Leeds Clinical Commissioning Groups Partnership

Changing the way we prescribe in Leeds

Engagement dates: March – July 2017

Assessment of Equality Impact and Engagement Report

Final Draft

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Executive summary

The NHS Leeds Clinical Commissioning Groups (CCGs) Partnership has a duty to make sure we spend our budget wisely and in the most cost effective way. If we review how we spend money we have the chance to look at how we can use it better, to pay for newer treatments and support other services.

As part of this work, we are proposing changes to the way we prescribe in Leeds. These proposals include:

- To not routinely fund gluten-free foods on a prescription basis.
- To not routinely fund a range of "over the counter" medicines on prescription.
- To not routinely prescribe branded medicines when a non-branded equivalent is available

This engagement seeks the views of and considers possible impact in relation to patients, members of the public and staff on these proposals. This report outlines the findings of the engagement.

We used surveys with patients, public, professionals and focus groups with seldom-heard communities to understand people's views on the proposed changes:

- Two thirds of people (**65%**) agreed that we should **not routinely prescribe gluten-free products.**
- The majority of people (**82%**) agreed that we should **not routinely prescribe 'over the counter' medicines**
- The majority of people (**84%**) agreed that we should **not routinely prescribe branded medicines when a non-branded equivalent is available**

- There was strong feedback that:
    - 'vulnerable groups' should be protected from any change that could have a disproportionate negative impact on their health;
    - changes to medication should be done in consultation with the patient;
    - information and support should be available to patients to support informed choice and self-care; and
    - the NHS Leeds CCGs Partnership should consider other opportunities to reduce cost

This report makes a series of recommendations to the project team at the NHS Leeds CCGs Partnership who will use the findings of the engagement and assessment of equality impact to develop guidance for GPs. These recommendations include:

- *Any future prescribing of gluten-free products should be limited to core/staple products and should be provided in a way that reduces waste and misuse.*
- *There should be clear guidance to prescribers which supports them to identify 'vulnerable' patients for whom exceptions might be appropriate.*
- *Any decision to change prescribing should consider the wider implications and national guidance.*
- *Any change in approach to prescribing should consider what information and support people need to make an informed choice to carry out self-care.*
- *The NHS Leeds CCGs Partnership should produce an update report in 2018 to outline to what extent they have met the recommendations in this report.*

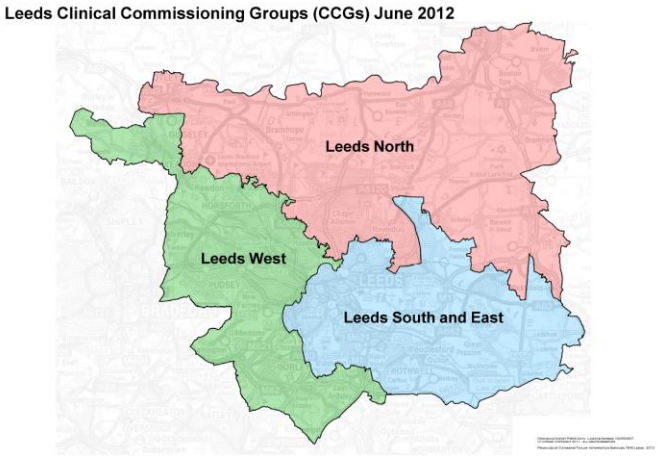
The patient feedback will also be used to inform a wider strategy for enhancing communication, access and the quality of services.

The report will be shared with those involved in the engagement and the report will also be available on the Leeds CCGs Partnership websites.

Background information

a. The NHS Leeds CCGs partnership

There are three clinical commissioning groups (CCGs) in Leeds; NHS Leeds West CCG, NHS Leeds North CCG and NHS Leeds South and East CCG. These organisations are responsible for planning and buying (commissioning) local healthcare services. The three CCGs are now working closely together under 'one voice' as the NHS Leeds CCGs Partnership, whilst currently remaining as three separate statutory organisations.



Leeds is an area of great contrasts, including a densely populated, inner city area with associated challenges of poverty and deprivation, as well as a more affluent city centre, suburban and rural areas with villages and market towns.

The most recent census (2011) indicates that Leeds has a population of 751,500 people living in 320,600 households, representing a 5% growth since the previous census of 2001. Leeds has a relatively young and dynamic population and is an increasingly diverse city with over 140 ethnic groups including Black, Asian and other ethnic-minority populations representing almost 19% of the total population compared to 11% in 2001. There are currently 105 GP practices in Leeds.

Involving people and the public in developing and evaluating health services is essential if we want to have excellent services that meet local people's needs. It is our responsibility, and one that we take very seriously, to ensure that our local communities have the opportunity to be fully engaged in the decisions we take.

b. Prescribing in Leeds

The NHS Leeds CCGs Partnership has a duty to make sure we spend our budget wisely and in the most cost effective way. Your thoughts on how we spend it are important. If we review how we spend money we have the chance to look at how we can use it better, to pay for newer treatments and support other services.

What are we proposing to change?

- To not routinely fund gluten-free foods on a prescription basis.
- To not routinely fund a range of "over the counter" medicines on prescription.
- To not routinely prescribe branded medicines when a non-branded equivalent is available unless there is a medical reason.

Ultimately, the GP will work with individual patients to make the final decision about their medication, using official and recommended guidelines. They will take into account people's individual circumstances and condition to make an informed decision. This will ensure that people receive the best and most effective care, whilst also helping the NHS be more efficient.

This engagement was to seek the views of patients, members of the public, staff and voluntary organisations.

Due to the announcement of the General Election, the consultation period for this engagement was extended.

c. Third sector engagement support

Two local voluntary sector organisations supported our engagement work. Leeds Involving People (LIP) and Voluntary Action Leeds (VAL) used their skills, knowledge and contacts to engage widely with the general public and seek the views of 'seldom heard' groups. They held a series of events and activities in the community and we have used their feedback in producing this report.

1. How did we identify and engage with stakeholders?

When we propose to change services it is important that we understand who the changes might affect and make plans to engage with all the groups that might be impacted.

These proposed changes will affect everyone in Leeds and so engagement was open to all citizens; this includes patients, the public, professionals and any other interested stakeholders (such as voluntary groups). While these proposals will impact on everyone who lives in Leeds, we know that some groups might be disproportionately affected.

We carried out an equality analysis to understand how these changes might affect people with different protected characteristics. Intelligence suggests that:

- People with long-term conditions and/or disabilities are more likely to be affected by the proposed change.
- The proposal could reduce demand at GP practices, freeing up appointments for people with more urgent needs.
- People can make dietary changes providing they are given guidance but changing that lifestyle maybe difficult for some groups.
- Low income households or people with mobility problems may be more affected by the withdrawal of gluten-free prescriptions (disability, deprivation).
- There is no strong clinical evidence that patients who receive gluten-free food on prescription are more likely to comply with a gluten-free diet or have better health outcomes than those who don't.

To ensure as many people as possible had an opportunity to be heard we promoted the engagement widely and provided different ways for people to share their views.

The equality analysis and engagement plan also suggests the change will have a greater impact on people who are exempt from prescription charges: families/carers of children and young people; pregnant women or new mothers; patients aged 60 or over; patients with long term health conditions.

We used this intelligence to develop an engagement plan which was taken to our Patient Assurance Group for scrutiny. We agreed to develop a stakeholder survey based on a similar approach carried out at NHS Wakefield CCG. This survey was shared widely with our patients, the public, professionals and wider stakeholders

Group	Who	Methods	How did we engage?
Patients and the public	All Leeds citizens	• Survey (available online and in paper copies)	• Posters and surveys in GP practices • Social media • Website • Public engagement by the engagement team and LIP • Via voluntary services • Via various patient and community networks
	Seldom heard groups	• Focus groups	• Using our third sector engagement support
Professionals	NHS staff, pharmacy staff, GP surgeries and staff	• Survey	• Briefing emails • Posters in GP practices • Pharmacies
Voluntary sector	Shared with the voluntary sector via VAL, charities	• Survey	• Contacted groups directly affected by the proposal by email, including: o Equality Leeds o Leeds Jewish Welfare board

			○ Black health initiative ○ Carers Leeds ○ Age UK Leeds ○ Leeds Medical society ○ Stonewall ○ Leeds GATE ○ St. George's Crypt ○ Simon on the Street ○ St. Vincent's ○ Leeds Poverty Truth ○ Samaritans ○ Leeds Academic Health Partnership ○ Leeds Citizen ○ Health for All ○ Recovery Leeds ○ Feel Good Factor ○ Mumsnet Leeds ○ Womens Health Matters ○ Getaway girls ○ Healthwatch Leeds ○ Better Lives Leeds ○ Barca ○ Touchstone ○ Emmaus ○ Better Leeds ○ Young Lives Leeds ○ Shoutout Leeds ○ Advonet ○ Volition ○ Inkwell ○ Time to Change Leeds ○ Student Minds ○ Community Links ○ Mencap ○ Leeds autism Services ○ Down Syndrome Leeds ○ Tenfold ○ People Matters Leeds ○ Inclusion North ○ VODG (Vol. Organisations Disability) ○ Change ○ People in Action ○ Foundation for People with Learning disabilities ○ Age Friendly Leeds • Shared widely via Voluntary Action Leeds network
Wider stakeholders	Councillors, MPs, Coeliac UK, Leeds Local Medical Committee, Scrutiny Board	• Survey	• Briefing letter/email • Example survey sent to all councillors and MPs • Telephone consultation with Coeliac UK after offer to meet face to face was declined.

We commissioned the voluntary sector to carry out targeted engagement work.

Leeds Involving People (LIP)
LIP carried out various events and activities with the public. They supported **1012** members of the public to fill in our survey.

Public places and GP practices where LIP held activities:

- One stop centre, Great George St
- Reginald Centre

- Otley library
- Compton Centre
- Bitmo Gate
- Horsforth Community Centre
- St Matthews Community Café
- Burley Brunch Club
- Dewsbury Road One Stop Centre
- St Georges Minor Injuries Unit
- Shadwell Medical Centre
- Kippax Health Centre
- City View Medical Practice
- Oakwood Lane Practice
- Chapeltown Family Surgery
- Armley Medical Practice
- Rawdon Surgery
- Swilington GP practice
- Cross Gates GP practice
- Meanwood Road GP Practice
- Westfield Surgery
- Craven Road and Holly Bank Surgeries
- Crossley Street Surgery, Wetherby
- Chevin Medical Practice (Bridge St, Bramhope, Charles St)

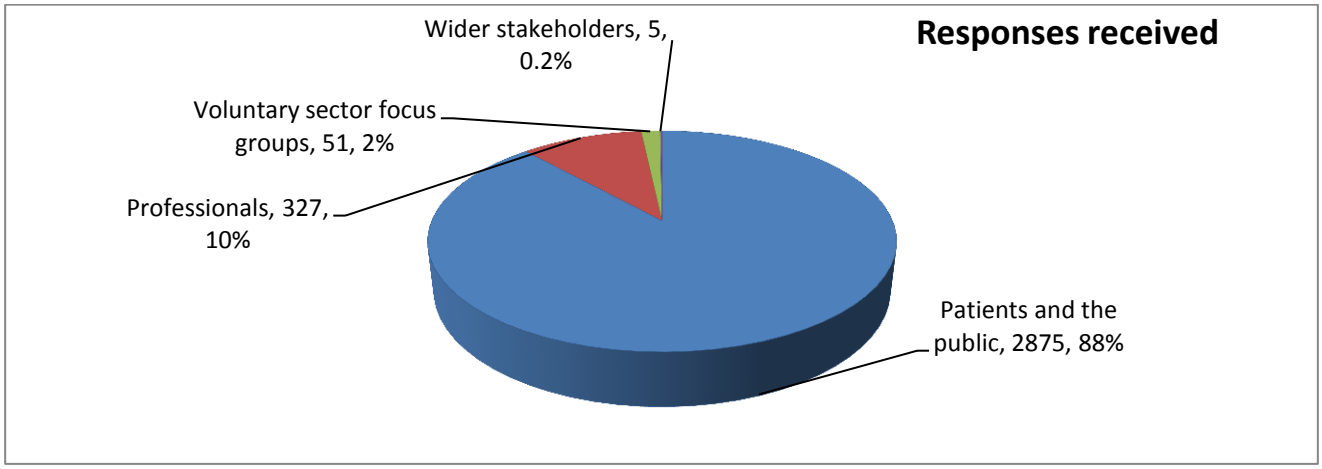
Voluntary Action Leeds (VAL)
VAL carried out a series of focus groups with 'seldom heard' communities. They supported **51** people to share their thoughts on the engagement.

There were focus groups arranged to discuss the consultation with the following groups:

1. **Young Dads @ Health for All** – (**seven** participants)
   http://www.healthforall.org.uk/?pid=79
2. **People with learning disabilities @ TCV Hollybush** – (**seven** participants)
   https://www.tcv.org.uk/hollybush
3. **People recovering from dependency - Recovery Academy @ Forward Leeds** – (**eight** participants)
   http://www.forwardleeds.co.uk/venue/leeds-recovery-academy-3/
4. **Adults with disabilities @ Paperworks** – (**four** and **eleven** participants)
   http://www.tenfold.org.uk/membership/member-profiles/paperworks/
5. **Support service for families who are experiencing difficulties while bringing up young children @ Home-Start** (**nine** participants)
   http://www.home-startleeds.co.uk/
6. **Eastern European Women's Group, Armley – Touchstone** – (**five** participants)
   http://www.volition.org.uk/eastern-european-conversation-club-armley/
7. **Black and Ethnic Minority (BME) Diabetes Project – Touchstone** – (groups cancelled due to pre-election period)
   https://www.touchstonesupport.org.uk/services/bmediabetesprogrammeleeds/

3. Who replied?

In total **3,259** people/organisations contributed to the engagement. Feedback was received from the following groups;



4. What did patients and the public tell us?

a. What did patients and the public tell us about gluten-free products?

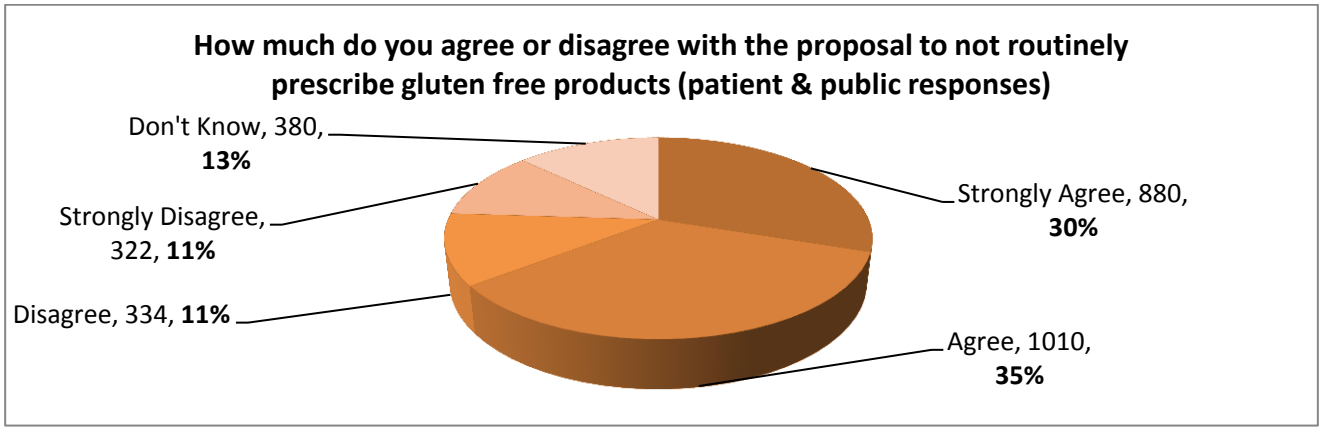
2,926 patients and members of the public filled in this section of the survey.

6.7% (194 out of 2,926) of those people currently receive gluten-free products on prescription.

5.7% (168 out of 2,926) of the patients and public who had responded had cared or currently care for people who receive gluten-free products.

65% (1,890 out of 2,926) of patients and the public who completed the survey **agreed that we should not routinely prescribe gluten free products**.

48% (93 out of 194) of people who receive gluten free products for themselves or someone they care for **agreed** that we should not routinely prescribe gluten free products.



70% (2,058 out of 2,926) of patients and the public who responded offered additional comments to tell us more about their answer. There were a number of key themes that emerged:

In agreement with the proposal

65% of patients and the public were in agreement that we **should not routinely prescribe gluten-free products**:

- *"As a person with a gluten intolerance I fully understand the need to follow a correct diet, however, I do not, nor have I ever believed that any part of a gluten-free diet should be NHS funded. This proposal is, in my opinion, the correct move in managing a budget."*
- *"I agree, but discretion has to be used in implementing this proposal, as is implied by the phrase "to not routinely prescribe". I would not want it to become a hard and fast ruling."*
- *"I fully agree with this proposal. My partner is gluten intolerant. Supermarkets now fully cater for a gluten-free diet and the price of substitute foods is coming down. Certainly the NHS should not be paying for this. Our diet mainly consists of naturally gluten-free foods anyways.*

Cost of gluten-free foods

Some people raised concerns that **gluten-free products are expensive in the supermarket**:

- "*Gluten-free foods are expensive, even at the supermarket. If I had a condition that required to live a gluten-free diet and had a low income I would not be able to manage."*

Some people argued that the **cost to the NHS (of prescribing, the appointment, administration and produce) outweighed the cost to the patient** and that people should be encouraged to change their diet and lifestyle:

- *"[I agree with proposal] if it costs more for the NHS to supply gluten-free products on prescription than to buy them from a supermarket. And that other naturally gluten-free foods are widely available e.g. potatoes, rice, corn AND that GPs will and sensitively advise patients of this."*
- *"I know several friends and neighbours who currently take advantage of this [gluten-free prescriptions]. All of them can afford to purchase themselves. I have found it wrong for many years, when the NHS needs every penny to be spent wisely, which it seems currently unable to do."*

Many people suggested that gluten-free products should be more affordable and that the NHS had a **responsibility to source affordable gluten-free products and negotiate better rates**:

- *"Why can't the NHS, with its purchasing power, negotiate better rates for gluten-free products?"*
- *"I feel it is unfair for coeliacs to be punished due to the poor procurement policies within the NHS with high delivery charges etc.; it should be noted that some suppliers do not charge a premium."*

Some people felt that this approach to gluten-free foods is a **'false economy'** and could lead to increased costs to the NHS in the future

- *"For gluten intolerant people, access to gluten-free products is essential to maintain health – if the diet is not followed, there are long term health effects which would cost the NHS more money, e.g. bowel cancer, osteoporosis, hospital stays etc."*

Vulnerable groups

A lot of people had indicated that they were in favour of not routinely prescribing gluten-free foods on prescription on the condition that **people who are not able to afford the items would still be able to access their gluten-free prescriptions**:

- *"I agree in principle but feel concerned about vulnerable patients. Those with mental health problems or no income, the homeless, asylum seekers and the isolated elderly. When it is understood that GPs will not prescribe, can we just assume a person will just go shopping?"*
- *"Gluten-free food is a lot more expensive. I think it will put people at risk who are on a lower income or pensions to have to make a decision between eating food which is cheap but can make them ill and to buy less food."*
- *"People on their pension or on benefits should still receive gluten-free on prescription and they would need to provide confirmation that they are in receipt of said pension/benefit."*
- *"It would adversely affect my health, as I am on benefits; I am a carer for my disabled daughter. I cannot afford a lot of the gluten-free foods at the supermarket."*

There were also concerns raised about the impact on **patients who are coeliac and have other conditions** or impairments (such as diabetes/learning disabilities):

- "*I suffer from chronic fatigue and other long-term medical conditions that can make cooking from scratch difficult."*
- "*As part of the consultation with the GP, the patient needs to inform them why a prescription for gluten-free is required: reading issues (illiterate, dyslexia, non-English speaker, sight impaired) which makes reading labels difficult.*

Availability of gluten-free foods and alternatives

People acknowledged that the **availability of gluten-free products** has vastly increased and that finding gluten-free products is easier than it was:

- *"I think gluten-free is more readily available now! Supermarkets have specific areas which are clearly marked out."*
- *"Gluten-free foods are more widely available in supermarkets therefore gluten-free foods do not need to be on prescription, plus there are also natural gluten-free foods which are normal staples in a healthy diet."*

Some people commented that there will be some who will **struggle to access** them, however:

- *"My local shops do not stock gluten-free food necessitating a car or bus trip."*
- *"Reading issues (illiterate, dyslexia, non-English speaker, sight impaired) makes reading labels difficult [for some people]."*

Education and awareness

Many people believed there is some work needed on **educating people on living a gluten-free lifestyle**:

- *"Recommending local cooking courses may offer better long-term success."*
- *"I think that suggestion leaflets on suggested diets or talking to a dietician maybe better."*

Inconsistency in prescribing

There were a number of comments about addressing the **inconsistency of prescribing**:

- "*I quickly become ill if I eat or drink anything containing dairy or cocoa. I have to check carefully everything I purchase. No prescription for this, I have to stand any extra costs."*
- *"Those with a nut allergy are advised by clinical practitioners not to consume nuts and to check food packaging for exposure to nuts and nut-containing products – the NHS does not fund nut-free food."*

Compromise, solutions and considerations

Many people suggested that some of the **"core/staple" items could remain on prescription** (such as bread, pasta and flour) but that "luxury items" (biscuits, pizza bases etc.) should be removed:

- *"Biscuits, cake mixture and pizza bases should be taken off prescription because you can buy those in the local supermarkets and they are certainly not "essential". Items such as flour and pasta, which form staples, should still be available to those who cannot afford it."*

Another solution suggested by many people is to arrange a **discount/voucher system for people to save money on gluten-free products** in supermarkets:

- "*I would suggest that local providers begin a conversation with one of the local based supermarkets, like Morrison's, about providing either some sort of price reduction over all, or at least a subsidised offer to those who 'carry a card' from their GP indicating they have a condition.*"

Some people suggested that changes to the way gluten-free products are prescribed could **reduce waste and misuse**

- *"I have stopped getting breads on prescription as I think it is diabolical that I have to order a minimum of eight items per script. I use two slices per day and have a very small freezer!"*
- *"I know several people who don't pay for their prescriptions and yet receive boxes and boxes of pasta each month, which they give away to relatives."*

Feedback on gluten-free products from our focus groups

1. **Young Dads Group (seven participants – young men)**
   - None of the participants received gluten free prescriptions
   - Four participants agreed that we should not routinely prescribe gluten-free products.

