Crohn's and Colitis UK's Response to NHS England's consultation on items which should be routinely prescribed in Primary Care: A consultation for CCGs

October 2017

INTRODUCTION

This submission responds to proposals that would act to introduce guidance in primary care restricting the prescription of medicines used in the treatment and management of longer term, chronic conditions including Inflammatory Bowel Disease.

While we understand that what is being outlined by NHS England are proposals that will undergo further consultation, we do not support any proposals or future guidance which would introduce additional barriers which serve to restrict access and reduce adherence to medications used in the management of long term, chronic conditions.

We would like to take this opportunity to note our concern that some CCGs have already begun to restrict access to 'over the counter' medication which may impact on people with long-term conditions before national guidance has been issued and a thorough impact assessment has been undertaken.

Who are we?

Crohn's and Colitis UK is a national charity leading the battle against Crohn's Disease and Ulcerative Colitis. We provide high quality information and services, support life-changing research and campaign to raise awareness and improve care and support for those affected by Inflammatory Bowel Disease (IBD).

At least 300,000 people or 1 in 210 people in the UK have Crohn's Disease or Ulcerative Colitis in the UK, collectively known as Inflammatory Bowel Disease (IBD). Inflammatory Bowel Disease is a lifelong condition that most commonly first presents in the teens and early twenties (mean age of diagnosis is 29.5 years). In Inflammatory Bowel Disease the intestines become swollen, ulcerated and inflamed. Symptoms include acute abdominal pain, weight loss, diarrhoea (sometimes with blood and mucus), tenesmus (constant urge to have a bowel movement), and severe fatigue.

Symptoms vary in severity from person to person and from time to time and relapses often occur suddenly and unpredictably throughout a person's lifetime. Between 50% and 70% of patients with Crohn's Disease will undergo surgery within five years of diagnosis. In Ulcerative Colitis, lifetime surgery rates are approximately 20-30%.

Our position

We could not support future guidance which would introduce additional barriers which serve to restrict access and reduce adherence to medications used in the management of long term, chronic conditions. For example, medications routinely prescribed to people with Inflammatory Bowel Disease to treat diarrhoea, constipation, pain, mouth ulcers, avoid skin cancer (in the case

of sun cream prescribed to patients taking drugs such as azathioprine) and associated conditions of the eyes and skin.

Our position is echoed by National Voices, the coalition of health and social care charities, which argues, based on consultation with its members, that 'stopping such prescriptions would be tantamount to introducing 'an ability to pay' as a barrier to accessing the treatments that people need'.

Patient organisations, the Royal Pharmaceutical Society, and the British Medical Journal have in the recent past challenged the outdated system for applying prescription charges for people with long-term conditions on this basis.

While we recognise the significant pressures on NHS funding, we believe any review of guidance must take account of the potential costs and consequences of the policy, **and not only what may be raised by charges**. Furthermore, based on patient feedback and international evidence we assert that restricting access to medicines offers little or no benefits to the NHS and the wider economy in the long-term. It will only act to displace hardship onto patients, carers and their families.

We hope that NHS England and the Government heed shared concerns and use this consultation as an opportunity to rethink their position and confirm that people with long-term conditions such as Inflammatory Bowel Disease will not have their ability to manage their condition/s negatively impacted by these proposals. We urge the Government to instead undertake a review of prescription charges and act to update the outdated current list of medical exemptions to include long-term conditions such as Inflammatory Bowel Disease to support equitable access to essential medication, medicine optimisation and effective self-management.

Summary of key points

We believe that the proposals, as outlined, in their application to people with long-term conditions will:

- Disproportionately impact upon people with a long-term condition or multiple conditions who rely on regular and often multiple medications to prevent debilitating symptoms.
- Be highly likely to have a negative impact on medicine-taking behaviour and quality of life.
- Have a punitive effect on people with long-term conditions, who are already burdened with the additional costs associated with their long-term condition and reduced incomes due to their often limited ability to work.
- Create a barrier to people with Inflammatory Bowel Disease and other long-term conditions obtaining the medications they require to stay well and result in additional unnecessary costs to the health service and wider society.
- Pull those groups currently exempt into the charging system such as people with cancer and diabetes (medically exempted), children, pregnant women, older people and those exempt following a means test - acting to increase health inequalities.
- Introduce additional uncapped charges for those with long-term conditions who have already purchased a prescription prepayment certificate- defeating the purpose of the scheme.
- Reduce health professionals' ability to use their clinical judgement and treat patient optimally.

The importance of medication for people with Inflammatory Bowel Disease

The NICE Quality Standard advocates for services to focus on the prompt detection and optimal management of disease flare-ups and effective maintenance of remission, based on both clinical and economic evidence. Medication is a key pillar of this approach.

