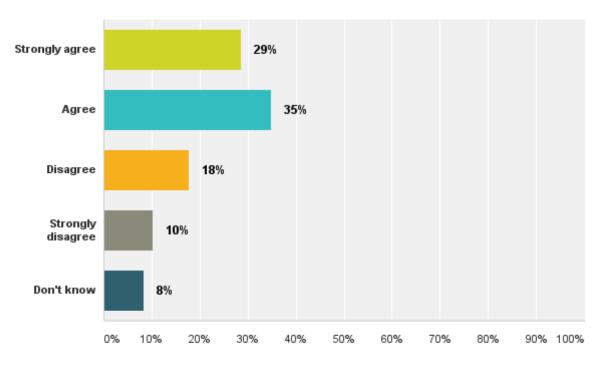
Those who receive gluten free products also ranked the prescription of gluten free food higher on what they prefer to spend money on:

Most prefer to spend money on	Access to physiotherapy services
<b>^</b>	Prescription of gluten free food
	Non urgent referrals to orthopedics for 3 months
	Prescription of baby milk and specialist infant formula
<b>V</b>	Prescription of over the counter drugs
Least prefer to spend money on	Prescription of oral nutritional supplements

#### Proposal 3: Specialist baby milks and infant formulae

Q9 When considering the prioritisation of healthcare funding due to more demand on our budget than we can meet, to what extent to do you agree with the proposal to restrict prescribing specialist baby milks and infant formulae?



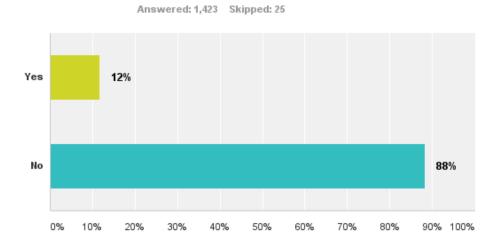


64% of respondents agreed or strongly agreed with the proposal to restrict prescribing specialist baby milks and infant formulae. This proposal received the largest level of disagreement with 28% either disagreeing or strongly disagreeing with the proposal. Of the 12% whose child or family member have been prescribed these 59% agree with the proposal and 38% disagree.

Comments received largely supported the proposal to restrict this prescribing, citing that these formulas are widely available in the supermarkets and pharmacists. "Baby milk is available from all stores now but they don't want to pay for it the list is endless of the abuse of prescriptions".

However, further comments clarified that specialist milks for certain conditions are only available on prescription and in the case of premature babies, this is an essential requirement on prescription for their growth and development. "The section on baby milks and specialist formulae is a great concern. I totally agree that thickened formulae and lactose free formulae, for the treatment of a primary or secondary lactose intolerance should be purchased by parents as these are a similar price to a normal baby formula. However the proposal doesn't stop there. Are we suggesting that babies and infants with serious medical conditions requiring a specialist baby milk or formula are only to get these if parents can afford £80 per week to buy them? If specialist formulae are made available over the counter how will the use of these formulae be regulated?"

Q10 Has your child, or a member of your family, been prescribed with specialist baby milk or infant formula?

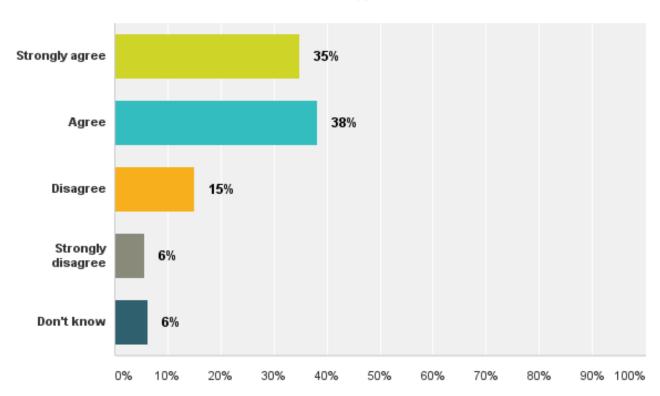


By far the majority of respondents have not been prescribed these products. However, as the feedback to question 3 demonstrates, the provision of specialist baby milks and infant formulae is the third most preferred choice to spend money on after physiotherapy and orthopedic appointments.