"If you have a condition and you need to eat specialised food there is no additional support from benefits."

"GPs should offer more guidance on where you can get gluten-free food."

2. **TCV Hollybush (seven participants with learning difficulties)**
   - None of the participants received gluten free prescriptions
   - All seven participants agreed that we should not routinely prescribe gluten-free products.

"I don't trust the doctor's discretion – it depends on what doctor you have. It's easy to brush off young women."

"It's cheaper now to get stuff from the shops."

3. **Recovery Academy – Forward Leeds (eight participants in recovery from drug or alcohol dependency)**
   - None of the participants received gluten free prescriptions
   - Participants were divided on whether we should not routinely prescribe gluten-free products.

"If you are on benefits or low income you should definitely receive it."

"I'm a diabetic. I have to have a healthy diet – I just cut out the food I can't have."

4. **Paperworks (two focus groups, one with four participants and another with 11 participants with disabilities)**
   - None of the participants received gluten-free prescriptions.
   - One person's mother receives gluten-free prescriptions.
   - Most of the participants agreed that we should not routinely prescribe gluten-free products.

"If you don't live near a supermarket, like in a tiny village, you may only have limited access to gluten-free foods."

"It would be cheaper to subsidise the "Free From" range in supermarkets – make it cheaper."

5. **Home Start (nine participants from families with difficulties raising young children)**
   - None of the participants received gluten-free prescriptions.
   - One participant's recently deceased husband received gluten-free prescriptions. One participant's daughter is gluten intolerant but does not receive gluten-free prescriptions and two other participants have non-immediate family who receive gluten-free foods on prescription.

"If people can afford to pay for gluten-free food then they should."

"They should limit the types of gluten-free products to the essentials such as bread and pasta, don't include the luxuries."

6. **Eastern European Women's Group Armley – Touchstone (five participants of Eastern European descent)**
   - None of the participants received gluten-free prescriptions.
   - Most of the participants agreed that we should not routinely prescribe gluten-free foods.

"ASDA and Morrison's have lots of gluten-free foods, every shop now has."

"The NHS can use the money for something else."

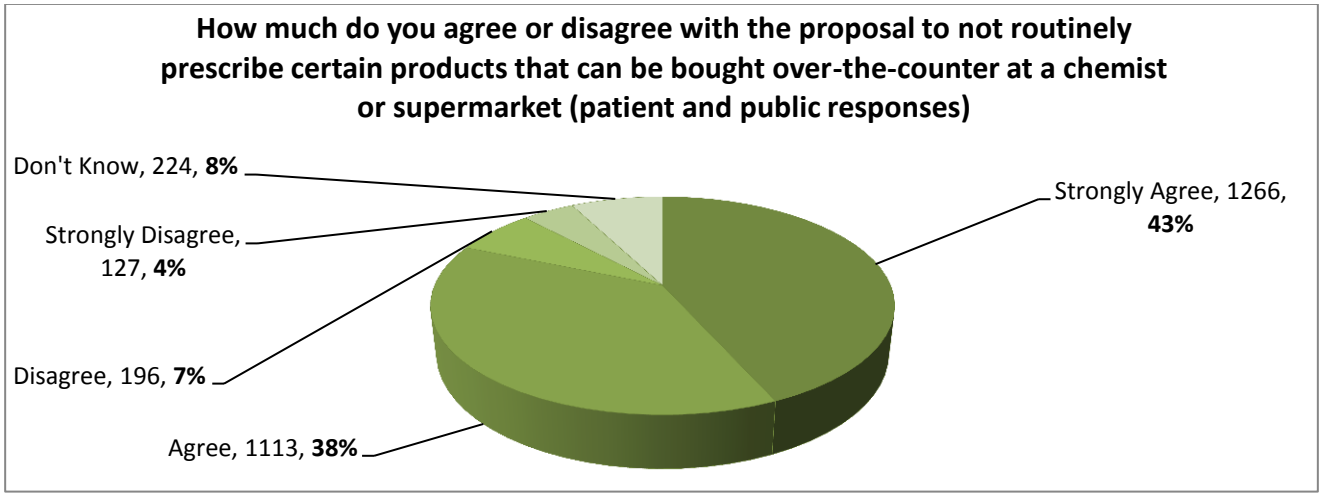
b. What did patients and the public tell us about over-the-counter medicines?

2,926 patients and members of the public filled in this section of the survey.

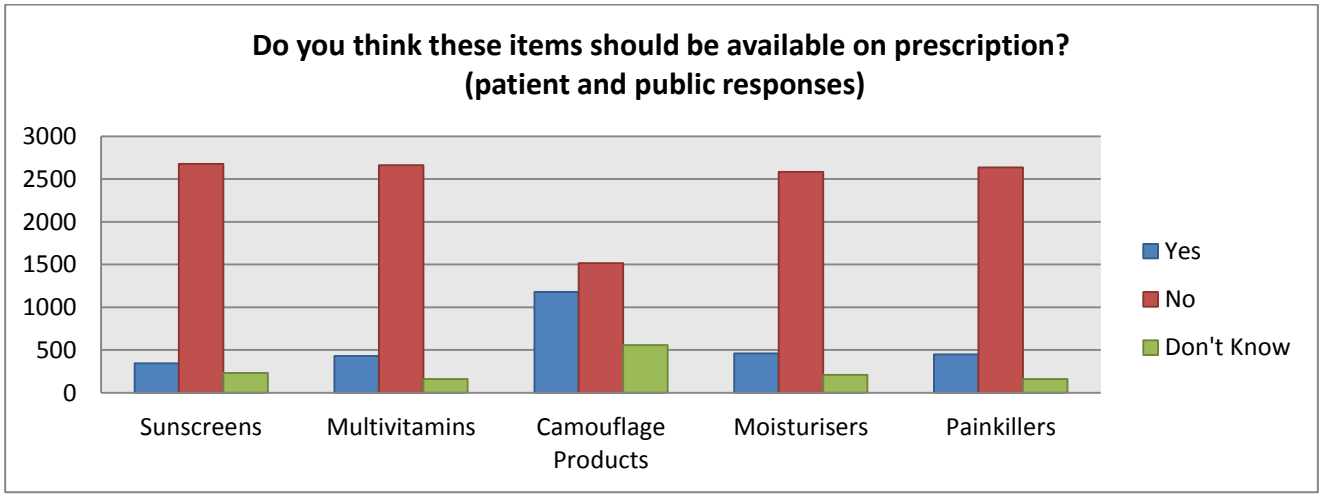
29% (848) of those people indicated that they currently receive over-the-counter medicines on prescription.

41% (1,207) of the patients and public who had responded had cared or currently care for people who receive over-the-counter medicines on prescription.

81% (2,379) of patients and the public who completed the survey **agreed that we should not routinely prescribe over-the-counter medicines**.



We asked people to tell us which items they thought should be available on prescription:



65% (1,888) of patients and the public who responded offered additional comments to tell us more about their answer. There were a number of key themes that emerged:

In agreement with the proposal

81% of patients and the public were in agreement that we **should not routinely prescribe over-the-counter medicines**:

- *"I agree providing that people who genuinely need these products for long-term conditions are not excluded."*

- *"This is a totally fair proposal. Shampoos, multivitamins and sunscreen are things that we all choose to use or not to use. They are not, in most cases, essential medical products."*
- *"I agree as a cost saving measure because generally it is cheaper to buy over-the-counter."*

Vulnerable groups

Many people were concerned how this proposal might **affect people on low-incomes** (benefits, pensions etc.). They told us that they would support the proposal, providing people with low-incomes could still receive items they need on prescription, if required:

- *"People shouldn't be put at a disadvantage if they are unable to afford the products they need to keep healthy. People on low-incomes should definitely still be able to access these items on prescription."*
- *"Disadvantaged families may choose not to buy over the counter paracetamol or ibuprofen when their child is ill. Same for eczema in children – emollients are essential and withholding these scripts is near neglect. Refusing these prescriptions to parents is not in the best interest of the child."*

Additionally people agreed with the proposal with the proviso that **individual circumstances (such as long-term conditions) are considered** and that vulnerable groups with these conditions can still access items on prescription when appropriate:

- *"I think sunscreen might be available if someone has a history of skin cancer"*
- *"My husband is prescribed paracetamol for a long-term condition and it would simply not be practical to source it from supermarkets (i.e. I would need to make several visits to get enough of a supply). So I am glad to see an exception is being made for long-term conditions."*

Patient/GP partnership – an individual approach

Patients and the public commented that **GPs need to work with the patient** to discuss individual treatment options:

- *"I asked to come off my anti-inflammatory for sciatica as since retirement I found it better to walk off the pain and didn't want too many tablets. My doctor agreed and suggested I just take paracetamol as and when."*

Patients and the public also suggested that where possible **patients need to be empowered to take responsibility for their own health**:

- *"Is there a system to let me put up what I am taking onto my electronic medical records? That way a doctor has all the information of what I have been taking so they have a better history for when trying to diagnose or identify an issue."*
- *"This isn't just about the cost of the prescribed products, it's about the time wasted by the GP in seeing the patient, writing the prescription, issuing repeats and that of the pharmacy staff in processing the prescription. People need to take responsibility for these things themselves if they can."*

Cost of over-the-counter medicines

Many of the respondents acknowledged that medicines **can often be found cheaply over the counter**:

- *"Paracetamol can cost as little as 15-20p in the shops but a prescription costs the*

NHS significantly more."

- *My GP likes to give prescriptions for medicines that I could buy cheaper over the counter anyways – the Lloyds pharmacy never flag this up with me when I take the script in either. I once paid £8 prescription charge for a Diprobase ointment that I could buy online for £2.40. Save us all some money and stop this – please."*
- *"The savings would be massive and if there is very little cost to the patient then stop prescribing.*
- *"The savings made could help other areas of the NHS."*

Some people felt that this approach is a **'false economy'** and could lead to increased costs to the NHS in the future:

- *"I am concerned about people who have been advised to take vitamins to prevent deficiency on a long-term basis as cost again could lead to non-compliance and ultimately lead to more expensive problems to the NHS i.e. osteoporosis > fractures."*
- *Camouflage creams can enable the patient in many ways, particularly psychologically, if they are no longer available on prescription and the patient is unable to afford to purchase, it could lead to anxiety, depression which in turn could have a greater cost to the health of the nation with potentially days lost at work, increased prescription of anti-depressants, counselling as well as suicide in some cases."*

Responses also highlighted a perceived **amount of significant wastage** in the NHS:

- *"I know of someone who routinely ordered paracetamol even though they didn't need it, because it was free and ended up with a huge stock pile."*

Camouflage products

A lot of people who responded noted **the potential psychological impact of not being able to access camouflage products on prescription**:

- *"Someone who needs to use a product on a daily basis will need extra support if they are on benefits as it will be a substantial cost."*
- *"I have reservations about not prescribing camouflage cream for those with disfigurements and scars as this could cause great mental suffering for some individuals."*
- *"Specialist makeup products are HORRENDOUSLY expensive and to deny them to those who need them is very cruel."*

Additionally, people stated that **the camouflage products require additional support in order to make them effective** and so would need specialist input to feel confident in their use:

- *"If long-term support is required, pay for makeup specialist to teach techniques then the patient can do it themselves."*

GP capacity

Many people acknowledged that reducing the availability of the over-the-counter medicines on prescription would **free up resources at the GPs**, allowing more appointments to be available to people who need them:

- *"If a prescription is free to a patient – this is all they will see, not how much it costs anyone else as it isn't affecting them that way. However, if you were to explain this to patients in terms of clinical/appointment time within practice that is wasted and what the money that was spent on those sorts of over the counter meds could have used for e.g. extra staffing for more appointments this may have more of an effect on the*

way patients think about this in the future for the sake of costing them less in the chemist/supermarket."

This would lead to an **increase in pharmacy use**, which people acknowledged is a good thing, providing that pharmacies can handle the increase in traffic:

- *"I guess, ideally, more and more people will be using the pharmacies as opposed to their GP in the first instances for mild conditions. Will pharmacies be able to handle the increase in people coming through the door and still provide the same guidance and service without detriment to the patient?"*

Education and awareness

People felt that better **education and information** could help people make better choices about over-the-counter medications and empower them to take a more active role in their own health.

- *"Advice could be available to assist patients willing to purchase their own medical products."*
- *"I definitely think more education is needed, even just to ensure people know how to take their medications. I had no idea that long-term ibuprofen use can cause gastric issues."*
- *"It would be good if the NHS did a webpage that linked to some reliable suppliers as some of these products are difficult to source without a prescription, like the camouflage products. I wouldn't mind paying and getting my own skin camouflage products without involving the GP and pharmacies but I wouldn't know how to source the right products I need from reputable people."*

Some people suggested that without "endorsement" from professionals the **importance or value in over-the-counter medicines** could be reduced:

- *"There could be a dilution of the message/requirement to use a product that can be purchased over-the-counter i.e. if the NHS won't fund it – it can't be that important!"*
- *"I think there is a certain mind set in some people that feel that 'getting it from the doctor' proves they have a medical condition."*

Availability

Many patients acknowledged that they would buy their own medicines if they could, but have found that they are **limited to how many they could buy over-the-counter**:

- *"The only issue I would have with this is if you have been advised to take pain killers (such as paracetamol) routinely for say 5-7 days taking the maximum dose per day. I have recently done this and unfortunately you can only buy limited supply of pain killers in most supermarkets so have to either shop around to get them all in one shopping trip or have to stock up after a few days which can be inconvenient if you're ill."*

Compromise, solutions and considerations

Some people suggested that **a note from the GP** might help them by large amounts of drugs over-the-counter:

- *"I would be happy to buy over-the-counter if it was made possible that I could buy enough, perhaps a special ID card?"*
- *"Another alternative would be for GPs to give patients a note to allow them to buy*

larger quantities over the counter if they needed them."

Many people made other suggestions as to **how the NHS could save money**:

- *"You should look at people who get help to stop smoking, should they be free or self-funded with support from the GP?"*
- *"I don't think aspirin should be prescribed."*
- *"I think anti-histamines and aspirin shouldn't be prescribed either."*

Feedback on over-the-counter medicines from our focus groups

1. **Young Dads Group (7 participants)**

- All 7 participants agreed that we should not routinely prescribe over-the-counter medicines.
- All seven participants said none of the listed items should be available on prescription except camouflage products, where all seven said this should be available on prescription.

"Aspirin costs pennies."

"A friend gets all the stuff for the bath, sometimes gives it away as gets so much stuff."

"With birthmarks and scars from self-harming it needs to be more considered. It could have effects on their mental health."

2. **TCV Hollybush (seven participants with learning difficulties**

- Most of the participants agreed that we should not routinely prescribe over-the-counter medicines but with caveats depending on individual circumstances.

"What is a minor skin irritation? It's not clear so it is hard to make an informed decision."

"I got a tattoo to cover the birthmark on my arm."

3. **Recovery Academy – Forward Leeds (eight participants in recovery from drug or alcohol dependency)**

- Most of the participants agreed that we should not routinely prescribe over-the-counter medicines.
- Most participants said that the listed items should not be available on prescription. An exception to this was camouflage products.

"I had a deficiency due to my addiction and lifestyle. I had no money so I relied on the vitamin drinks from mv doctor"

"Some chemists get you on repeat prescriptions. They convinced me that they would deliver them to my house. I thought this was a good idea but then they kept coming every week with carrier bag full of medicines and they wouldn't take it back."

4. **Paperworks (two focus groups, one with four participants and another with 11 participants with disabilities)**

- Most of the participants agreed that over-the-counter medicines.

"Needs to be education about what type of sunscreen to use – what does SPF and UV filter mean, when do you use it? At least if it is prescribed the person is getting the right type for their skin. This is especially true for someone with learning difficulties."

"If you have a scar on your face it can have a huge impact on your self-confidence, which affects everything else."

5. **Home Start (nine participants from families with difficulties raising young children)**

- Eight of the participants agreed that we should not routinely prescribe over-the-counter medicines and one participant disagreed.

"I can afford to buy emollient so I shouldn't have a prescription."

"There needs to be an approach to look at each person's situation individually and how their condition impacts them and then make a decision. It can't be a blanket approach."

6. **Eastern European Women's Group Armley – Touchstone (five participants of Eastern European descent)**

- Most of the participants agreed that we should not prescribe over-the-counter medicines.

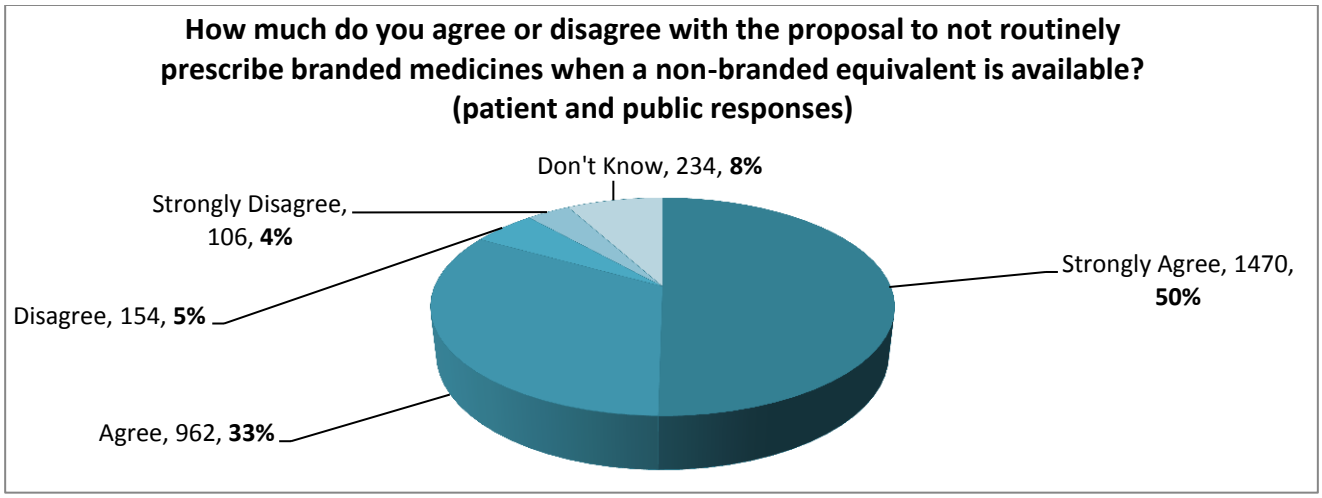
"You can buy all the creams from the shop – there's no need to prescribe them when it is mild."