'Over the counter' medications are essential to the management of Inflammatory Bowel Disease. These symptomatic drugs do not reduce the underlying inflammation causing the symptoms, but do help ease the symptoms themselves. These drugs can include (but the list is not exhaustive):

- Antidiarrhoeals: loperamide (Imodium, Arret), codeine phosphate and diphenoxylate (Lomotil) help to reduce diarrhoea.
- Antispasmodics such as mebeverine (Colofac), hyoscine butylbromide (Buscopan) and alverine citrate (Spasmonal) reduce painful gut cramps or spasms by relaxing the intestinal muscles.
- Painkillers.
- Bulking agents or 'bulk formers' contain a water-absorbent plant fibre – usually ispaghula or stercula. Popular brands include Fybogel, Isogel and Normacol.
- Bile salt binders.
- Laxatives: osmotic laxatives, such as Movicol and Laxido, which contain a compound known as macrogol, are usually considered the best type of laxative for people with IBD. Others such as lactulose and senna are sometimes used, particularly in young people.
- Anti-foaming agents: e.g. Simethicone
- Anti-sickness medication
- Iron supplements: many people with IBD are iron deficient, which can lead to anaemia, a lower level of haemoglobin in red blood cells.
- Calcium and Vitamin D
- Probiotics
- Sunscreen

We must give greater recognition to the value of symptomatic medicines

The unhelpful focus on items such a paracetamol and lack of proper explanation about why patients might be prescribed items such as sun cream for clinical reasons has served to load and distort discussions around these proposals. As an organisation, supporting patients with an incurable condition, in which medicine is the mainstay treatment, it is very concerning to us that the subsequent narrative surrounding this issue has served to erode the value of these medications and their use in the treatment of chronic conditions.

These 'over the counter' medications can have a dramatic impact on symptom and pain management, drastically improving and retaining people's quality of life, keeping them well, reducing the side effects of other more expensive drugs and enabling people to continue to work, study and look after their families.

Furthermore, while an individual item of medicine may be relatively low cost, when required on a regular and ongoing basis (for one or more chronic conditions) the cost is considerable, especially in addition to other costs such as the Prescription Prepayment Certificate and prescription charges.

We would query the logic of undermining investment in valuable and much-needed specialist health and primary care services for patients with long-term conditions by putting a barrier in place that prevents or dissuades patients from taking their medication recommended by their clinician for the purposes of staying well. We believe that restricting access to these drugs by

forcing people to purchase them over-the-counter will serve as a false economy, ultimately, leading to greater costs to and demands on health services in the long term.

This submission offers examples of patient feedback to support this assertion.

What patients said

While many respondents to our 'call for evidence' sympathised with the pressures the NHS is facing, the majority expressed concern over the impact of the proposals on their ability to afford and access medicines. We also learnt that, where people can afford to buy products over the counter the majority already do so.

"I take 15 loperamide a day, even cheap own brand loperamide is a £1 for 5 or 6 so effectively I'd be paying £3 a day for that medication. I pre-pay for all my medications at the moment and do not get an exemption. I have very little bowel left after surgery and cannot live without these meds. The proposed changes would have a dramatic effect on my health and well-being." Dominic, 47, Crohn's Disease

"I already feel I am at a disadvantage with regard to my earnings potential due to my illnesses and this greater cost for medications would put more pressure on me financially. I suffer mentally as well as with my physical conditions and there is a cycle where each in turn worsens the other if not kept under control, so my focus (which I've learnt from many hard years of work with psychologists), is keeping my mind calm as this helps me physically too. So I feel added barriers which can be assisted with should be where possible, like the financial side of health aspects, pressure to earn etc. It actually makes me quite angry to read the considerations to change this." Ellie, 31, Ulcerative Colitis

"I take 8 loperamide a day minimum and there is no way I could afford to pay the over the counter prices. Stopping these medicines being available would mean I would not be able to live my life and be a prisoner in my own home. I have had two bowel surgeries so even when not flaring I always have diarrhoea. I am really shocked and upset to hear this is being consulted on." Hannah, 36, Crohn's Disease

"I've received prescriptions for both diarrhoea and constipation, mouth ulcers and indigestion. I only use these during a flare, but I've ended up with a stomach ulcer from medication before so I always get omeprazole when I'm on steroids and I also get intermittent mouth ulceration which I use Difflam for and betamethasone tablets. I've needed codeine to control my pain and so I've had laxatives alongside that, but I've also got an emergency supply of loperamide. If I had to pay for all of these then I simply wouldn't be able to and I would no doubt suffer as a result. I only use them when I need to, but they are lifesavers when I need them. A flare-up is not a minor or self-limiting condition and should not be classified as such." Alison, 44, Ulcerative Colitis

"If there was some kind of exemption the doctor could give without a prescription that would just allow us to buy more, as I think the current limit is something like 12 tablets without a prescription, that would go some way towards a resolution. However, I also acknowledge that for many people having to buy medication in this kind of quantity would be difficult for financial reasons, too, and as I see it the whole point of the NHS is to ensure that everyone can access adequate healthcare regardless of their financial status. I think that if medication is vital to allowing you to leave the house, as is the case for me with loperamide, it should be accessible on the NHS." Laura, 29 Crohn's disease