#### **Proposal 4: Nutritional supplements**

Q11 When considering the prioritisation of healthcare funding due to more demand on our budget than we can meet, to what extent do you agree with the proposal to restrict prescribing nutritional supplements?

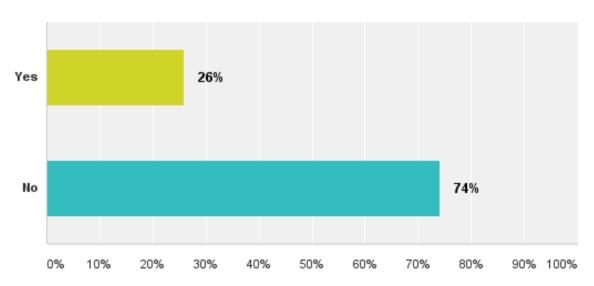




72% of respondents agree with the proposal to restrict prescribing of nutritional supplements and 21% disagree. Of the 20% who themselves or a family member has been prescribed oral nutritional supplements, 73% agree with the proposal and 24% disagree.

# Q12 Have you, or a member of your family, been prescribed oral nutritional supplements?

Answered: 1,428 Skipped: 20



Just over a quarter of respondents have themselves or a member of their family, been prescribed oral nutritional supplements.

#### Q13 comments

Many of the 836 comments in this final comments box of the survey reiterated the feedback regarding the specific proposals which have been summarized and captured within the rest of this report.

A number of these comments focused on the prescription of oral nutritional supplements which was considered on one hand to be essential, particularly for the elderly and infirm, if no other alternative was available and if they had received an appropriate assessment. "My father was prescribed these following a long period of hospitalisation with Crohn's. He weighed 6st and would have died without these supplements. There are very hard to source, the pharmacy ordered them in especially each week".

However, it was also considered to be an easy solution and often abused. "There are ways to add nutritional value to foods without resorting to supplements. Supplements are just care homes

taking the easy way out, so these should not be prescribed unless food cannot be taken at all".

#### **General comments**

Comments on all of the proposals suggested that there was a need for <u>adequate assessment and means testing</u> to ensure those who require prescriptions receive them and that it is a clinically based decision. With regards to oral nutritional supplements, it was felt that <u>care homes</u> give this out too easily and if they do they should be made to pay for it including education of care homes. <u>Abuse</u> of the current system was also mentioned, citing that people get simple painkillers on prescription 'because they can' and they know of people who use prescribed gluten free food for the whole family when it is not required. Self-funding and <u>self-care</u> was raised as a practical solution to reduce the instances of prescribing unnecessarily supported by education and information on what is medication and food products are suitable and available. Differing views on the <u>survey</u> itself were also fed back with some feeling it needed more objective information and context for someone to have strong opinions in areas where they have no personal knowledge and questions were biased while others agreed with the proposals and felt it was balanced and fair.

#### Formal responses to the consultation

In addition to the completed surveys, formal responses were received from the following organisations with their summarized feedback. Full responses with additional information are attached as appendices 1-7:

#### The Health Scrutiny Committee for Lincolnshire

### <u>Proposal 1: To restrict providing over the counter / minor ailment medicines for short term, self-limiting conditions</u>

The Committee supports the principle of self-care for very minor ailments and notes that some medicines are cheap and widely available whereas others are more expensive and not as widely available and are therefore concerned of the impact on low income families.

#### Proposal 2: To restrict the prescription of gluten-free foods.

The Committee supports the proposal to limit prescription of gluten free foods to bread, bread flour and bread mixes although GPs should be allowed discretion to take into account the wider impact of these proposals with support from the CCGs.