"If you've had skin cancer – you need to make sure people are protected."

c. What did patients and the public tell us about branded medicines?

2,926 patients and members of the public filled in this section of the survey.

83% (2,432) of patients and the public who completed the survey **agreed that we should not routinely prescribe branded medicines** when a non-branded equivalent is available.



66% (1,944) of patients and the public who responded offered additional comments to tell us more about their answer. There were a number of key themes that emerged:

In agreement with the proposal

83% of patients and the public were in agreement that we **should not routinely prescribe branded medicines** when a non-branded equivalent is available:

- *"I see absolutely no reason to prescribe branded products when generic items of the same quality are available."*
- *I agree, I'm not bothered what kind of medicines I receive as long as it makes me or my family better."*
- *"I agree, provided that the option to prescribe the branded goods is available where there is a need through allergy or the non-branded medicine causes a problem."*

Performance of non- branded medicines

Patients and the public often discussed that they would support this proposal providing the **non-branded medicines perform in the same way as the branded equivalent** and do not have a negative impact on people's existing conditions:

- *"The name/brand of a product is not relevant. Provided that the active ingredients are the same and the non-branded alternatives are as effective then they should be prescribed rather than the branded versions."*
- *"I agree as long as those individuals who need a more expensive alternative for all medications are able to receive them, and that any issues they have with alternatives are properly listened to and considered."*

Patients wanted assurance that any **changes in medications are monitored**:

- *"Having seen the devastating effect a generic can have on a person I think that there should be a follow-up appointment made to assess how the patient is getting on and tolerating a new brand."*

Education and awareness

A lot of patients and the public felt that **better information** needs to be provided to ensure people (including staff) know that what they are receiving will do the same job and that the 'active ingredients' are the same:

- *"I suffer with eczema and was prescribed Diprobase. One day, without warning, the GP changed my prescription to Zerobase."*
- *"Patient education will be required to accept non-branded versions, which the GP and pharmacists are ideally placed to provide."*
- *"If patients are not confident in the medication it could result in repeated return visits to the GP if they are convinced they are not working."*

Patients and the public thought it would help people understand the situation better if the **costs of medications, and other NHS services, were more transparent**:

- *"Where does the money for a prescription charge go?"*
- *"Why do Scotland, Ireland and Wales get free prescriptions but England doesn't? We are all in the UK. Surely if everyone paid for their prescriptions as we do then there would be more money in the NHS overall?"*

Costs

Many of the respondents were surprised at the high costs of branded medicines, they acknowledged that it would save the NHS a lot of money and suggested that **drug companies were taking advantage of the NHS**:

- *"I have thought for a long time that companies are ripping off the NHS on a major scale. How can they justify a price over 56 times the price of the generic brand?! Why don't the NHS simply buy in generic brands and issue them through surgeries and chemists, rather than line the pockets of big companies?"*

Some of the feedback suggested that patients wanted to **choose to pay more for branded medicines** and recoup the cost if a cheaper brand was being prescribed:

- *"I pay for medicines myself, so does it mean that I will pay the prescription charge to get a medicine or will I get it for the £1 price mentioned in this document. I know the NHS doesn't want to overpay, but I don't want to overpay too."*
- *"Would there be a possibility of a patient being able to purchase or pay the difference in price between a branded and a non-branded medicine if they prefer the more costly medicine?"*

Research

Some patients raised concerns that switching to non-branded might impact **drug research**

- *"I do not know enough to be aware of the impact on pharmaceutical companies – is this likely to prevent them from developing new drugs?"*

Consistency of prescribed medicines

Patients told us that their **medication varied in colour, shape and packaging** and that this often lead to confusion:

- *"In many pharmacies for patients on multiple daily medications the following issues can occur:*
    - *A plain white box is used for packaging.*
    - *There isn't an information sheet.*
    - *The medication is a different colour to last time.*

If the patient has poor sight, or mental health problems, dementia or learning difficulties this could be confusing. These are all safety issues and happen more frequently as pharmacies purchase whichever generic drug is cheapest."

- *"Providing generic medication can be confusing for the elderly or those with cognitive impairment. Different brands of the same generic medication can cause confusion because their appearance can be different. Is, at the end of the day, this going to cause more confusion and work for GPs and pharmacists providing assurance that the medication is indeed the same in each packet?"*

Feedback on branded medicines from our focus groups

1. **Young Dads Group (7 participants)**
   - All 7 participants agreed that we should not routinely prescribe branded medicines when a non-branded equivalent is available.

> *"If both achieve the same results, then it makes sense."*

2. **TCV Hollybush (seven participants with learning difficulties**
   - All seven of the participants agreed that we should not routinely prescribe branded medicines when a non-branded equivalent is available.

> *"If it works well then buy the other one."*

3. **Recovery Academy – Forward Leeds (eight participants in recovery from drug or alcohol dependency)**
   - All nine participants agreed that we should not routinely prescribe branded medicines when a non-branded equivalent is available.

> *"It depends on the individual doctor."*

> *"Meds change packaging all the time – it's confusing."*

4. **Paperworks (two focus groups, one with four participants and another with 11 participants with disabilities)**
   - All participants agreed that we should not routinely prescribe branded medicines when a non-branded equivalent is available.

> *"Prescribe the cheaper one, unless the ingredients are not the same and you might be allergic to them."*

> *"I don't want the NHS to a pay a lot of money."*

5. **Home Start (nine participants from families with difficulties raising young children)**
   - All participants agreed that we should not routinely prescribe branded medicines when a non-branded equivalent is available.

"There should be prescription reviews, I've never had one."

"You have to ask to have medicines removed from your repeat prescription if they are no longer needed – it is not automatic so there is so much wastage and unnecessary prescribing."

6. **Eastern European Women's Group Armley – Touchstone (five participants of Eastern European descent)**
   - All participants agreed that we should not routinely prescribe branded medicines when a non-branded equivalent is available.

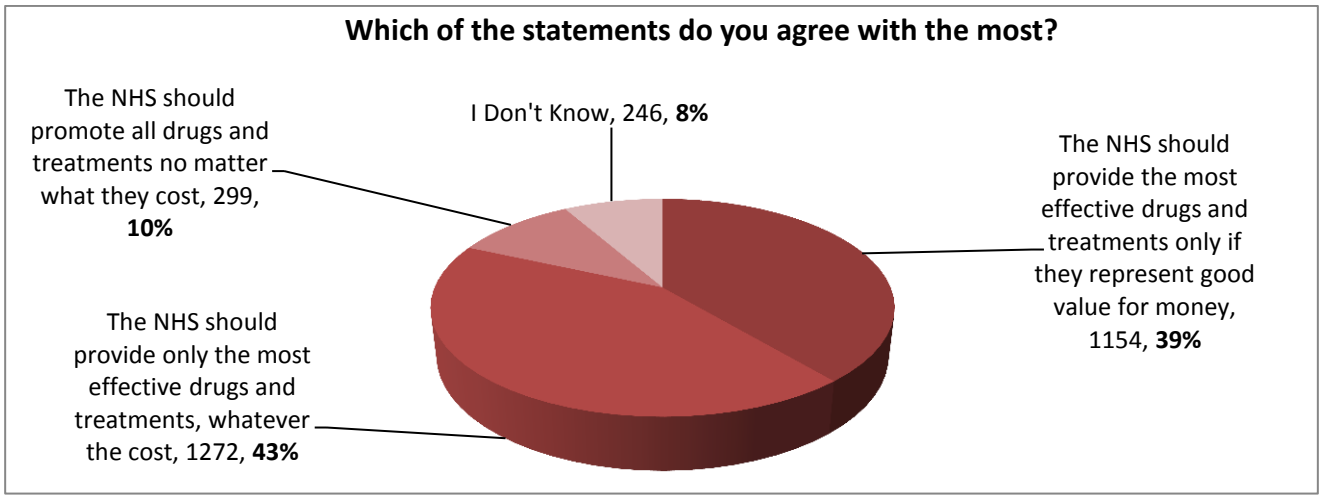
"Doctors say there's no money for tests as they need to save money, so why prescribe expensive branded medicines?"

"Branded meds should be excluded if non-branded is available, so long as it has the same effect."

d. Your Views

Before any decision is made, it is important for us to gather any additional views of patients and the public regarding these proposals. Patients and the public were asked to consider three statements and indicate which one they agreed with most:

a. "The NHS should provide the most effective drugs and treatments only if they represent good value for money."
b. "The NHS should provide only the most effective drugs and treatments, whatever the cost."
c. "The NHS should promote all drugs and treatments no matter what they cost."



22% (646) of patients and the public who responded offered additional comments to tell us more about their answer. There were a number of key themes that emerged:

Management costs

Some patients and the public felt that **reducing management costs** could save the NHS money:

- *"Money should be channelled into services and medications NOT in to paying the enormous salaries of several layers of management."*
- *"Stationery and other supply budgets need to be seriously reviewed as well! I used to work for the NHS and our stationery prices that we were forced to pay were 75% higher than other local suppliers."*

Waste

Some patients and the public felt that **reducing waste** could save the NHS money:

- *"There seems to be willingness to just waste medication, I was admitted to hospital recently and I brought all my current medications with me, which was freshly dispensed, the staff took the medication off me and disposed of it, without telling me. It does seem odd given they just prescribed me the same medicines, with a couple of changes, leading me to have to re-order everything again when I was discharged. Five or six medicines, all with a month's supply, just incinerated."*

NHS procurement

Some patients and the public felt that looking at the way the **NHS purchases and provides its medication** can save money:

- *"Perhaps pharmaceutical companies should be taken into democratic public ownership which would provide free or cheap drugs for all, would save the NHS billions, it would enable research into drugs for "less profitable conditions" and perhaps people with severe conditions may not be robbed of a few precious extra years of life because of the very high costs of some drugs."*
- *"More pressure should be put on drug companies to keep costs down. National deals should be brokered with drug companies by CCGs as a group."*

Individual funding

Some patients and the public felt that **people should pay for unessential medical treatments and procedures** (such as cosmetic surgery and IVF) to help keep the NHS focused on treating people who need it:

- *"There are treatments within the NHS which should be paid for by the person/people wanting them e.g. cosmetic surgery, fertility treatment, unless there is a really good reason for the process to be provided free by the NHS."*
- *"The NHS was designed for acute treatments and not cosmetic items like breast enhancement (unless for clinical reasons of deformity etc.). IVF should also be discontinued or severely limited; there are lots of children that need to be adopted."*

Inconsistency in prescribing

Some patients and the public felt that **a review of which medications were available on prescription** would reduce inconsistency:

- *"I fail to see why some groups of patients, such as thyroid patients, receive ALL their medications free for life, whether additional medications are prescribed for the thyroid problem or not, when other long term conditions don't."*
- *"My husband is diabetic and therefore since diagnosis, his prescriptions have all been free prior to this he suffered from asthma and a chronic chest conditions and had to pay for all prescriptions, but if he did not take his inhalers he would have died and has more health problems due to that condition. "*
- *"I would love a review of asthma medication. I am a chronic asthmatic and need regular medication. I pay for these through a pre-paid prescription card as it is better value, but I do feel there is some inequality in the fact that chronic asthmatics have to pay for their regular medication and other sufferers of chronic illnesses don't have to (such as diabetics). I am not arguing that they don't need it but I do feel a review of asthma sufferers, or chronic conditions should be done so it is the same across the board."*

Value for money

Patients and the public suggested that people often have a different view of "**good value**":

- *"I appreciate that there is a limited budget but human life is intrinsically valuable and we must do everything in our power to preserve it and treat conditions that limit it and cause pain and suffering."*
- *"Ethically, how much is a life worth? How much is a month of someone's life worth? Is it fair to weigh any of these things against the financial cost? I don't think so."*

Planning for the future

Patients and the public were keen to emphasise the **importance of long term planning and long term savings** for a potentially more expensive upfront cost. Patients and the public were keen to emphasise that the NHS should not be swayed by potential short-term savings:

- *"There always has to be a cost/benefit decision but the vision has to be long term. £50k on successful treatment now may save £100k over the next 20 years, whereas a less effective treatment costing £25k may need repeating twice more over the same time span. Therefore spending more now will save more over the longer term."*
- *"Remember that prevention is usually a whole lot cheaper than the cure so whilst saving £1.5 million per year now might seem appealing, consider what the potential impact this may have on other costs if certain patients are unable to afford the medicines they really need."*

Education

Many people spoke about the importance of **informed choice and self-care**:

- *"Education for prevention would reduce the need for many of the medications mentioned in the document; how to dress for protection, safe timings in the sun, foods which exacerbate skin complaints and excessive eating and drinking of sugars, fats and starches which lead to major costs for the NHS."*
- *"The cost of meds should be displayed on the prescription."*
- *"Health education classes should be provided at schools to raise awareness about how to use the health service."*

Postcode lottery

There were also concerns about **'postcode lotteries'** in that local decisions may well be different to neighbouring locations and throughout the country, creating health inequalities:

- *"It should not be turned into a postcode lottery. If we are talking only about the Leeds trusts then we should try to give the best treatment possible for each individual case. If treatment is somewhere else then it should still be provided."*
- *"I am concerned about differences in areas, i.e. postcode lottery, that if matters are left to individual GPs there will be a variable in treatment between areas across Leeds, which is not good, and could increase health inequalities."*

Generating income

Several suggestions were made by patients and the public as to how the NHS might be able **to generate more money in order to support itself**:

- *"Some preventative items could be stopped to save money. For example, drugs to help people stop smoking could be purchased by those needing them, as you are proposing for gluten-free foods."*
- *"Now that the retirement age has gone up (to 66 I think) and people are working longer, prescriptions should be paid for after 60 and not free to everyone as they are now. It should be when you reach your retirement age."*
- *"If anyone misses a doctor's appointment more than three times then they should have to pay."*
- *"I think there should be no free prescriptions. If people can afford they should pay, what is now free should go up to £1. This shows the patient that there is a cost to*

providing medicines and may reduce those who just tick the boxes on repeat prescriptions for items they may not need or never get around to using."

- *"I think that a contribution to help fund birth care for people who are not ill should be introduced. A low flat fee per child would help subsidise the NHS and better support child services."*
- *"You need to look at other ways to save money, such as more efficient appointment systems and administration costs e.g. not sending out letters 1st class."*
- *"All working age adults should pay for their prescriptions unless they are on low income."*
- *"People who arrive in A&E as a result of drinking too much should pay a fee for doing so."*
- *"If the NHS were to build their own drug/chemical plant to produce the drugs needed for the treatment of patients, even if only under licence it would save the NHS a fortune as the prescriptions given out at hospitals and through GPs would be available at cost."*

5. What did professionals tell us?

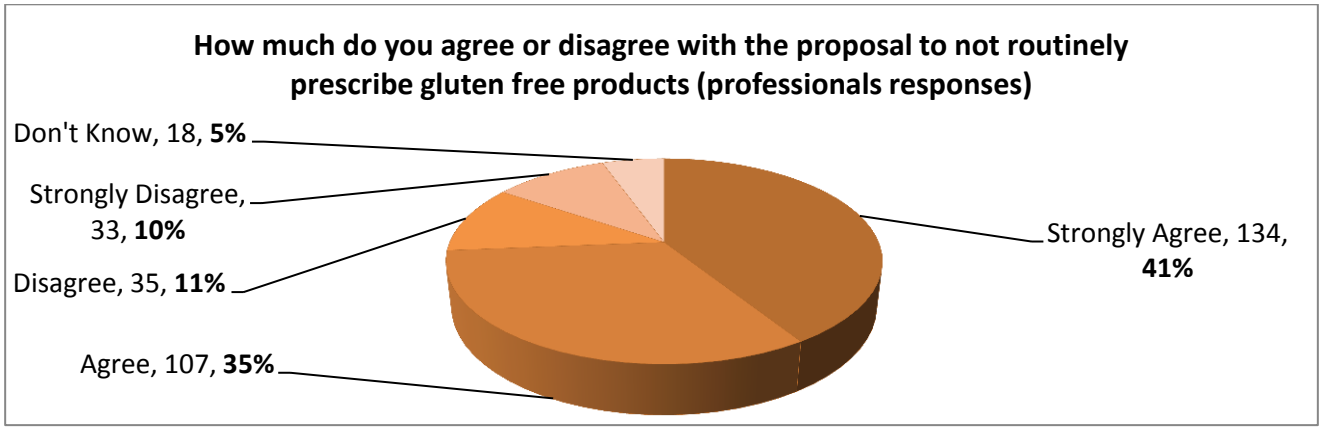
a. What did professionals tell us about Gluten-free products?

327 professionals filled in this section of the survey.

2.1% (7) of those people currently receive gluten-free products on prescription. There were three professionals who said they receive gluten-free prescriptions who did not give a response to the question indicating whether they agree with the proposal or not.

18.8% (39) of the professionals who had responded had cared or currently care for people who receive gluten-free products.

73% (241) of professionals who completed the survey **agreed that we should not routinely prescribe gluten free products**.



54% (25) of professionals who receive gluten free products for themselves or someone they care for **agreed that we should not routinely prescribe gluten free products**.