#### Proposal 3 - To restrict prescribing of baby milks and specialist infant formula

The Committee notes that specialist baby milks and infant formulas can be expensive and is concerned about the potential impact on low income families and believes that GPs should be allowed the discretion to take account of exceptional circumstances, including any serious financial impacts on families with support from the CCGs.

#### Proposal 4 – To restrict prescribing oral nutritional supplements

The Committee strongly supports the "food first" approach and are concerned that some care homes rely too heavily on nutritional supplements although GPs should be allowed discretion.

#### **General Comments**

The Committee are reassured that discretion will be applied by GPs to take into account individual circumstances. The Committee are concerned the six week period of consultation is too short although acknowledge the pressure on the CCGs with regards to the timescales, and that the consultation document has not been widely circulated as some GPs have decided not to make the consultation document available although they acknowledge the efforts to promote this consultation.

#### **Healthwatch Lincolnshire**

Healthwatch Lincolnshire believes it is right to give people living in our county the opportunity to comment on any proposed changes that will affect the medication they are prescribed. The consultation period of 6 weeks is noted and ask that future consultations are open for a minimum of 12 weeks. If it decided to proceed with the recommendations robust support should be given to prescribers and patients regarding discretion. We have concerns about how reduction of over the counter prescribed medication might affect low income patients and families. There perhaps needs to be some national requirement to raise the exemption age limit for those eligible to receive free prescribed medications.

#### **Department of Nutrition & Dietetics United Lincolnshire Hospitals NHS Trust**

#### Proposal 2: To restrict or limit the prescribing of gluten free foods

We would support the continuation of the availability of staple gluten free foods on prescription for patients with Coeliac Disease and Dermatitis Herpetiformis as recommended by Coeliac UK.

#### Proposal 3: To Restrict prescribing baby milks and specialist Infant Formula.

A clear guide of when to direct patients to their local pharmacy and when a prescription for a baby milk or specialist formula is appropriate to consider would be more helpful. Age ranges that a prescription would be expected to be required and timely re-introduction programmes would all help to reduce unnecessary and costly prescribing. If a recommendation is made by a Paediatrician or Paediatric Dietician for a specialised infant formula then this should be prescribed.

#### Proposal 4: To restrict prescribing of nutritional supplements (ONS)

A very clear pathway for managing nutrition in the community is required. Previously a PACE Bulletin (Guidance on the Prescribing of Oral Nutritional Supplements Vol 8 No. 8 May 2014) has been produced which describes the process for nutritional assessment and intervention. We would reinforce this process. Nutritional screening should be undertaken using a validated nutritional screening tool e.g. Malnutrition Universal Screening Tool (MUST). For those identified to be at Medium or High Risk on MUST then food first interventions should be used to help increase dietary intake e.g. snacks and food fortification advice. On re-assessment, after all dietary interventions have been implemented, if the patient remains as Medium or High Risk and there is no improvement then

ONS should be considered. Goals should be set to assess the effectiveness of the intervention. Regular re-assessment should take place. Where ONS has been requested by a Dietician following individual patient assessment this should be prescribed.

#### Coeliac UK

#### Proposal 2: To restrict the prescription of gluten-free foods.

We are concerned that you are considering removing access to gluten-free food on prescription and our concerns are shared by the British Society of Gastroenterology. We are concerned that the consultation does not provide an option for continuing with the current policy for gluten-free prescribing and does not reference coeliac disease and only refers to gluten free food. Research shows gluten free foods are not readily available to purchase in budget supermarkets and convenience stores and are expensive, therefore gluten free food on prescription is especially vital for the elderly or those with limited transport.

#### **British Society of Gastroenterology**

#### Proposal 2: To restrict the prescription of gluten-free foods.

The proposed removal by CCGs of prescriptions for Gluten Free Diets poses a direct impact on the care of patients with coeliac disease, as well as wider cost implications for the health economy and we would like to put on record our support for Coeliac UK on this issue. As part of your review the BSG would urge that due regard is paid to the impact of any withdrawal of gluten free diets prescriptions on patients and wider healthcare costs. We are concerned that the consultation document lacks direct reference to coeliac disease but instead states that gluten-free foods are prescribed for people with 'particular dietary requirements'.

#### **British Specialist Nutrition Association Ltd**

#### Proposal 3: To Restrict prescribing baby milks and specialist Infant Formula.

We support the ambition to explore ways to make our health services more sustainable, to help patients to take responsibility for their own health and to reduce the need for unnecessary prescriptions. However, it is necessary to highlight the importance of 'specialist infant formulae' to

avoid any confusion with baby milks in general. It is vitally important that these products remain available on prescription as they must be used under the supervision of a healthcare professional. We believe it is important to retain the option for the doctor to prescribe such formulas when the diagnosis is made. This is necessary to ensure the baby receives the correct formula via a prescription dispensed by a pharmacist.

#### **Lincolnshire Local Pharmaceutical Committee**

As the committee representing NHS pharmacy contractors we are acutely aware of the needs of the NHS to find efficiencies. However, we believe the consultation is flawed, in particular with regard to the desire to restrict prescribing of non-prescription-only-medicine for those suffering from short term or self-limiting conditions. Community pharmacy is the most accessible NHS primary care provider and can do more to take the burden away from general practice, out of hours providers and emergency departments. We would like to see commissioners and stakeholders work with community pharmacy to develop services locally that can play a real and significant part in reducing the demand on primary and urgent care services.

With regard to the other elements of the consultation, the committee would wish to make the observation that Lincolnshire is a large, rural and to make the generalised assumption that patients have easy access to large retailers selling specialised foods and infant formula at prices comparable to normal groceries is a flawed one and provision must be made to support those patients.

#### Themes from events and meetings

In addition to the wide circulation of the consultation document, drop in events and public meetings were held in some CCG areas and others attended existing community meetings to promote the opportunities for involvement. These events were targeted to areas identified in the Equality Impact Assessment as likely to be most affected by the proposals. The drop in events were hosted by CCG Clinical Leads and offered people the opportunity to ask questions and provide feedback on the consultation proposals. Drop in sessions targeted children from low income families. Overall, over 100 people were engaged at these events and the feedback from all has been themed and summarised below:

• Surprise was expressed that prescribers can't refuse to prescribe over the counter medicines and that this agenda isn't a national one with statutory directives.

- It was recognised that CCGs are under considerable financial pressure and have to make difficult decisions
- It was questioned how GPs could enforce much of the above without legislative support and back up
- "Some felt outraged that this hadn't been introduced sooner and they were shocked at the amount of money being wasted"
- Some felt that waste medication via repeat prescribing felt like a much bigger issue and much more important to tackle as there were safety concerns as well as costs.

#### Over the counter medications:

- General agreement that proposals were sensible and patients should attend a pharmacy in the first instance other than for those medications which also have a public health implication
- Concerns that stopping prescribing medicines for long term use could have significant knock on effects
- Agreed thrush treatment should be restricted as although expensive it is usually required infrequently. However, some more expensive medications could prevent patients from getting treatment
- Concerns raised relating to Non-steroidal anti-inflammatory drugs (NSAIDs) that will bought
  over the counter and how GPs will be able to monitor the use of all medicines if patients
  purchase them themselves and how they interact with other medicines
- Nicotine Replacement Therapy was felt should not be available on prescription
- Self-care needs promotion and community support
- Education on this should be introduced at school age level

#### Gluten free products:

- Costings of gluten free foods were questioned as still felt to be more expensive than standard products and that NHS purchase price might be over inflated. Concerns for impact of proposals on low income families
- It was felt a 'no change' option should be available but general agreement to limit the supply of gluten free products as a fair compromise to prescribe only staple foods
- More support required for low income families to enable making gluten free food from scratch