70% (230) of the professionals who responded offered additional comments to tell us more about their answer. There was feedback from a wide variety of different professionals including: GPs, dietitians, pharmacists, nurses, psychiatrists, professionals of the Leeds Teaching Hospital Trust (LTHT) and Leeds and York Partnership Foundation Trust (LYPFT). There were a number of key themes that emerged from this additional information. Most of the themes mirrored comments from patients and the public:

In agreement with the proposal

73% of professionals were in agreement that we **should not routinely prescribe gluten-free products**:

- *"I agree, some things have to give, the NHS is struggling too much, so whatever cuts can be reasonably made to improve services that are desperately needing more funding should be."*
- *"I have often felt that this [prescribing of gluten-free] is an unfair use of a limited budget. Although some bits are more expensive there are sometimes lifestyle choices [to aid medical condition]. There are many alternative products that are gluten-free."*
- *"Gluten-free foods are now widely available in many supermarkets and bakeries, restaurants and cafes. Other patients do not receive free food when they have dietary needs."*

Cost of gluten-free foods

Some professionals raised concerns that **gluten-free products are expensive in the supermarket**:

- *"Consideration and exception should be made for children and those living in poverty, gluten-free food, although available at the supermarket, is often three times more expensive. We are all aware that there are many families struggling in the current climate and this will make it worse for those families."*
- *"If the gluten-free foods are removed from prescriptions and patients feel unable to fund a gluten-free diet (as typically these foods are 2-4 times the cost of the gluten containing version) then they will be compromising their health and thus in theory in the long run costing the NHS more due to the increase risk of other conditions requiring medications, investigations and procedures, not to mention possible hospital admissions and the cost of these."*

Excessive prescription of gluten-free products is putting a greater strain on NHS resources:

- "*I don't feel it an appropriate use of general practice/pharmacy resources processing prescriptions every month for food."*
- *"As a GP it takes a lot of time to prescribe items. When there are supply shortages prescriptions get sent back.*
- "*The costs stated in this document do not take into account the considerable costs to the GP practice in dealing with prescription requests. The savings, therefore, will be greater than you suggest."*

Vulnerable groups

Like patients and members of the public, many professionals indicated that they were in favour of not routinely prescribing gluten-free foods on prescription on the condition that **people who are not able to afford to purchase the items themselves would still be able to access their gluten-free prescriptions**, so as not to damage their health:

- "*Definitely do not exclude children, perhaps those with other gastrointestinal co-morbidities or on low income."*

Some professionals suggested that **'vulnerable groups' does not extend to people with Coeliac disease**:

- *"I believe that people shouldn't be disadvantaged if they have a health condition but I don't feel it is equitable for people with coeliac disease to have a large proportion of their food shopping subsidised by the rest of society."*

Professionals discussed whether **"means testing"** patients who require gluten-free prescriptions are viable:

- *"I think means testing for gluten-free prescriptions could be an option but would the admin justify the money saved?*
- *"It is not financially viable to means test these patients and the decision not to prescribe would only be effective if it was across the board. As a GP I would not want to have to make decisions as to who did and who didn't quality for gluten-free product prescriptions. So is there a way to protect those patients for whom this maybe a significant financial burden?"*

Like patients and members of the public, some professionals felt that this approach is a **'false economy'** and could lead to increased costs to the NHS in the future:

- *"Without this produce, it can lead to other illnesses like cancer."*
- *"As a consultant psychiatrist, I am aware of a proportion of my patients with coeliac disease are so disabled by their mental health problems that they cannot cope with shopping in supermarkets and do not have anyone in their lives who can acquire the gluten-free products for them. As a group of people with severe and enduring mental health problems, they tend to neglect their physical health, default from necessary health-related appointments and not be very proficient at advocating their health needs. In my view, it is important that gluten-free foods can be prescribed by GPs to named patients whose specific circumstances necessitate this."*

Concerns that **patients may not adhere to a gluten-free diet** if they are not able to get gluten-free prescriptions and cannot afford to purchase the items themselves:

- *"I believe it would be of benefit to commission cookery classes for adults/teenagers to help with the transition to a gluten-free diet and improve compliance."*
- *Gluten-free food is an absolute necessity for anyone with coeliac disease, especially a child. If it is not available on prescription, I believe, it will be highly likely that affected people will not adhere to the diet as strictly as currently and will suffer the consequences."*

Compromise, solutions and considerations

Like patients and the public, some professionals suggested that a **discount/voucher system for people to save money on gluten-free products** in supermarkets:

- "*Is there any possibility of some sort of voucher scheme to use in supermarkets to offset the increased cost of some products?"*

Like patient and members of the public, many professionals suggested that some of the **"core/staple" items could remain on prescription** (such as bread, pasta and flour) but remove the "luxury items" (biscuits, pizza bases etc.):

- *"There may be a place for some limited prescriptions of staple items to those on lower income/free prescriptions."*
- *"I think basic essentials maybe should be available to those in need, but not a huge list of luxuries."*
- *"Scotland has recently introduced a limited formulary of gluten-free foods and a 'ration' of a certain number of units per person per month from the formulary. This is then managed by the pharmacy. We believe that this is a much better way of controlling gluten-free expenditure."*

Some professionals shared their experiences of **gluten-free prescriptions being misused**:

- *"Gluten-free products are available in all supermarkets. Some people take advantage of getting it on the NHS and over order."*
- *"As a pharmacist by trade I come across many people that use their prescription entitlement to feed entire families or even friends because it's free!"*
- *"The prescribing of these products has been open to abuse for years with people ordering many loaves of fresh bread and "forgetting" to pick them up before they go out of date as they can know they can easily get another prescription."*

Availability of gluten-free foods and alternatives

Like patients and members of the public, some professionals commented that there will be some who will **struggle to access** gluten-free foods:

- *"Although in some area with large supermarkets, gluten-free foods will be readily available, what is the evidence of smaller supermarkets and those in deprived areas, where transport maybe an issue?"*
- *"Patients without access to these items are at greater risk of not adhering to the diet, resulting in growth and development problems, requiring additional supplements such as iron/calcium due to poor absorption from atrophied gut and present the NHS with much larger cost implication in the future."*
- *"I work as a diabetes dietitian and some of our patients with type 1 diabetes also has coeliac disease. Many patients that I see will rely on a flour based product as a starchy staple carbohydrate e.g. chapatti, roti, paratha, injera, flatbread, etc. which may not be readily available as gluten-free choices. Many people from ethnic minority groups may not have potatoes or corn as part of their everyday diet."*

Other professionals argued that **gluten-free foods are much more readily available** and are stocked in many places:

- *"I have worked in community and hospital pharmacy for over 22 years and have seen a huge increase in prescribing costs for gluten and low protein foods. They are readily available in the majority of supermarkets now."*

Inconsistency in prescribing

Like patients and members of the public, some professionals suggested that there are some **inconsistencies regarding items available on prescription**:

- *"Patients that have other conditions that restrict the intake of certain food products are not issued with NHS prescriptions e.g. diabetics do not receive sugar free foods."*
- *"Coeliac disease is very different to type 2 diabetes, treated by diet alone, as the food items concerned are staples and the risks of contamination are much more serious – excluding gluten is much more difficult than reducing sugar in the diet."*

Education and awareness

Many professionals believed there is some work needed on **educating people on gluten-free foods**; what they can have, where to find them and how to live a gluten-free lifestyle:

- *"Patients with coeliac disease should be provided with access to a dietitian to help them to learn which types of food they can and can't eat, as well as nutritional education to ensure they get a full and varied diet.*
- *"GPs have little education on all the different gluten-free products available."*
- *"If the NHS stops gluten-free prescriptions, good quality information about how to manage and maintain an affordable gluten-free diet should be easily available in a variety of formats."*

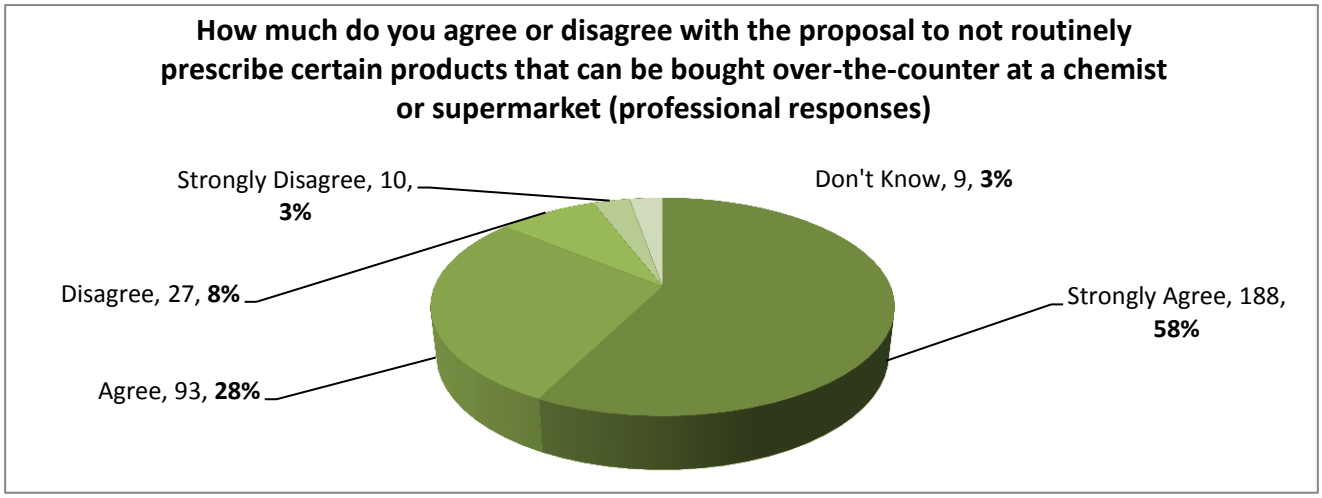
b. What did professionals tell us about over-the-counter medicines?

327 professionals filled in this section of the survey.

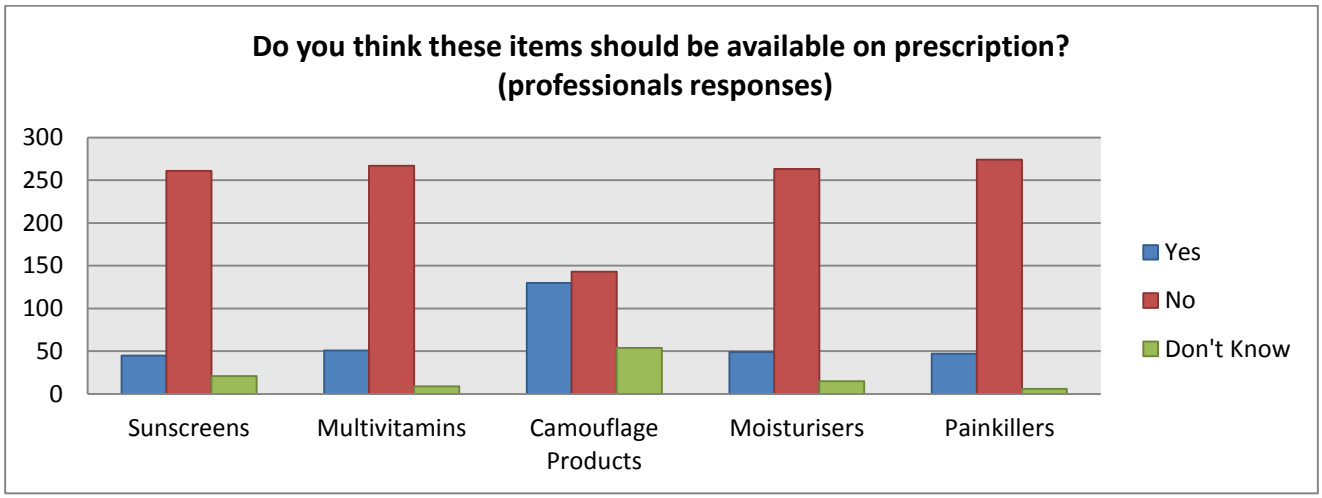
23% (77) of those people indicated that they currently receive over-the-counter medicines on prescription.

69% (226) of the professionals who had responded had cared or currently care for people who receive over-the-counter medicines on prescription.

85% (281) of professionals who completed the survey **agreed that we should not routinely prescribe over-the-counter medicines.**



We asked people to tell us which items they thought should be available on prescription



57% (185) of professionals who responded offered additional comments to tell us more about their answer. There were a number of key themes that emerged from this additional information:

In agreement with the proposal

73% of professionals were in agreement that we **should not routinely prescribe over-the-counter medicines**:

- *"I agree, paracetamol costs as little as 20p in shops but a prescription costs the NHS significantly more."*

- *"We are now able to get these drugs cheaply and it is using up lots of appointments at GP surgeries to issue them."*
- *"These medicines are not expensive and the NHS is paying out more money than people would for the same thing which does not benefit us at all. I think the majority of people would be happy to buy these products if they understand how much it will help the NHS."*

Vulnerable groups

Many professionals noted that **people on low incomes (such as pensions or benefits) should still be able to access over-the-counter medicines on prescription** if needed:

- *"The proposal is a minefield of complicated decision making, patients on low-income come to us for prescriptions of many of the drugs mentioned in this proposal for financial reasons and this is likely to get worse with the change in benefits. Painkillers in particular for acute conditions should be prescribable. Emollients for dry skin – used in diabetics to prevent problems on the feet for example, appropriate to stop deterioration in eczema. This will just involve more GP work to code eczema for the most mild cases."*
- *The majority of people I see getting prescriptions for over-the-counter products usually seem more than able to afford acquiring expensive items in the pharmacy while awaiting items on their prescription that could be bought over-the-counter and many are in a financial position to do so."*
- *"I see a problem with the increasing rates of skin cancer and stopping the provision of sunscreen for those on low income who request it. Otherwise they may not purchase and we are transferring the cost burden to the future when they may present with skin cancer."*

Patient/GP partnership – an individual approach

Most professionals told us that they would be in support of the proposal providing that **individual circumstances (such as long-term conditions)** could still warrant a prescription of an over-the-counter medicine being dispensed:

- *"This suggestion actually makes sense, though the need to identify thoroughly and accurately those who need to continue to receive such medicines/products via prescription, or should be allowed to request such products on prescription, has to be of the utmost priority. For example, it may be beneficial to offer a low income family a multivitamin on prescription if there is reason to believe children are at threat or being under or malnourished, before more serious malnourishment becomes an issue that requires more costly intervention. Essentially it boils down to continuing to ensure those that have a genuine need for any product available on prescription continue to receive it, and that those on low incomes are unduly affected. This also may mean that extra effort has to be put in to education regarding health matters, or funding more GPs to see that the health of the population is monitored properly."*
- *"Certain items like these may need to be provided by a GP as excess use can lead to problems. Regular usage should be monitored, who will monitor over-the-counter usage?"*
- *"Certain psychotropic medications can cause marked photosensitivity. As a psychiatrist, many of my patients are on a very low income and may be unable to afford to buy an effective sunblock – thus I would want GPs to proactively prescribe these for patients."*

They also added that **patients need to take a greater responsibility for their own healthcare** but noted that there are some difficulties that can get in the way:

- *"Restrictions on the amount of paracetamol and ibuprofen which can be bought at one time need to be reviewed if this goes ahead – especially for families where a parent cannot buy an appropriate amount to keep at home."*
- *"People need to take some responsibility for their health which includes paying for cheap and simple medicines. Very few people cannot afford these medicines and many can.*

Cost of over-the-counter medicines

Many professionals acknowledged that many medicines **can be found cheaply over the counter**:

- *"Paracetamol is so cheap at the supermarket."*
- *"Paracetamol can be purchased for as little as 25p as well as many other cheap OTC medicines. This is a waste of resources in GP and staff time prescribing and reordering when it can be purchased at convenience elsewhere far cheaper than the NHS supply it."*

Some professionals raised concerns about **an increased cost to the NHS if people** were accessing the wrong items, wasting them, not complying or not coming to the GP when they need to:

- *"Most people end up with a stockpile of these as they order every month whether needed or not. If they had to pay they would think twice. We often get dozens of packets of unused painkillers returned to my pharmacy and of course they have to be binned."*

Camouflage products

Many professionals fed back that **camouflage products are very important for people's psychological well-being** and that they should still be available:

- *"If patients can no longer get access to camouflage products, will this have an effect on increased need for psychological support?"*
- *"Camouflage creams are really important to psychological wellbeing with disfiguring scars, birthmarks etc. – please do not ban them."*
- *Camouflage creams should be an exception to this proposal even if cosmetic as could have mental health effects/anxiety/loss of confidence etc. resulting in increased costs via other things such as NHS consultations, other input/support."*

Education and awareness

Professionals felt that better **education and information** could help people make better choices about over-the-counter medications.

- *"I think education is needed around how much GP time is wasted seeing patients and dealing with requests for medication such as this that can be bought in the chemist/supermarket."*
- *"Given the current price of most over-the-counter drugs it is unrealistic to expect the NHS in its current funding crisis to continue funding such preparations. However, the public need to understand the arguments around protecting budgets for social care etc. versus over-the-counter prescribing."*

Professionals acknowledged it would be useful for them if they had a **full list of exclusion and inclusion criteria** for the medicines affected by this proposal:

- *"Clear guidance would be welcomed on inclusion/exclusion criteria and conditions; some national guidance on issues such as sunscreens are not very specific about which conditions to include for NHS prescribing."*
- *"How will you define the dermatology criteria for emollients etc.? Dry skin and mild eczema are a spectrum."*
- *"I am concerned that in practice, patients with significant skin disease may be denied topical therapy which they need. I would expect clear guidance to be given to GPs that it is acceptable to prescribe emollients, long-term, not just for eczema. Failure to do so may perversely increase costs, if patients require second line systemic therapy rather than controlling their skin disease with topical therapy alone."*

GP capacity

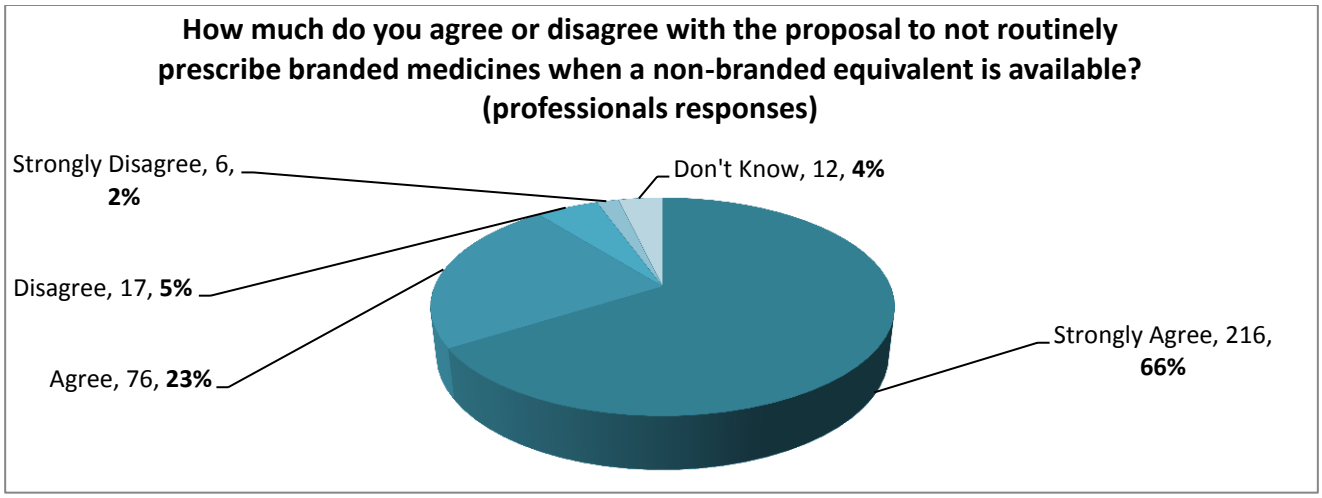
Professionals commented that not routinely prescribing over-the-counter medicines would **save the NHS money as well as GP time**:

- *"It is not just drug costs that are the issue; it's the GP appointments and other practice resources that are impacted by requests for prescriptions of these items."*
- *"Patients tend to be annoyed at waiting 48 hours for prescriptions to be issued for items such as painkillers and when suggested they buy them over the counter they complain more. However, if it becomes common practice not to issue for the general population it would help all GPs a lot."*

c. What did professionals tell us about branded medicines?

327 professionals filled in this section of the survey.

89% (292) of professionals who completed the **survey agreed that we should not routinely prescribe branded medicines when a non-branded equivalent is available**.



58% (190) of professionals who responded offered additional comments to tell us more about their answer. There were a number of key themes that emerged from this additional information:

In agreement with the proposal

73% of professionals were in agreement that we **should not routinely prescribe branded medicines when a non-branded equivalent is available**:

- *"The NHS should never give a branded item if a generic is available."*
- *"I work in a pharmacy and am well aware of the cost involved for the NHS so non-branded has to be the way forward."*
- *"I have seen no difference between branded and generic products. In cases where it is specifically indicated, this should be taken into consideration."*

Performance of non- branded medicines

Many professionals commented that as long as the non-branded medicine **works in the same way** and does not interfere with patient's condition negatively then they will support the proposal:

- *"If they do the same job, I don't know why the most expensive brand should be used."*
- *"I agree with the proposal but exceptions need to be made for people with genuine allergies."*
- *"If generics and branded meds do the same thing then always prescribe generic. The savings are massive."*

They also noted that **prescribing needs to be on an individual basis** and that branded items should be prescribed if it is clinically necessary:

- *"Price should not be the determining factor, efficacy should. If one drug, be it branded or generic, is proven to be the more effective, then that is the one the NHS should be buying and distributing on prescription."*
- *"If it for any reason e.g. the patient is allergic to certain ingredients in one of the non-branded medicines then that is different and a valid reason for choosing the branded*

version."

- *"I fully support this proposal, so long as individual cases that require a specific drug for a specific reason are also allowed."*

Professionals told us that **patients should be monitored when switching to a non-branded medication**:

- *"Patients should always be tried on the generic product (unless allergies are already known) first but there should still be a range of medications available to ensure tolerance can be improved. Ideally, GPs and pharmacists should be able to access a list of medications from least to most expensive and take patients through in said order to reduce expenditure. Caution should be taken in trying to force patients to switch medications as non-adherence can be more expensive in the long run than the cost of the medication."*
- *"If a patient has a problem with a generic, there are usually several manufacturers to choose from and unlikely to have a reaction to all of them."*

Branded generics

Many professionals commented on **'branded generics'** and generally felt that the pressure to prescribe 'branded generics' was not helpful and there should be a push to prescribe all medications generically on the whole, with relevant clinical exceptions:

- *"We try to prescribe non-branded anyway, although that is undermined by Optimise Rx, suggesting branded substitutes. Would still need freedom to prescribe branded when bioavailability differences."*
- *"It should be all or nothing, whatever system you pick places ridiculous extra workload on GPs > be it scriptswitch, Optimise etc. If it was all generic bar the obvious (anti-epileptics, cyclosporine etc.) we wouldn't have a problem."*
- *"The CCGs should go further and stop the dangerous practice of encouraging branded generics."*
- *"This policy also needs to be extended to a 'ban' on prescribing branded generics which simply manipulate the market and cause huge stock management and supply issues for pharmacy contractors. This can mean that patients find it difficult to get a specific branded generic product which can impact their care."*

Education and awareness

Like patients and the public, a lot of professionals felt that **better information** would help patients and professionals make informed decisions about branded medicines:

- *"Advice needs to be in place for how this would be implemented as already known in practice but when a person feels strongly about a branded medication it can be difficult to implement. Guidance could include options when agreement can't be made e.g. is private prescribing allowed for an NHS patient? Would refusal to take an important medication in its generic form be a "medical reason" to prescribe by brand as harm could ensue from not taking?"*
- *"If patients were able to see the actual costs of medicines this may make them rethink their choice?"*
- *"I completely agree with this proposal. I can understand patients being concerned if they are familiar with a particular brand and I think an educational approach to highlight the similarities would be beneficial for all."*
- *"Patients need to be told by their GP that generics are the same as branded medications as many do not and they do not believe us pharmacists when we try to counsel them! Their understanding needs to be reinforced from all angles."*

Private prescriptions

A number of professionals commented that patients who insisted on receiving branded medicines when there was no clinical need, should be able to get it but only if they pay for the item via a **private prescription**:

- *"It is not acceptable in a publicly funded system to choose to take the same drug at higher cost for reasons of personal choice. If patients wish to take more expensive branded drugs this should be on a private prescription in my opinion."*
- *"If they wish to have branded, then pay for it themselves through a private prescription."*

Consistency of prescribed medicines

Some professionals told us that **inconsistency with non-branded medicines** might confuse vulnerable patients:

- *"The problem here is that the CCG sometimes demands generic brands for cost-saving. We should be either all generic or not at all. Patients need consistency."*
- *"I think clinicians should consider the ability of some patients to recognise their tablets by size, shape and colour – it's cheaper to maintain a person's independence and avoid errors (which can lead to a hospital admission). This might mean issuing a consistent non-branded medication, rather than going for whatever is cheapest each month."*

Costs

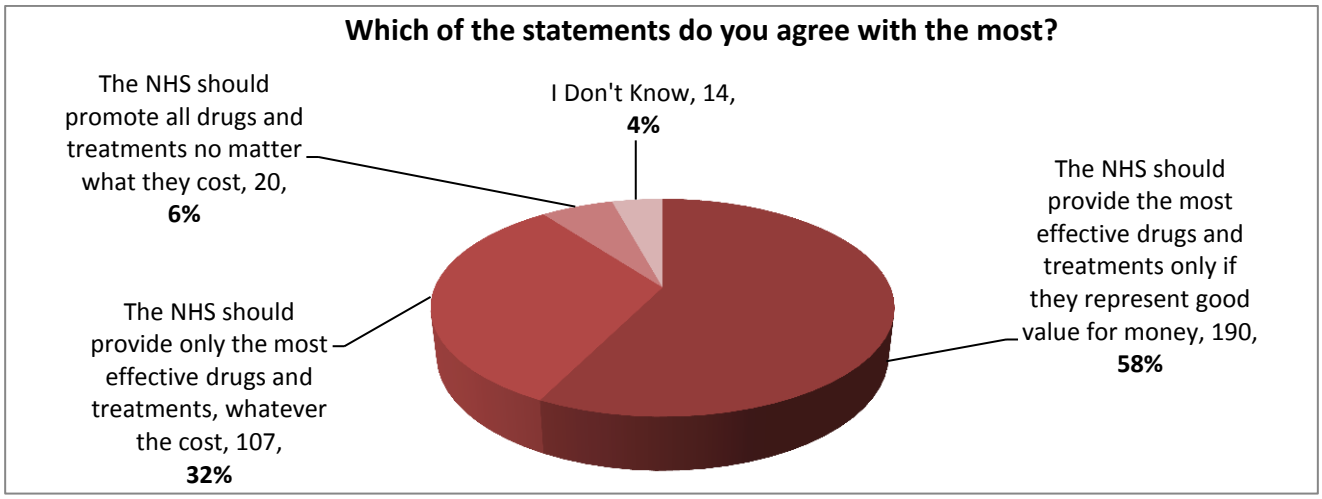
Some professionals suggested that there would be less need for a discussion about the difference been medications if **non-branded was the always the first choice for patients**:

- *"I am all for patients who are naïve to a drug to start off on the generic but as soon as you start to mess around with swapping to generics, clinics like ours have to pick up the pieces through additional reviews and more discomfort for patients and this is not cost effective."*
- *"It will be much easier to start all new treatments on cheaper, generic medication (and monitoring adherence to that) than trying to switch all of the existing prescriptions over so I would be suspicious of the potential savings for the amount of time and investment required in such a scheme."*

d. Your Views

Before any decision is made, it is important for us to gather any additional views of professionals regarding these proposals. Professionals were asked to consider three statements and indicate which one they agreed with most:

a. "The NHS should provide the most effective drugs and treatments only if they represent good value for money."
a. "The NHS should provide only the most effective drugs and treatments, whatever the cost."
b. "The NHS should promote all drugs and treatments no matter what they cost."



17% (57) of professionals who responded offered additional comments to tell us more about their answer. There were several key themes that emerged from this additional information:

Consultation with the public

Professionals discussed that this consultation was a **good place to start** with regards to making the NHS more efficient and making savings, providing that the exemptions discussed would be maintained:

- *"Unless everyone in the UK is willing to pay more taxes to fund a "no matter what the cost NHS service" it is inevitable that some form of rationing will come in to play. In this case, these proposals seem a sensible place to start providing that there is room for exemptions and exceptions."*

Procurement

It was also noted that patients might understand the situation better if the **NHS was more open and transparent about costings**:

- *"People are constantly surprised when I tell them the cost of antimicrobial treatment. Perhaps we should be more transparent about what it costs us as the taxpayer to treat with various drugs. It should be made clear that value for money includes best evidence and cost. Not just cost."*

Value for money

It was discussed that there is an issue about **who decides what "good value for money" is**:

- *"It's very difficult to assess "good value for money" and the key question is "who decides…?"*
- *"The decision making process for what determines good value for money needs to be much more transparent. Some of these decisions need to be taken at a national level (i.e. by the government) with a proper debate about what the NHS can or cannot afford."*

6. What did wider stakeholders tell us?

A number of stakeholders contacted the CCG about this consultation. We have themed their feedback below and you can read their comments in full in **Appendix D**

Vulnerable groups

Coeliac UK raised concerns that not routinely prescribing gluten-free products could lead to inequalities '*due to the higher cost and limited availability of gluten-free products.'*

Healthwatch Leeds told us that they would oppose a 'blanket ban' and that they had "*major concerns"* that disadvantaged people would be affected.

Leeds Local Medical Committee Limited suggested that legislative changes may need to be made to support GPs in the decision-making.

Leeds Local Medical Committee Limited expressed concerns about potential health inequalities for vulnerable groups.

Scrutiny Board also raised concerns about the potential impact on health inequalities.

Community Pharmacy West Yorkshire (CPWY) told us they are concerned over the inequalities that these proposals could create.

Significance of a gluten-free diet

Coeliac UK reiterated the risks and long term complications of not adhering to a gluten-free diet.

Coeliac UK stated that it is '*not always realistic or convenient'* for people to base their diet on naturally gluten-free food such as rice and potatoes. (more detail on this can be seen in Appendix D)

NHS Procurement

Coeliac UK suggested better procurement by the NHS could reduce the cost of gluten-free foods on prescription.

Compromise, solutions and considerations

Coeliac UK suggested that a pre-payment card could reduce the difference in cost between gluten-free and gluten-containing staple foods and save clinicians time.

The British Specialist Nutrition Association pointed out that since the start of this engagement NHS England have also launched a consultation on prescribing. They suggested that we should consider the findings of this engagement when making our decision.

Scrutiny Board also referred to national proposals around prescribing and suggests that local changes should take this into consideration.

Community Pharmacy West Yorkshire recommend that the decision in Leeds should await the outcome of the national consultation.

Patient/GP partnership – an individual approach

Coeliac UK reiterated the importance of prescribers making decisions on an individual basis.

Availability

Healthwatch Leeds raised concerns that some over-the-counter medicines can only be bought in restricted quantities.

Education and awareness

Healthwatch Leeds stressed that any changes should be accompanied by '*clear and appropriate*' information for patients.

Community dieticians in Leeds suggested that closer monitoring and assessment of people who require gluten-free products could be more beneficial that reducing prescribing.

Community Pharmacy West Yorkshire told us that messaging to patients about these changes needs to be clear.

Inconsistency and 'postcode lotteries'

Leeds Local Medical Committee Limited raised concerns about inconsistency between the NHS England approach and individual CCGs. They suggested that this could lead to a 'postcode' lottery when accessing prescriptions in different parts of the country.

Scrutiny Board also raised concerns about a 'postcode lottery' prescribing approach.

Community Pharmacy West Yorkshire suggests that these changes could lead to an inequitable impact on patients in West Yorkshire.

Capacity of pharmacies

Scrutiny Board raised concerns about the additional responsibility placed on pharmacies as a result of this approach to prescribing.

Community Pharmacy West Yorkshire pointed out that some places that sell over-the-counter medicine may not have a community pharmacy and are not in a position to give advice and guidance or identify patients who are more seriously ill.

Community Pharmacy West Yorkshire raised concerns about the impact on community pharmacy of reducing the number of items on prescription.

Cost

Community dietitians in Leeds raised concerns that not routinely prescribing gluten-free foods could reduce compliance in patients and result in addition costs to the NHS.

Community Pharmacy West Yorkshire questioned some of the cost saving calculations made by the CCG.

Medications affected

Community Pharmacy West Yorkshire raised concern about the number of items that this engagement could affect. They suggested that the engagement did not cover all potential items and that this could be misleading.

Branded generics

Leeds Local Medical Committee (LMC) raised concerns regarding the prescribing of “branded generics”. It was felt that patients may not know the different names that the generic medicine can take which could cause a potential safety risk for patients.

7. Assessment of Equality Impact

Evidencing that we have considered the impact our activities will/may have on patients and the public in relation to the protected characteristics as defined by the Equality Act 2010; and identifying changes we can make to reduce/remove any negative impacts is a **statutory duty.** Our equality analysis and engagement plan identified the following groups we should particularly consider and engage with as a result of this proposed change.

As part of our engagement we spoke to people from these communities, as identified in the equality analysis, and their feedback:

Protected characteristic/ group or other relevant groups	**Positive or negative impacts/issues identified** Please state whether the identified impact is positive or negative	**Recommended actions/changes/ considerations**
Age	**Negative**: Older people on pensions may struggle to afford the increased cost of paying for their own gluten-free foods and over-the-counter medicines if not deemed clinically appropriate to prescribe. There could also be increased cost to older people who may need to travel further afield to get their items if their local shops do not stock what is needed. Additionally, young people, particularly students, or young people on low incomes may not be able to afford additional costs to fund these items.	Any patient where the doctor thinks it is clinically appropriate for the patient to receive the medication can still receive it on prescription. Students in full time education over the age of 19 are not automatically entitled to free prescriptions they have to apply for an exemption certificate based on income. Student may find that it is cheaper to buy the products over the counter than pay prescription fees.
Disability	**Negative**: People with long term health problems may not be able to get out to acquire the items they need that are no longer available on prescription which could lead to greater impact on their health if they are unable to or find the increase strain damaging to their health.	Any patient where the doctor thinks it is clinically appropriate for the patient to receive the medication can still receive it on prescription and receive it from their pharmacy in their normal way. There are other options available such as online and internet pharmacies that can support patients with mobility problems and deliver medicines to the patient.

Protected characteristic/ group or other relevant groups	Positive or negative impacts/issues identified Please state whether the identified impact is positive or negative	Recommended actions/changes/ considerations
Disability	**Negative**: People with mental health issues may be adversely affected by not receiving camouflage products on prescription. People with visible scars/marks may be affected psychologically and become more socially isolated or withdrawn if they do not feel confident in their image, having a greater impact on their mental health. Additionally people with mental health issues may struggle to self-manage their conditions (especially if changes are made) and may need the additional support provided by receiving items on prescription and guidance directly from the GP.	The CCG already provides guidance on medicines for cosmetic purposes and this will continue to be applied. Any patient where the doctor thinks it is clinically appropriate for the patient to receive the medication can still receive it on prescription.
Disability	**Negative**: People with coeliac disease may be adversely affected if they are unable to maintain a gluten-free diet due to issues related to income and location. This could create health inequalities, leading to increased use of NHS resources and detriment to their health.	Any patient where the doctor thinks it is clinically appropriate for the patient to receive the medication can still receive it on prescription. Most foods are naturally gluten free, such as fruit, vegetables, meat, fish, poultry, diary, potatoes, rice etc., so patients can maintain a gluten free diet with some adjustment and advice from dietitians, which will still be available to patients who are diagnosed as having Coeliac disease
Disability	**Negative**: People with co-morbid physical health conditions may be adversely impacted upon if they are unable to receive gluten-free items or other medications on prescription (i.e. over-the-counter medicines).	Any patient where the doctor thinks it is clinically appropriate for the patient to receive the medication can still receive it on prescription.

Protected characteristic/ group or other relevant groups	Positive or negative impacts/issues identified Please state whether the identified impact is positive or negative	Recommended actions/changes/ considerations
Disability Race	**Negative**: People with learning disabilities may struggle to identify correct and appropriate items (gluten-free or over-the-counter) medicines if they need to purchase them. Additionally, they may struggle to know how to use the items correctly. Likewise, people whose first language is not English may also struggle to identify appropriate items.	Any patient where the doctor thinks it is clinically appropriate for the patient to receive the medication can still receive it on prescription. There is a scheme available within Pharmacies within Leeds call “Making Time” which is aimed at supporting patients with learning disabilities with their medication needs. Many pharmacies have staff that are multilingual.
Pregnancy and Maternity	The Equality Analysis and Engagement Plan also identified the changes will potentially have a greater impact on people who are exempt from the prescription charge including pregnant women and new mothers.	Any patient where the doctor thinks it is clinically appropriate for the patient to receive the medication can still receive it on prescription.
Families/carers of children and young people.	The Equality Analysis and Engagement Plan also identified the changes will potentially have a greater impact on people who are exempt from the prescription charge including families/carers of children and young people.	Any patient where the doctor thinks it is clinically appropriate for the patient to receive the medication can still receive it on prescription.
Consideration was also given to other protected characteristics		
Gender; gender reassignment; religion or belief; sexual orientation; marriage and civil partnership	No impacts, either negative or positive have been identified.	No actions required

8. What are the key themes from the feedback?

Gluten-free

The majority (**65%**) of all respondents who filled in the survey agreed that gluten-free products should not be routinely prescribed.

- The cost of gluten-free products is prohibitive for both patients and the NHS.
- The NHS should work with providers of gluten-free products to reduce costs.
- Efforts need to be made to reduce wastage and misuse of gluten-free prescriptions.
- Not prescribing gluten-free products regularly will free up a lot of resources for NHS services (GPs pharmacies etc.).
- "False economy" of short term savings but increased future cost to NHS due to health implications of not receiving gluten-free items.
- People who cannot afford to purchase gluten-free foods should still receive the items on prescription (people on low incomes, benefits, pensions, and children).
- Proposal could greatly impact people with co-morbid conditions or other impairments (such as learning disabilities).
- Availability of gluten-free products has greatly increased but people may still struggle to access them (issues with mobility, location, additional costs).
- People with visual impairments or difficulties in reading labels may struggle to identify appropriate gluten-free foods (issues such as reduced visibility, illiteracy, cannot read English).
- Means testing could be introduced to help determine who is eligible for gluten-free foods on prescription.
- Patients may not adhere to a gluten-free diet without gluten-free items on prescription.
- There is a need for education on a gluten-free diet and how to maintain a gluten-free lifestyle.
- There are inconsistencies with what is and what isn't prescribed; people with other conditions that affect diet do not receive free prescriptions for related food items.
- Gluten-free prescriptions should be provided to those who need it, but only "core" staple items should be available, remove luxury items.
- The CCG could adopt a discount/voucher scheme to subsidise costs for gluten-free costs, as emulated in other places in the country.
- Concerns regarding a 'postcode lottery' and health inequality as some CCG areas may still allow gluten-free prescribing.
- Each prescription request needs to be assessed on individual circumstances.

Over-the-Counter Medicines

The majority (**82%**) of all respondents who filled in the survey agreed that over-the-counter medicines should not be routinely prescribed.

- People on low incomes (such as benefits and pensions) should still be able to access over-the-counter medicines on prescription to help maintain their health.
- People's individual circumstances (such as long-term conditions) need to be taken into consideration when deciding whether or not to prescribe over-the-counter medicines.
- GPs need to work collaboratively with patients to discuss treatment options.
- Patients and the public need to take responsibility for their own healthcare.
- Many of these medicines can be found cheaply elsewhere (such as chemists and supermarkets).
- "False economy" and increased cost to the NHS if people cannot access over-the-counter medicines correctly when they are needed and require further NHS

interventions.

- Camouflage products should still be available on prescription with additional support to help use and apply it correctly as the psychological benefits of these products is significant.
- There is a large amount of wastage and misuse of the prescribing of over-the-counter medicines.
- More people will use pharmacies for support.
- Better education and information is needed to help people make informed choices.
- Professionals need to endorse over-the-counter medicines to indicate that they are as equally effective.
- There is an issue with restrictions to the number of certain medications a person can buy.
- Professionals need a full list of exclusion and inclusion criteria for the medicines affected.
- Not prescribing over-the-counter medicines will free up GPs time and save the NHS money.

Branded Medicines

The majority (**84%**) of all respondents who filled in the survey agreed that branded medicines should not be routinely prescribed when a non-branded equivalent is available.

- People would support the proposal providing the non-branded medicines perform in the same way as the branded medicine.
- Use of the non-branded medicine needs to be monitored if switching from a branded medicine to ensure that there are no adverse effects, and if there are, switch back to original medicine.
- Better information and communication to patients about changes to their medicines would help them better understand and make informed decisions.
- Publicising the costs of medications and other NHS services would help people understand.
- Every prescription needs to be done on an individual basis, people who require the branded medicine can still receive it on prescription.
- Drug companies are taking advantage of the NHS; the NHS needs to find better suppliers and work to bring the costs down.
- Will switching to non-branded impact drug research?
- A lot of inconsistency with changing medicines (packaging, shape, colour etc.).
- The CCG needs to stop pressuring professionals to prescribe “branded generics”.
- If there is no clinical reason but patients insist on a branded medicine can they receive it on a private prescription and pay for it?
- Will switching to cheaper non-branded medicines mean that patients can benefit from a cheaper prescription (i.e. just paying cost of medicine)?
- Non-branded medicines should always be the first choice, unless there are clinical exceptions.
- Prescribing branded generics can be problematic for both staff and patients as they can fluctuate in their provision (appearance, name, availability etc.).

9. Recommendations

Following the engagement, the project team are asked to consider feedback from patients, the public, professionals and wider stakeholders. We make the following recommendations:

If it is decided to **continue prescribing gluten-free products**, the Leeds CCGs Partnership should consider:

- limiting this to 'core/staple' items; and
- providing prescriptions in a way that reduces waste and misuse.

If it is decided to **not routinely prescribe gluten-free products**, the Leeds CCGs Partnership should consider**:**

- working with voluntary, statutory and private organisations at a local and national level to support improved access to gluten-free products; and
- alternatives to prescribing such as a 'pre-payment card'.
- any prescribing should be limited to 'core/staple' items and prescriptions should be provided in a way that reduces waste and misuse.

If it is decided to **not routinely fund a range of over the counter medicines**, the Leeds CCGs Partnership should consider**:**

- making 'camouflage products' exempt from the guidance in line with existing guidance from the CCG; and
- providing guidance that considers the needs of people who need to purchase large amounts of 'over-the-counter' medications.

If it is decided to **not routinely prescribe branded medicines when a non-branded equivalent is available**, the Leeds CCGs Partnership should consider**:**

- providing clear guidance around private prescriptions;
- recommend to NHS England to review national procurement policies regarding prescribing; and
- ways to reduce variation in the presentation of medication.
- continuing to prescribe non-branded medicines as a standard unless there is a safety or financial reason that dictates the use of branded medicines (including branded generics).