#### Baby milk:

- General discussion supported restriction of prescriptions
- Expectant mums should be made aware if they plan to buy formula rather than breastfeed
   especially as some can be costly and provided with a list of products available from chemists

#### Oral nutritional supplements:

- General discussion supported restriction of prescriptions unless recovering from major or terminal illnesses
- Consideration should be given to elderly patients in rural areas whose prescribed medicines are delivered to their door
- Care homes should do more to encourage residents to eat normal food with support for staff to implement this

## Themes from telephone calls, letters and emails received from PPGs and members of the public (40)

A number of telephone calls and emails were received during the consultation process, the main points of which are outlined below.

#### Over the counter medications:

- Over the counter medications are restricted to buy in large quantities and more convenient to receive as one single prescribed pack than multiple purchases
- Frustration (some were outraged) that this hadn't been introduced sooner and were shocked at
  the amount of money being wasted. All proposals agreed with and felt it needed to be rolled
  out nationally with governmental influence and prevent a 'post code lottery'.
- If particular drugs are recommended they should still be prescribed for those who don't pay.

  "For those who do pay, they should be told the price of both options and given the opportunity to purchase it themselves over the counter"
- Suggestion that education around this should be introduced at school age

#### Gluten free products:

- It is a challenge to buy gluten free products in supermarkets and when they are available they
  are expensive
- Pensioners, particularly those in rural areas, with no transport and no local shops who sell
  gluten free food will particularly struggle if they did not receive this on prescription
- Offers made to meet with local interest groups to discuss the proposals and suggested ways of working moving forward
- "The availability of these foods is a lifeline to me as I would find it very difficult to afford the basic bread, flour etc. I do not expect to have the luxury items"
- Those with multiple dietary allergies would not know where to buy the foods they get on prescription and it isn't available in supermarkets
- Suggestion for pharmacists to see 'medical diet foods' at cost price
- Suggestion to convince the Government that action should be taken to persuade manufacturers to reduce the costs of gluten free food
- Suggestion that the NHS should negotiate and not pay more than prices in local shops

#### Baby milk:

 Request specifically to continue to prescribe Nutriprem which is for most vulnerable, premature babies and very expensive compared to normal milk. Without this, it could result in an expensive readmission to hospital. Multivitamins, especially Sytron, is also essential and not available at supermarkets

#### **General comments**

- Greater savings could be made by reforming the structure of the NHS and removing layers of bureaucracy rather than service changes which impact on patients.
- Self-care should be promoted and supported
   all patients should follow this course of action
   before consulting a GP
- Times have changed and the proposals reflect that with the availability of all of these products more widely available

Some comments and concerns have been received throughout the process regarding the consultation process itself:

- Who will make the decisions on who is prescribed medications and will it take into account financial and other health considerations?
- To change the working practice of prescribing for the whole of Lincolnshire can lead to a lot of extra work
- Consultation process considered to be too short
- Lack of specific targeting of consultation to patients
- Dissatisfaction with survey wording and no option to continue prescribing gluten free food as it is currently

#### Recommendations

- Implement the proposals, subject to formal endorsement at the 4 CCG Governing Body meetings on 30<sup>th</sup> November and 1<sup>st</sup> December 2016
- 2. Agree implementation for future restricting of prescriptions for over the counter medications or option to implement retrospectively
- 3. Agree implementation date of all proposals as 5<sup>th</sup> December 2016
- 4. Consider the outcomes of the Equality Impact Assessment alongside this consultation
- 5. Produce and implement a comprehensive marketing and communications plan to provide feedback on the outcome to the public and other key stakeholders 'You Said We Did'.
- 6. Work with key stakeholders including GPs, practice staff, community pharmacists, providers, nurseries, schools and care homes to gain support for implementation of the proposals.