Cross cutting recommendations

- There should be clear guidance which **supports prescribers to identify 'vulnerable patients'** for whom exceptions might be appropriate.
- Any decision regarding amendments to prescribing in Leeds should consider:
    - the **wider impacts** and seek to provide some assurance that changes will not lead to additional costs to the NHS in the future; and
    - any **national guidance from NHS England**.
- Any decision about altering medication covered by the policy should:
    - be made in **consultation with the patient**; and
    - take into account **individual circumstances**
- Any change in approach to prescribing should consider **what information and support people need to make an informed decision and self-care**. Information and support should be available in alternative formats.

- Decisions about prescribing should not be made in isolation and should **consider other opportunities to increase income and reduce costs**, waste, misuse and inequalities.
- When encouraging patients to access the **'pharmacy first'** the Leeds CCGs Partnership needs to ensure appropriate capacity.
- Any guidance around prescribing should be **transparent and publically available**.
- In 2018 the Leeds CCGs Partnership should produce an **update report** which outlines to what extent they have met the recommendations in this report.

10. What happens next?

The report will be shared with all the people involved in the project. The report will also be included in our next e-newsletter which is sent out to patients, carers, the public and voluntary, community and faith sector services and all the Leeds CCGs websites.

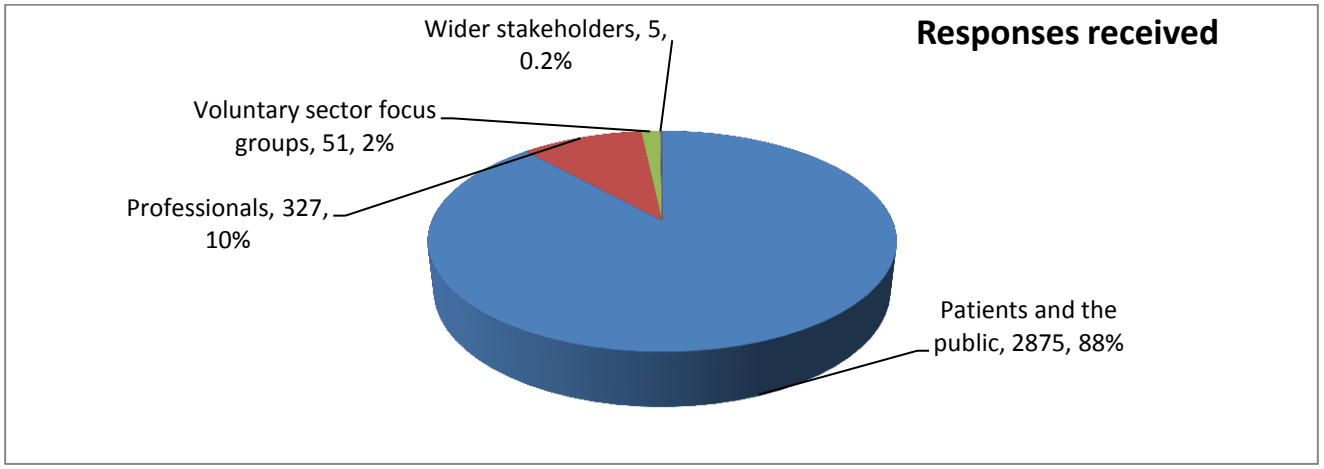
The project team will use the report to underpin the project going forward. A briefing will be produced once the project has begun, to show to what extent the recommendations have been implemented. This briefing will be shared with the people involved in the project.

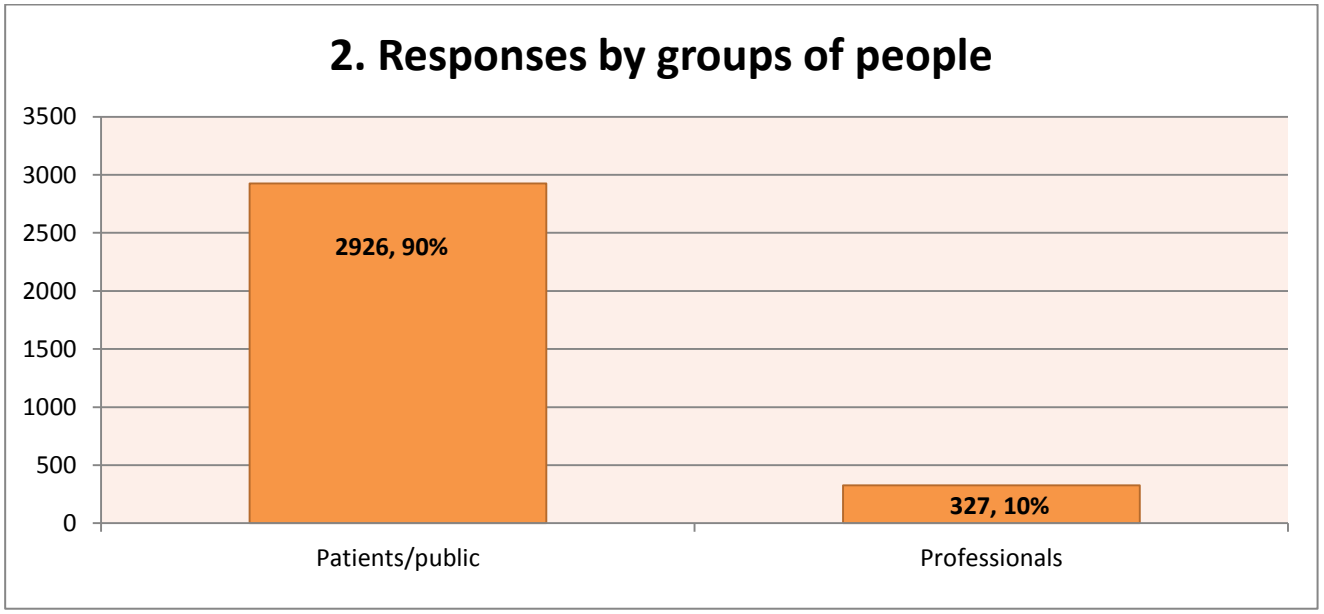
The patient feedback will also be used be used to inform a wider strategy for enhancing communication, access and the quality of services.

An update report will be produced in 2018 to feedback on how the project is moving forward and what has taken place following this engagement.

Appendices

Appendix A – Feedback from the survey

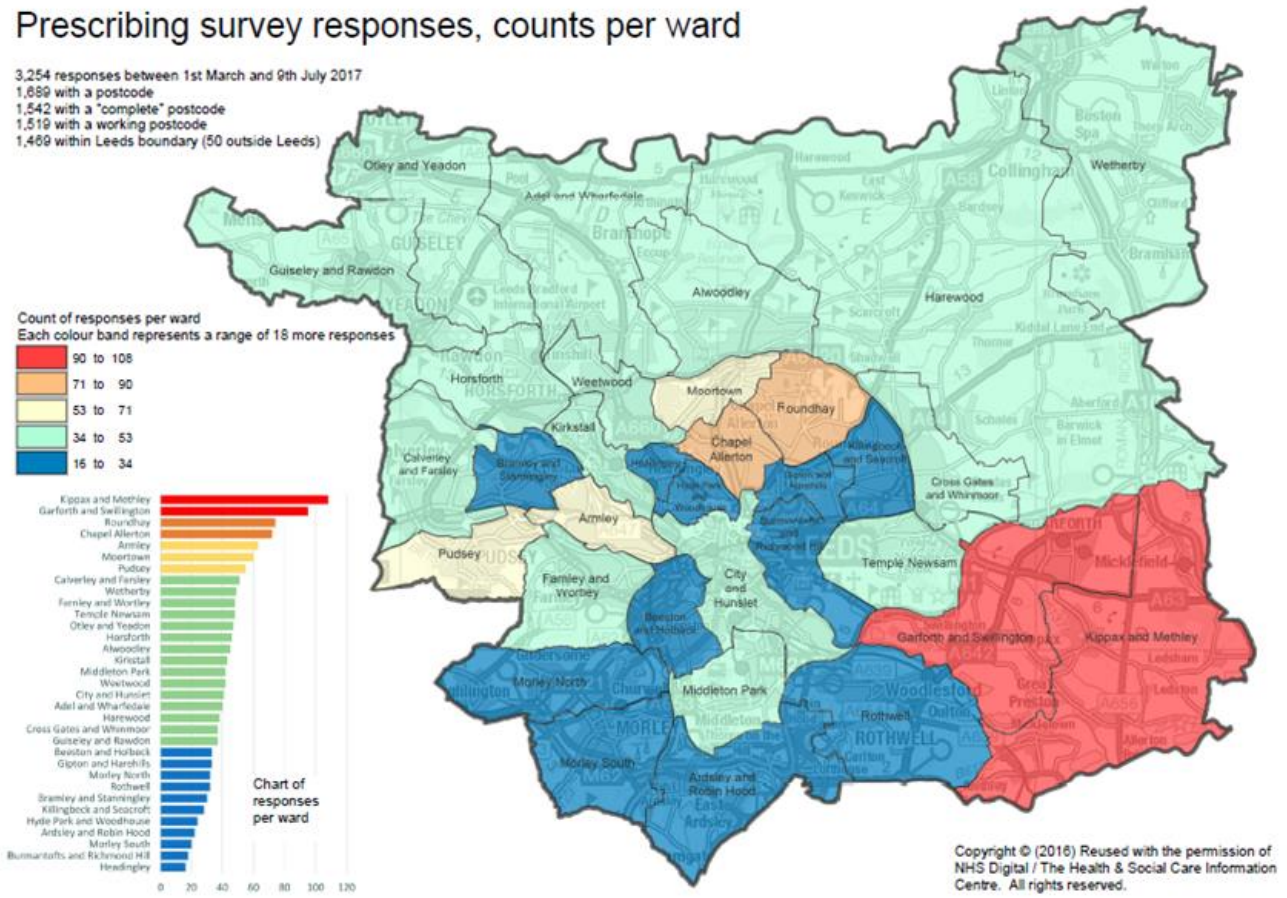


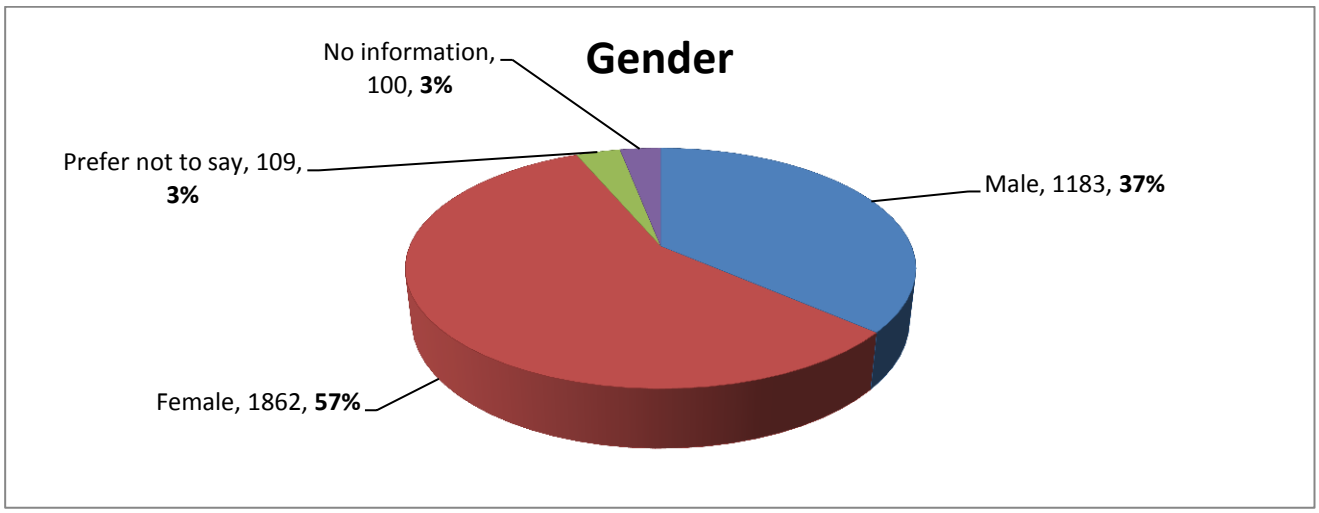


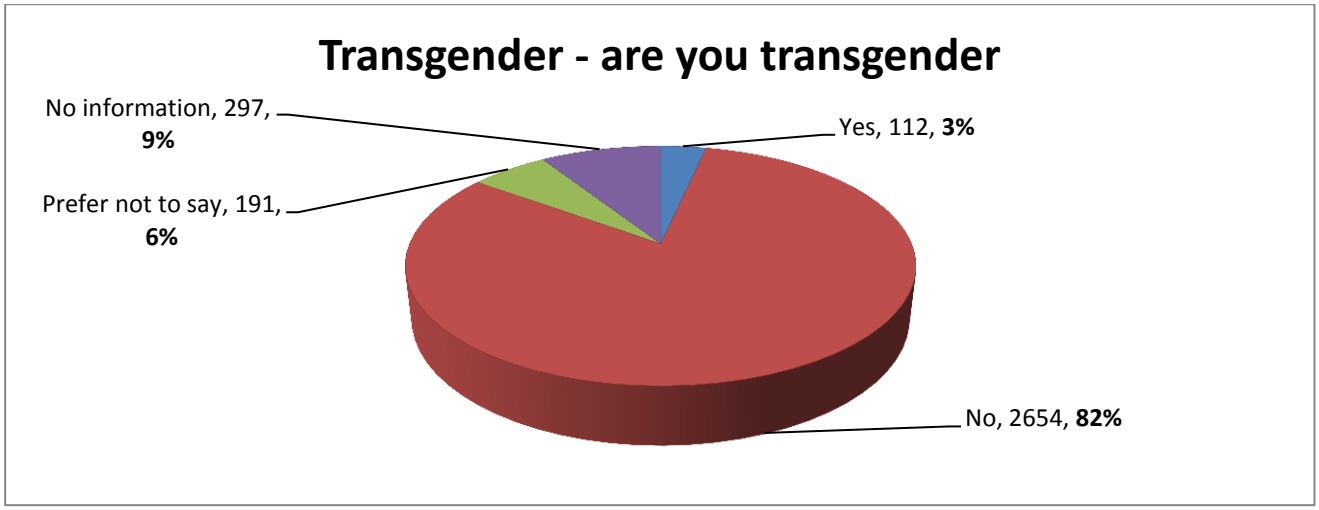
Appendix B – Detail about the people who were involved

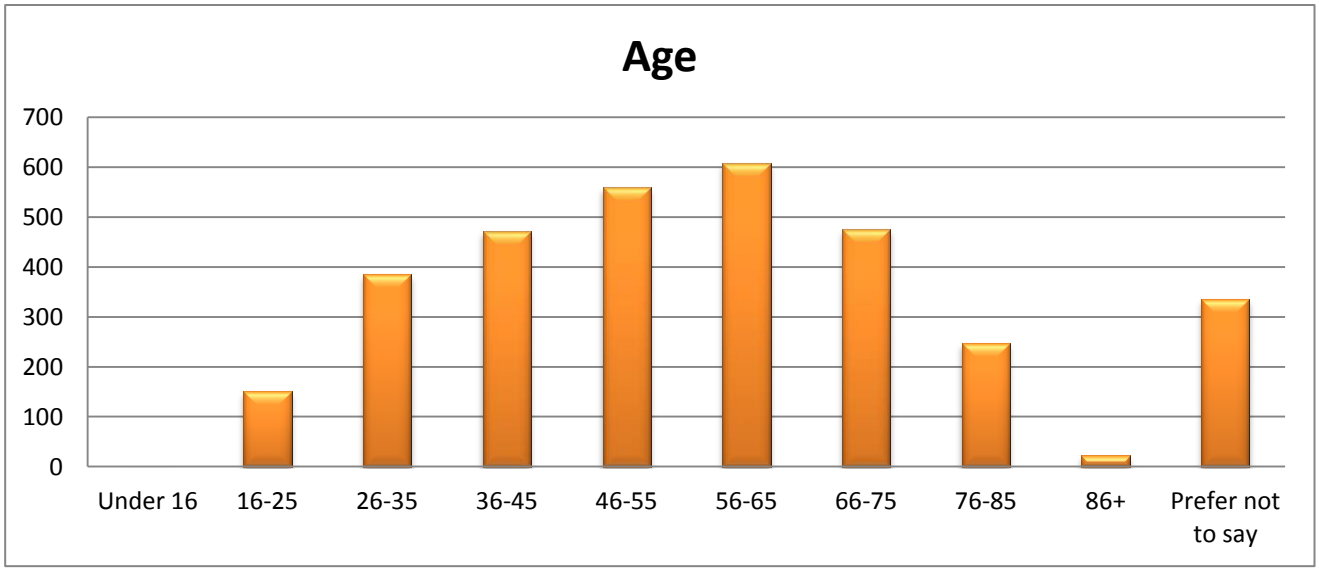
We want our engagements to involve a representative section of our population. As part of the survey we also asked people to give us some information about themselves so that we have a better understanding of which groups are not represented. Using this information we will work hard in future engagements to invite people from under-represented communities. Patients are able to opt out of giving personal information.

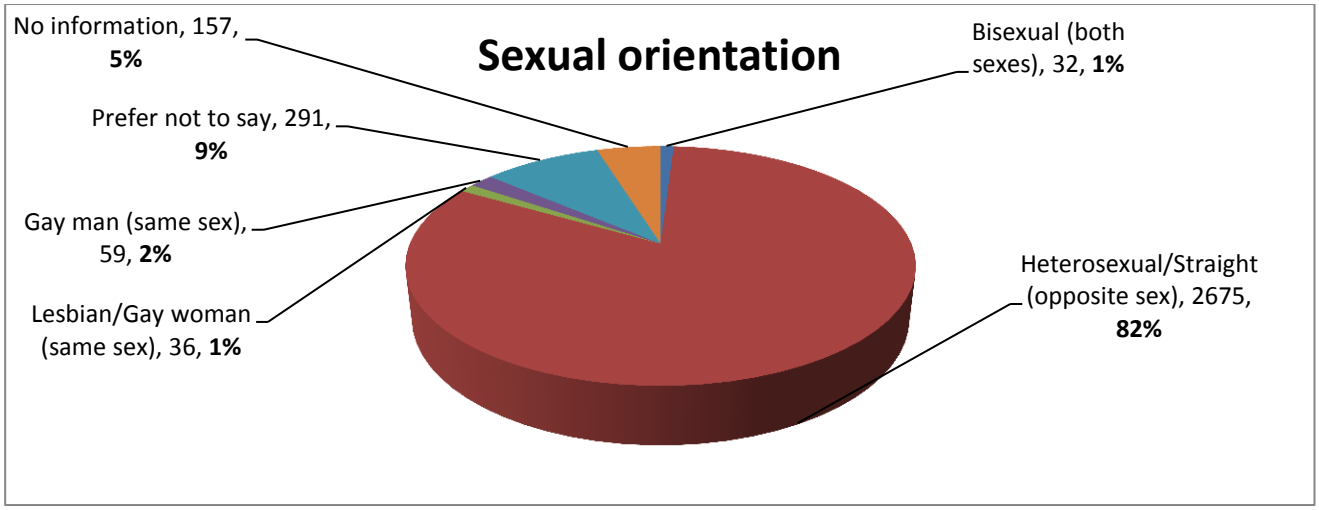
Postcodes map

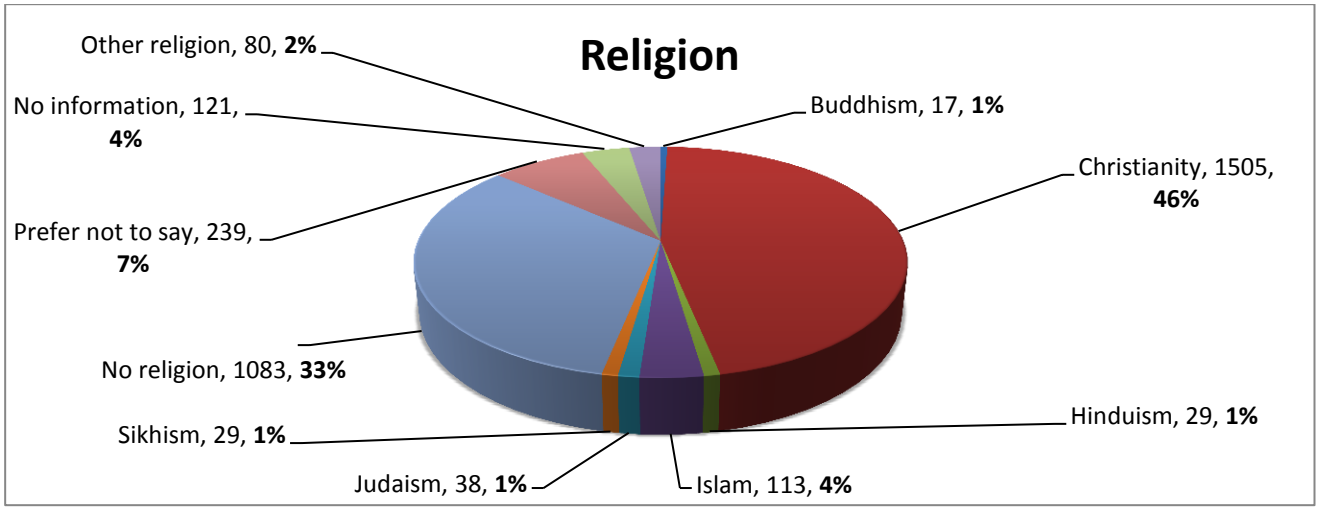


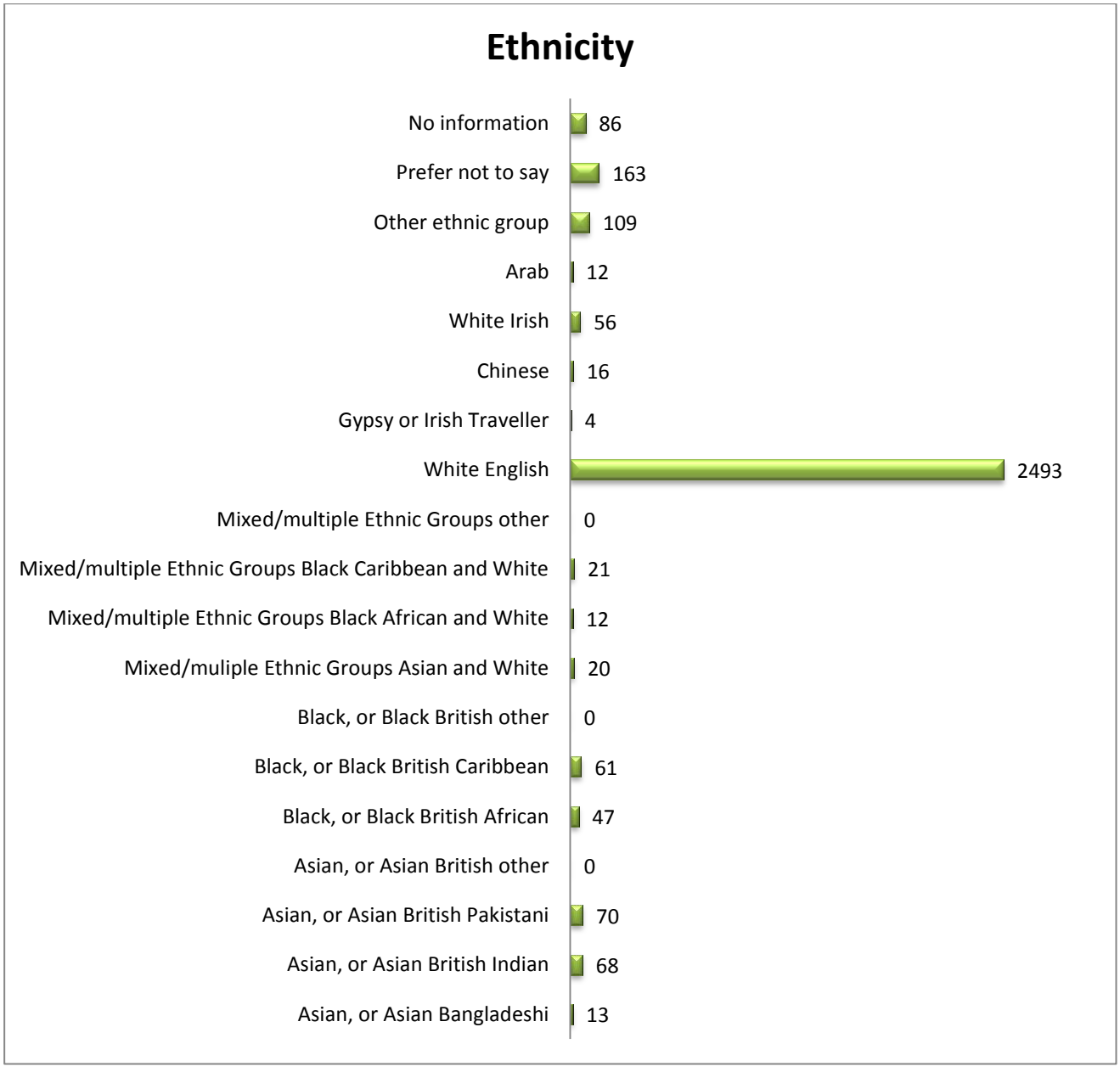


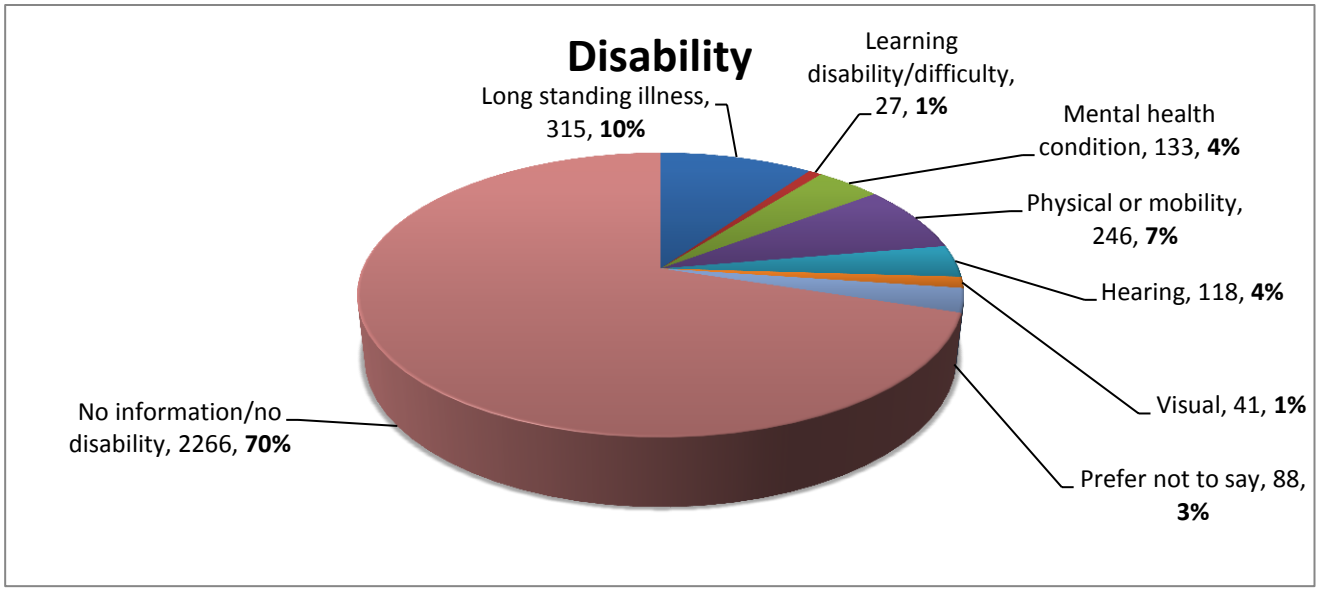

Transgender - are you transgender
No information, 297, 9%
Yes, 112, 3%
Prefer not to say, 191, 6%
No, 2654, 82%

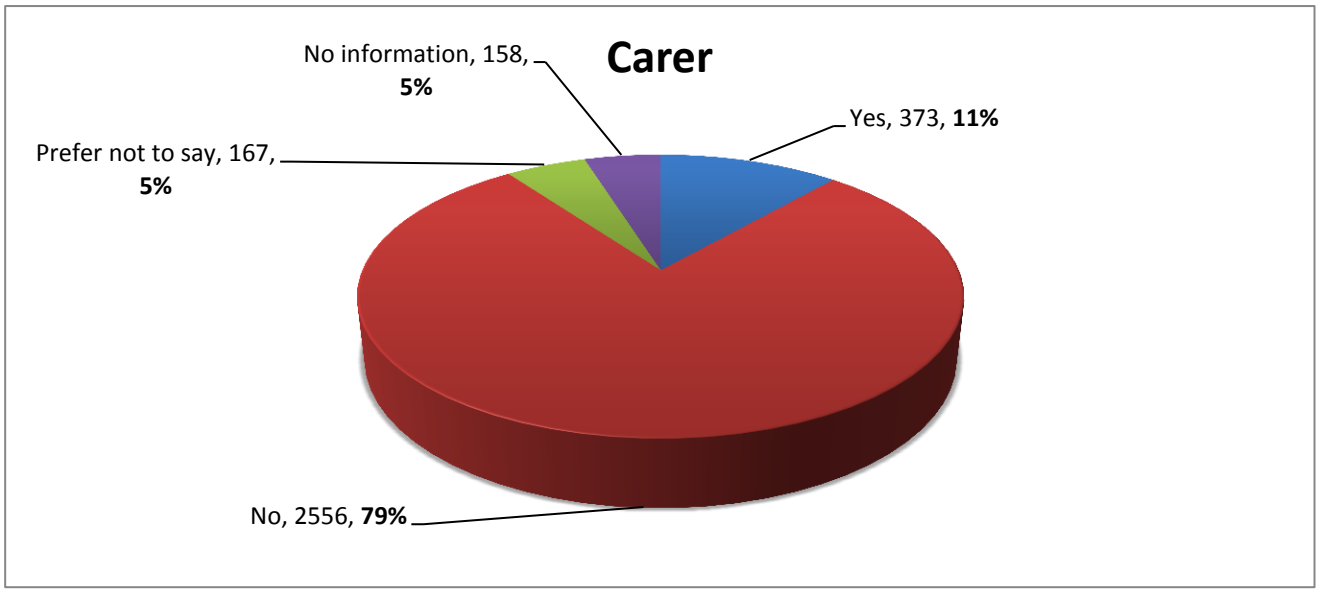

Age
700
600
500
400
300
200
100
0
Under 16
16-25
26-35
36-45
46-55
56-65
66-75
76-85
86+
Prefer not to say

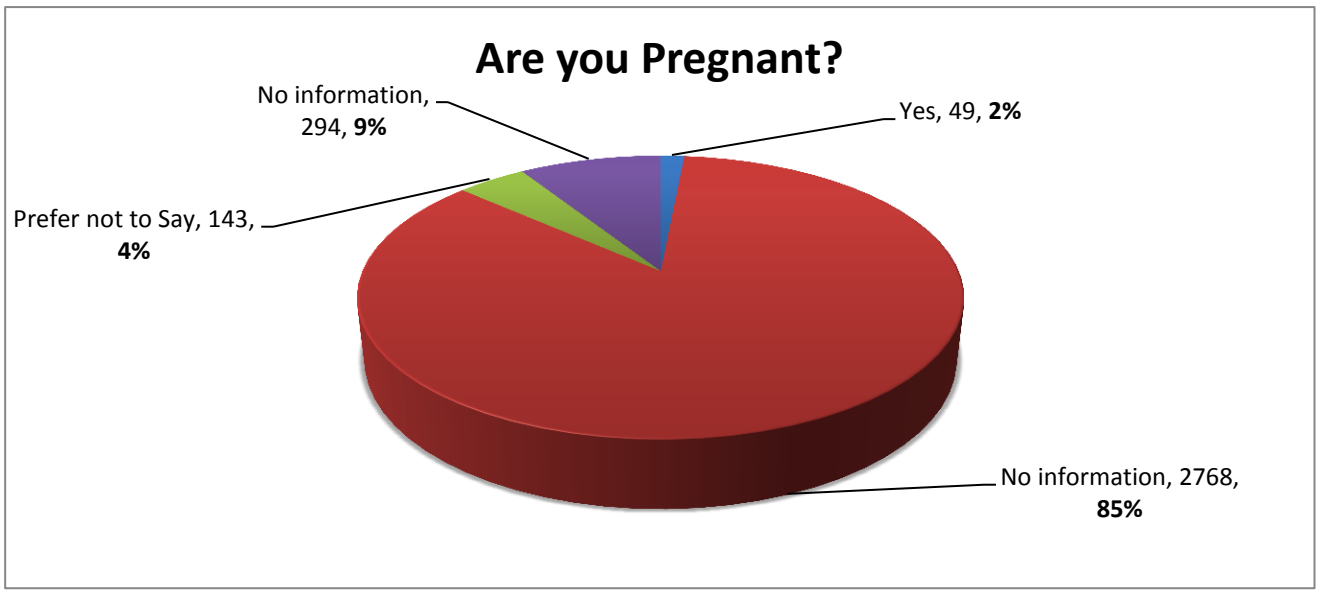

Sexual orientation
No information, 157, 5%
Bisexual (both sexes), 32, 1%
Prefer not to say, 291, 9%
Gay man (same sex), 59, 2%
Lesbian/Gay woman (same sex), 36, 1%
Heterosexual/Straight (opposite sex), 2675, 82%

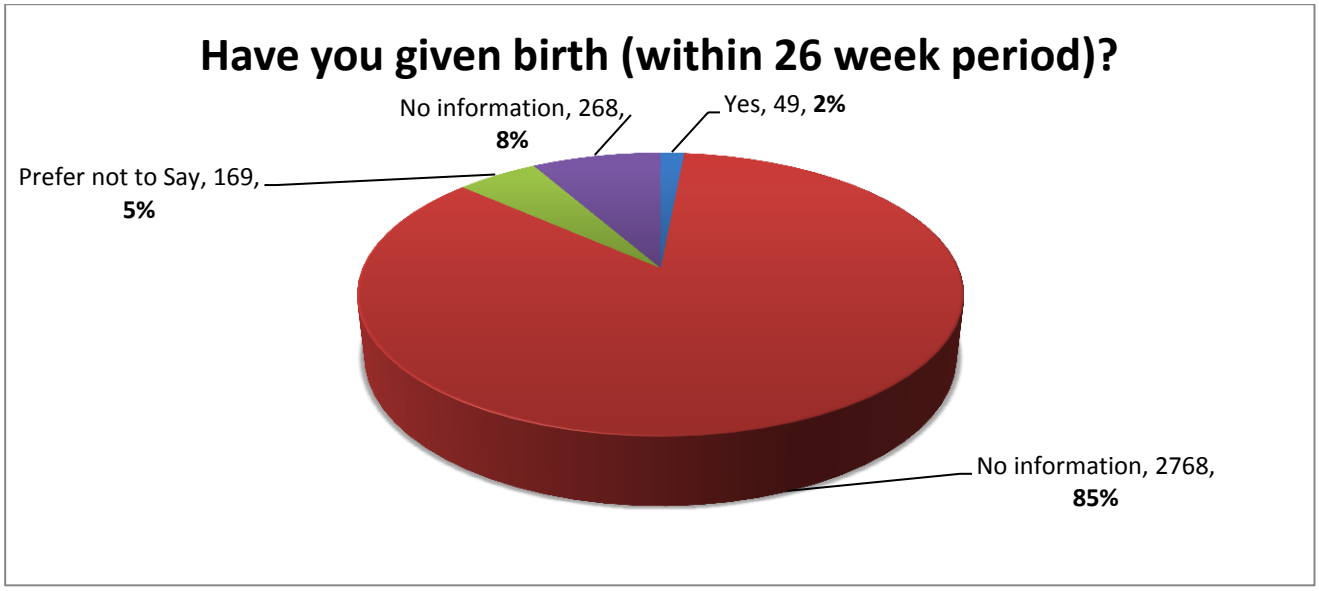

Religion
Other religion, 80, 2%
No information, 121, 4%
Prefer not to say, 239, 7%
No religion, 1083, 33%
Sikhism, 29, 1%
Judaism, 38, 1%
Islam, 113, 4%
Hinduism, 29, 1%
Buddhism, 17, 1%
Christianity, 1505, 46%


Ethnicity
No information 86
Prefer not to say 163
Other ethnic group 109
Arab 12
White Irish 56
Chinese 16
Gypsy or Irish Traveller 4
White English 2493
Mixed/multiple Ethnic Groups other 0
Mixed/multiple Ethnic Groups Black Caribbean and White 21
Mixed/multiple Ethnic Groups Black African and White 12
Mixed/muliple Ethnic Groups Asian and White 20
Black, or Black British other 0
Black, or Black British Caribbean 61
Black, or Black British African 47
Asian, or Asian British other 0
Asian, or Asian British Pakistani 70
Asian, or Asian British Indian 68
Asian, or Asian Bangladeshi 13


Disability
Long standing illness, 315, 10%
Learning disability/difficulty, 27, 1%
Mental health condition, 133, 4%
Physical or mobility, 246, 7%
Hearing, 118, 4%
Visual, 41, 1%
Prefer not to say, 88, 3%
No information/no disability, 2266, 70%


Carer
No information, 158, 5%
Yes, 373, 11%
Prefer not to say, 167, 5%
No, 2556, 79%


Are you Pregnant?
No information, 294, 9%
Yes, 49, 2%
Prefer not to Say, 143, 4%
No information, 2768, 85%



Who was under-represented during this engagement?

The survey was completed by 3,254 people. A number of people chose not to complete the equality monitoring section of the survey used by NHS Leeds West CCG and therefore it is difficult to ascertain which population groups in Leeds were under-represented. However, the data suggests that future events should consider targeting the following communities.

- **White Scottish/White Welsh** – it is acknowledged that the survey asked for "White English" and "White Irish" ethnic groups but not Scottish or Welsh. This was an oversight when compiling the survey and the "White English" category should have stated "White British". A number of responders fed this back, but did use the "Other" category to indicate their ethnic origin.
- **Transgender groups** – though the numbers suggest we received a high response from transgender people, it has been noted from people completing the survey that the question was unclear and may have led to some incorrect completion of the survey if people got confused. Therefore it is difficult to say 112 transgender people completed the survey.
- **Visually impaired groups** – given that the feedback was via a survey (paper or online), it is perhaps not appropriate for those who have difficulty seeing. It will be important to work with visually impaired groups in the future to ensure they have the opportunity to feedback.
- **Learning disability groups** – an easy read document was made available, however this was on request from a focus group that was planned. It may have been more accessible to other learning disability groups if this was readily available in the first instance. A number of people completed the 'easy read' version over the standard survey, despite not having a specific learning difficulty.
- **Other seldom heard groups** – it is always important that as much is done as possible to reach out to seldom heard groups and communities to continue to best represent the overall view of Leeds as a city.

Appendix C – Feedback from wider stakeholders

Coeliac UK:

Further to the launch of the consultation on gluten free prescribing by NHS Leeds North clinical commissioning group (CCG), Leeds West CCG and Leeds South and East CCG, we would like to submit this letter as a formal response to the consultation.

We would like to highlight our concerns regarding the proposal to remove access to gluten free food on prescription, a service providing essential NHS support to help people manage a lifelong autoimmune disease. We are particularly concerned that if approved, this policy would result in health inequality due to the higher cost and limited availability of gluten free food and would have a disproportionate impact on the most vulnerable. Our concerns are shared by the British Society of Gastroenterology and are reflected in the recently published National Institute of Health and Care Excellence (NICE) quality standard for coeliac disease. We would like to know whether as part of the policy development and equality impact assessment has been completed and if so what were the findings?

Pre-paid card as an alternative to FP10 prescribing
As part of the review, will you be considering alternatives to FP10 prescribing?
The Vale of York CCG has launched a pilot which uses a pre-paid VISA card, supplied and managed by the company, P&MM. The card covers the difference in cost between gluten free and gluten containing staple foods and can be used in any retail outlet that accepts a VISA card. Vale of York CCG provides patients with £12-£16 per month (depending on age). This scheme has the potential to make cost savings compared to FP10 prescribing as well as saving clinical time. We would be happy to provide further information or facilitate contact with Vale of York CCG and P&MM.

The significance of the gluten free diet
Coeliac disease is an autoimmune disease caused by a reaction to gluten, found in wheat, barley and rye. Adherence to the gluten free diet remains the complete medical treatment and having coeliac disease therefore requires significant dietary modification. Rates for adherence to the gluten free diet can vary between 42-91% [1] and access to gluten free staples on prescription can be related to adherence [2]. The consultation document states that the gluten free diet 'helps to control the symptoms'. This is an underestimation as the gluten free diet is the only available medical treatment for management of coeliac disease. Non adherence to the gluten free diet is associated with an increased risk of long term complications, including osteoporosis, ulcerative jejunitis, intestinal malignancy, functional hyposplenism, vitamin D deficiency and iron deficiency [3]. These long term complications will impact upon quality of life for the patient and treating these complications will result in financial implications for the NHS.

Cost and availability of gluten free staple foods
Gluten free staple foods are not readily available to purchase in budget supermarkets and convenience stores. Therefore, it cannot be assumed that all people with coeliac disease will be able to purchase gluten free foods in their local shop. Access to gluten free food on prescription is especially vital for the most vulnerable such as the elderly or those with limited transport options. Research shows that gluten free staple foods are 3-4 times more expensive than gluten containing equivalents. An example of the increased cost of gluten free staple foods is gluten free bread, recent data shows gluten free white bread is still on average 6 times the cost of gluten containing by volume, and has not reduced since 2008. Gluten free staple foods on prescription therefore help to address the financial burden for patients and are essential for people on fixed or low incomes.

While the cost to the NHS may be higher than in the supermarket, patients should not be penalised on the basis of poor procurement by the NHS. We understand that there is a need to control costs within the NHS but are concerned that this proposal will have an impact on long term health outcomes. This raises the issue of false economy, where small savings in prescription costs could lead to higher treatment costs associated with poor health outcomes and increased health complications. For example, the cost of gluten free food over a 40-year period is approximately £7,770 (£194.24 per year) and the cost of treatment for a hip fracture £12,170 (increasing by £70,000 per patient if cases become more complex).

The consultation document

Your consultation document states that, naturally gluten free carbohydrates such as potatoes, rice and corn are available. The British Dietetic Association (BDA) highlights the importance of gluten free substitute staple foods for people with coeliac disease in their policy statement explaining that while people with coeliac disease are encouraged to consume as many naturally gluten free foods (including rice and potatoes) as possible, it is not always realistic or convenient to base the diet upon these staples alone. There are also nutritional differences which must be taken into account. In the UK bread is an important source of energy, dietary fibre, vitamins and minerals. It provides more than 10% of our intake of protein, B vitamins and iron, and one fifth of our dietary fibre and calcium. Replacing the average amount of bread consumed daily in the UK (72g [8], roughly 2 slices) with other carbohydrates may therefore have a significant effect on the nutrient content of the diet.

For example, replacing 72g gluten free bread with a portion of rice containing the same amount of calories would reduce the iron content by 96% and the calcium content by 90%. Similarly, replacing gluten bread with portion of peeled, boiled potatoes containing the same amount of calories would reduce the iron content by 71% and the calcium content by 93%. Calcium recommendations for people with coeliac disease are higher (1000mg) than the general population (700mg) because of the increased risk of malabsorption which may affect bone health. Therefore including good sources of calcium in the diet is particularly important for people with coeliac disease.

We note that your consultation document contains one mention of coeliac disease and provides no explanation of what coeliac disease is. The consultation document subsequently refers only to 'gluten intolerance'. We do not feel that this provides reasonable context to those completing the survey who many not be aware of the issues surrounding management of the gluten free diet. Gluten free foods on prescription are approved by the Advisory Committee on Borderline Substances (ACBS) for patients with a medical diagnosis of coeliac disease or dermatitis herpetiformis.

Prescribing for individual needs

We are reassured that you have acknowledged the importance of clinical discretion when prescribing and would like confirmation that this clause was directed at gluten free prescribing as well as over the counter medicines. It is key that clinical judgement is used to identify cases of individual need to ensure vulnerable patients are not put at clinical risk. There have been other cases where policies have incorporated frameworks for prescribing for individual need, for example Harrogate and Rural District CCG make the following statement in their patient information leaflet:

"In exceptional circumstances, patients can continue to receive gluten free products on prescription. Exceptional circumstances would include patients or children of families who are in receipt of either Income Support, Income-based Jobseeker's Allowance, Income-related Employment and Support Allowance paid on its own or with contribution-based

Employment and Support Allowance, Pension Credit (Guarantee Credit) paid on its own or with Pension Credit (Savings Credit), NHS Tax Credit Exemption Certificate, Universal Credit"

Somerset CCG recently changed their gluten free prescribing policy to a blanket ban for all patients. Somerset CCG explicitly ruled out prescribing for specific vulnerable groups. As a result, the charity took legal action to overturn this policy to ensure support of vulnerable patients by prescribing of gluten-free foods in cases of individual need, based on use of clinical judgement. Policies implemented by CCGs should not be allowed to impact on the responsibility of a GP to make decisions appropriate to the circumstances of the individual patient.

British Specialist Nutrition Association:

"The British Specialist Nutrition Association (BSNA) is the Trade Association representing manufacturers of products designed to meet specialist nutritional needs. Our members include manufacturers of staple gluten-free foods for people diagnosed with coeliac disease.

BSNA wanted to make your CCG aware that on 28 March 2017 NHS England announced they will be leading a consultation of prescription items, including gluten-free foods, to set out national guidelines which can be adopted by individual CCGs across England. On 31 March the Department of Health (DH) launched a consultation reviewing the 'The Availability of Gluten Free Foods on Prescription in Primary Care'. This consultation closed on 22 June 2017 and a formal response to the consultation is expected from the DH following their analysis of the submissions received.

We appreciate that there are barriers to overcome, but would urge the CCG to defer a decision until after the NHS England review in order to explore options which ensure that coeliac patients continue to receive a foundation of support to facilitate them in self-managing their life-long chronic condition."

Healthwatch Leeds:

"We have been contacted by a number of people and provided information and articles to oppose any generic "blanket ban". The savings quoted are fairly small and we have major concerns that disadvantaged people who are not always heard will be affected. Issues like capacity and cost of travelling to where the "over-the-counter" products are available and the fact that many pain killers can only be bought in restricted quantities should be considered. Clear and appropriate information to the whole population including how to raise a concern or appeal (not talk to your GP or practice) should be included in the information."

Leeds Local Medical Committee Limited:

"This issue was discussed at the March meetings of Leeds LMC and our committee members commented as follows:

Whilst the LMC is naturally supportive of the principle of saving NHS expenditure wherever appropriate, our committee raised the following concerns:

1. *NHS England has also announced a review of the prescribing of certain medications and products but their proposed list appears to be different to that of the CCGs. This highlights the potential problem of creating a postcode prescribing arrangement. We believe all patients should have equal access to NHS prescriptions no matter where*

they live. Leeds LMC believes therefore that any prescribing changes should be on a national basis.

2. *We note that the Leeds CCGs are undertaking a public consultation regarding their proposals and this is to be welcomed. However, should this plan be implemented, If a patient were to insist on having a prescription for certain recommended medications, GPs could find themselves in the difficult position of still have to provide such a prescription because of their contractual requirements. The LMC believes therefore that legislative changes will be necessary to support these prescribing proposals if they are implemented.*
3. *Most importantly, the LMC committee members expressed concern about potential health inequality issues. Whilst it is no doubt true that many people would be able to purchase over-the-counter medicines for minor conditions, we also recognise the bizarre situation whereby the same product costs more the NHS to prescribe than if it is bought over the counter. We are aware however that some of our patients really cannot afford to routinely buy essential items e.g. gluten-free food. We believe, therefore, that some form of safety net such as a voucher scheme or an extension of the Pharmacy First should be explored for those patients currently eligible for free prescriptions.*
4. *Finally, the LMC note that the current proposals do not address the issue of the prescribing of branded generic medication which the CCGs currently encourage, purely as a cost saving exercise. This causes concern for many patients and is a problem for GPs who, whilst familiar with the generic names of drugs, may not be familiar with every brand name. We believe this poses a potential safety risk for patients and therefore unnecessary switches from generic to branded generic medication should be avoided."*

Scrutiny Board:

"At its meeting in April 2017, the former Scrutiny Board (Adult Social Services, Public Health, NHS) considered proposals from Leeds Clinical Commissioning Groups (CCGs) around changes to prescribing in Leeds.

In summary the proposals covered the following matters:

- *Stop prescribing treatments / medicines for short-term, minor conditions/ailments that are available over the counter (in pharmacies or shops) at a price cheaper than an NHS prescription (or where there is insufficient evidence of clinical benefit or cost effectiveness);*
- *Stop prescribing branded medicines where alternative medicines are available; and,*
- *Stop prescribing gluten-free foods.*

However, following the announcement of the General Election 2017 and the subsequent pre-election period, advice provided to the Clinical Commissioning Groups (CCGs) prevented representatives from the CCGs attending to present the proposals and address any questions from the Scrutiny Board.

In addition to the proposals from the Clinical Commissioning Groups, the Scrutiny Board also considered information on the proposals from:

- *Community Pharmacy West Yorkshire (CPWY)*
- *Leeds Local Medical Committee (LMC)*
- *Leeds' Director of Public Health*

Appropriate CCG representatives have been invited to attend the meeting to discuss the proposals, the associated implications and address any specific questions from the Scrutiny Board.

To help inform the further discussion with CCG representatives, the following key areas of discussion were recorded during the meeting held in April 2017:

- *Concern about the potential issue of creating a postcode prescribing arrangement.*
- *Concern about any potential impact on health inequality if certain items were unavailable on prescription.*
- *Concern about greater responsibilities placed on pharmacists and the level of engagement that had taken place.*
- *Concern around any local changes within the context of planned work / proposals at a national level (which had been the subject of recent announcements from NHS England).”*

Community Dieticians in Leeds:
“*After discussion, the unanimous decision is that the team feel this will have a negative impact on our patients and overall patient care. The main issue being that they feel this is a false economy; the cost saving will not necessarily be seen as we feel the most in need of gluten-free prescription such as those on lower income will not be able to afford gluten-free products from the supermarket and are therefore likely to be less compliant which will lead onto further complications associated with this which will have a greater impact on NHS resources as opposed to the prescription.*

Apparently a case study in Scotland showed that more cost effective prescribing was able to achieve the same overall outcomes as stopping the prescription would. Therefore, we feel looking at more appropriate prescribing, working with the patients to find out which products would most benefit them and the best way to receive them (adjusting unit prescription based on need not age and gender) would be more cost effective.

More dietetic involvement would also aid this to ensure they are monitoring and assessing a patient’s need for gluten-free products. All in all, closer monitoring and more accurate prescribing would be as beneficial as opposed to stopping the prescription all together.”

Community Pharmacy West Yorkshire:
“CPWY are aware that NHS England are consulting on the availability of gluten free foods on prescription in primary care https://www.gov.uk/government/consultations/availability-of-glutenfree-foods-on-nhs-prescription

CPWY recommend that the decision of the Leeds proposals await the outcome of this national consultation. To forge ahead with a local solution will lead to inequitable impact for patients. Patients in Leeds may not be able to receive products that a patient in a neighbouring CCG may be able to receive on a prescription.”

Community Pharmacies West Yorkshire

CPWY are aware that NHS England will be leading a review of low value prescription items from April 2017 and introducing new guidance for Clinical Commissioning Groups (CCGs). NHS England will review a range of low value prescription items, Including: over-the-counter products for pain relief, cough/cold, hayfever, indigestion and

suncream.

NHS England state that in developing the guidance, the views of patient groups, clinicians, commissioners and providers across the NHS will be sought. This guidance will support CCGs in making decisions locally about what is prescribed on the NHS. CPWY recommend that the decision of the Leeds proposals await the outcome of this national consultation.

In addition, CPWY would like to make the following comments relating to the Leeds CCGs proposals:

Impact on patients
Whilst we agree that all patients should be supported to self-care and manage their own self-limiting conditions careful consideration must be given to ensure that particular groups of people are not disproportionately affected.

- *CPWY are concerned over the inequalities this proposal will create, especially for those on low incomes. The CCGs state that medicines are cheaper than a prescription charge but this is only relevant to those who currently pay for prescriptions. Patients may delay treatment and wait until the condition worsens.*
- *Liquid formulations of paracetamol / ibuprofen are more expensive than tablet formulations which impacts on parents / carers with young children.*
- *The current local approach proposed in Leeds to restrict the prescribing of some medicines leads to inequitable impact for patients. Patients in Leeds will not be able to receive medicines that a patient in a neighbouring CCG may be able to receive on a prescription.*
- *If the Leeds CCGs implement a policy to restrict prescribing of certain OTC medicines, patients must be informed and supported through this change. The messaging to patients needs to be clear that they are expected to buy the product themselves (rather than simply directing the patient to a pharmacy for the pharmacy to explain the patient needs to pay for the product).*
- *CPWY are mindful of the NHS Constitution and patients' rights to NHS care and treatment.*

Patient safety
CPWY strongly feel that a distinction needs to be made by the CCGs between community pharmacy and non-pharmacy retailers, and the CCGs should routinely advise patients to access advice and medicines from community pharmacy.

Community pharmacy is part of the NHS and offers patients access to free advice, without the need for an appointment, to a health care professional. A community pharmacist is a highly-qualified health care professional, training to Master's Degree level for five years to become experts in medicines and in giving health and wellbeing advice. All staff working on the medicines counter in a pharmacy must be trained and work to operating procedures to identify patients who need advice from the pharmacist / further medical input. A non-pharmacy retailer cannot offer patients any advice or support and do not have processes in place to identify patients who are more seriously ill. NB Supermarkets may, or may not, have a community pharmacy within them and using supermarkets, rather than shops, is unhelpful.

The case for change
- *CPWY do not agree with the cost saving calculation of the CCG, certainly if the savings have been calculated using a community pharmacy model. The NHS reimbursement price for 16 or 32 paracetamol based on the March Drug Tariff would be 35p / 70p respectively. Although pharmacies also receive a single activity fee for*

dispensing the product, this remuneration (and any margin element of reimbursement) are part of the core funding for pharmacy (see impact on pharmacy below) so essentially are not saved by the NHS but will be redistributed to ensure pharmacy funding remains at the agreed level. The only money that would be saved by the NHS not prescribing paracetamol would be the element of reimbursement which is not margin - i.e. the amount that the pharmacy has to pay for the drug. From the recent margin survey, that is an average of 24p per 32 or 58p per 100 paracetamol, not the £3.17 quoted by the CCGs.

- *In the case for change the CCGs state that "We also want our clinicians to only prescribe medicines that are known to be clinically effective and have a health benefit for patients". This implies that all the medicines listed are not clinically effective which is not the case.*

Impact on community pharmacy

- *Currently the Leeds CCGs commission a Pharmacy First service and CPWY would like an assurance that this service will continue despite the proposed change in prescribing policy for paracetamol and ibuprofen. Pharmacy First is a CCG funded self-care service enables community pharmacists to support patients to self-care for minor ailments, provide printed advice and medicines to patients where necessary. Evaluations of Pharmacy First and similar services from other areas have demonstrated the benefits of these services to patients and the NHS. NHS England have outlined their intention to see minor ailment schemes commissioned by all CCG areas by April 2018. An independent review into community pharmacy clinical services was commissioned by the Chief Pharmaceutical Officer ("the Murray Review") to identify the barriers preventing the best use of community pharmacy, and to make recommendations for new models of care and commissioning. The review, which was published in December 2016, notes the current pressures on the urgent and emergency care system and particularly on GPs and makes the clear recommendation that the provision of minor ailments services by community pharmacy should be supported to help manage these pressures.*
- *Reducing the number of items on prescription will have a detrimental impact on the community pharmacy sector in Leeds. Community pharmacy funding is heavily-based on prescription items (90-95% of community pharmacy funding comes from the NHS) so a fall in prescription volume will directly impact on pharmacy funding. Community pharmacy funding is essentially a national fixed sum. A reduction in prescription volume due to reduced prescribing of OTC or other products would lead to fees and margin on other items increasing. However, as pharmacy funding is nationally set, the impact locally in Leeds would be a net loss of NHS income. We accept that sales of medicines over-the-counter may increase but patients are likely to also buy these products from non-pharmacy retailers.*
- *The consultation documents discuss supply of vitamin D via a Healthy Living Pharmacy Scheme. There is currently no Vitamin D supply scheme from community pharmacy, and such a service would need to be discussed and agreed with CPWY. Licensed Vitamin D products are not 'cheap' as is suggested by the consultation.*

Products

- *There is a large difference in the products affected within the consultation for patients and the guidance to reduce prescriptions for minor conditions, other conditions suitable for self-care, gluten free products and branded prescribing. The guidance includes medicines for a much wider range of conditions than the consultation. This is misleading as people may respond to the consultation based on the much smaller list of products rather than understanding the large range of products affected.*
- *Vitamin D are included in the products affected. Many of the Vitamin D products are*

classed as "food substitutes" and are not covered by the Advisory Committee on Borderline Substances (ACBS) regulations and/or do not appear in the current British National Formulary (BNF) or the Drug Tariff (DT). They are often not manufactured to the same high pharmaceutical standards used for licensed medicines hence there is no guarantee of consistency in formulation and potency. These treatments will not have undergone rigorous clinical trials to demonstrate that they are effective and safe. There is a wide variation in the actual vitamin D content of products, particularly unlicensed formulations versus the stated dose. It is inappropriate to direct NHS resources towards products that do not have proven efficacy or safety in preference to licensed medicines.

- *The CCG state that the products can be bought, without the need for a prescription. This is the case but it must be considered that the product licences limit the sale of products;*
    - *A maximum quantity of 16 paracetamol / ibuprofen 200mg can be purchased from a non-pharmacy retailer. This limits the number of days' supply to just 2 days. Patients would who require pain / fever relief may need to make repeated visits to a non-pharmacy retailer and the product information states that the products are for short-term use only. NB Pharmacy is permitted to supply greater quantities.*
    - *Babies under 2 months are not included in the over-the-counter paracetamol license and under 3 months for ibuprofen.*
- *The list of drugs in the appendix need to be proof checked by someone as it currently contains inaccuracies.*

Community Pharmacy West Yorkshire provided some additional feedback on the proposal to prescribe non-branded medicines over branded medicines:

CPWY support the proposal that the NHS prescribes medicines generically, rather than by brand, unless there is a clinical reason to supply a specific brand. CPWY would like to make the point that currently the CCGs in Leeds make recommendations that prescribers use specific brands (including branded generics) for non-clinical reasons. The CCGs state that this is as these drugs are cheaper to prescribe. Prescribing by brand may mean that the drug is cheaper to the CCG in question but does not offer good value for the NHS as a whole and negatively impacts on the community pharmacies within the CCG. The Office of Fair Trading have outlined that this practice was not in the interests of the NHS and NHS Employers has also issued guidance explaining the detrimental effects of branded prescribing on Community Pharmacy, the wider NHS and patients. It would be a positive move for community pharmacy if the CCGs ended their current practice of prescribing of branded (included branded generic) medicines.

NHS
Leeds Clinical Commissioning Groups Partnership

Alternative formats

An electronic version of this report is available on our website at https://www.leedswestccg.nhs.uk/get-involved/we-need-your-views/prescribing-changes-across-leeds/ or please contact us direct (adam.stewart1@nhs.net) if you would like to receive a printed version.

If you need this information in another language or format please contact us by telephone: **0113 843 5470** or by email: commsleedswestccg@nhs.net

'Jeśli w celu zrozumienia tych infomacji potrzebuje Pan(i) pomocy w innym języku lub innej formie, prosimy o kontakt pod numerem tel.: **0113 843 5470** lub poprzez email na adres: commsleedswestccg@nhs.net

اگرآپ کو ان معلومات کو سمجھنے کے لیئے یہ کسی اور زبان یا صورت میں درکار ہوں تو برائے مہربانی سے اس نمبر پر فون کرکے رابطہ کریں: 0113 8435470 یا اس پتہ پر ای میل لکھیں:
commsleedswestccg@nhs.net

Further information

If you would like any more information about this project, please contact:

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