"I have Crohn's disease and am prescribed Laxido (which I take daily) and Dioralyte (which I take as required). If I didn't take these I would be admitted more regularly to hospital with obstructive symptoms. The packs available OTC are too small and are very expensive compared with the cost

of paying these via prescription pre-payment on direct debit. These medicines are not always for "minor ailments", but are vital preventative treatment for a debilitating condition. Fortunately I am finding strategies to manage my own health and avoid regular emergency admissions, but these prescriptions are vital to enable me to do this. As a result of effective management of my condition I can continue in paid employment (my business is also an employer) and look after my children… Ultimately the NHS saves hundreds of pounds in consultations and admissions if I take regular laxatives and have rehydration solution available for emergencies. It allows me to continue to be economically active. Most importantly, I feel better!" Linda, 41, Crohn's disease

Cost as a barrier to accessing necessary medication

A recent report undertaken by the Prescription Charges Coalition, made up of 40 patient organisations, into prescription charges for people with long-term conditions found that the cost of prescriptions was preventing people from taking or picking up their necessary medication.

One third (of 4200) respondents admitted to skipping or reducing medication doses. As a result, nearly three in five (59%) become more ill, with half of these needing to take time off work. 34% needed to visit their GP or hospital.

Similar findings have been found in several previous surveys.

A poll, published in *Pulse,* found that 40% of GPs link prescription charges to adverse patient outcomes, also indicating that these can lead to far greater costs and adverse outcomes down the line. The 2016 National Review of Asthma Deaths highlighted widespread under-use of preventer inhalers and excessive over-reliance on reliever inhalers and that some patients had not collected their prescriptions for preventative treatment. Asthma UK research has identified that cost plays a key role in these behaviours.

Working age people with long-term conditions are more likely to have below average incomes because of the impact their condition has on their employment options. Often, they also incur a range of extra costs associated with the management of a long-term condition – transport charges to and from medical appointments, car parking costs and lost time at work amongst others. That they may also have to bear the additional cost for the medications that they need to manage their ongoing symptoms, as well as the bulk of the burden of prescription charges in England would be particularly unfair.

Over the years the Coalition has found evidence of people being forced to choose between paying for medicines and putting food on the table. We feel strongly that people with long-term conditions should be able to obtain their essential medication without having to worry about whether or not they can afford it. As recognised in Scotland, Wales and Northern Ireland, this should improve health outcomes and reduce costs elsewhere in the system.

Concerns regarding patient safety

The proposals as outlined give rise to concerns around patient safety, supported self-management and joint decision making. It is unclear how patients will be counselled about their medicine use if they are steered towards purchasing medications over the counter. We currently advise patients to check with their doctor or IBD team before taking 'over the counter'/symptomatic drugs. They may not be suitable for a patient's type of IBD, or might interact with their IBD medication. Some can also mask serious symptoms.

"Your GP/ treating team need to know what medication you are on so they can see how much you are using and can see if anything needs changing. This will be lost if you are left to purchase medication on your own." Alison, 44, Ulcerative Colitis

"I am very concerned about the proposed changes because these medications e.g. haemorrhoid treatments, painkillers, vitamin supplements etc. and any medication that is used to help either control or relieve Crohns symptoms are vital to me. If I had to buy them I would not be able to have them either as needed or regularly enough to work effectively. I also need to see my doctor to make sure I need this medication and to get other advice at the correct time this is vital in managing Crohns Disease." Debbie, 51, Crohn's Disease

Policy threatens future success of self-management

It is unclear how this guidance fits with and will impact upon the NHS self-management agenda. In 2014 we asked people with long-term conditions in Northern Ireland about the impact of free prescription charges on self-management. When we asked respondents whether the abolition of prescription charges had changed the management of their condition, over half said that it had made it easier. When asked what impact those surveyed thought the reintroduction of prescription charges might have on them:

- Only 8% said that they did NOT think it would have a significant impact.
- Nearly half said that they might sometimes prioritise other costs before my medication (e.g. food/grocery bills, gas/electricity, rent/mortgage).
- Nearly two thirds of respondents said that the reintroduction of charges would affect their ability to manage their condition.

Lack of evidence base

These proposals are framed in terms of reducing 'substantial' costs to the NHS. While we understand that the NHS is under significant financial pressure, it is concerning that no justification for these changes is being made based on improving outcomes, safety and patient experience. Furthermore, while 'extensive activity' has been undertaken by NHS clinical commissioners to evaluate the cost savings of these proposals, there is no supporting research provided into the impact of these proposals from a clinical or societal perspective. We believe that this information is vital for the public and people with long-term conditions to consider in order to be in a position to make an informed decision about what is being proposed.

CONCLUSION

Given the wealth of evidence to show that charges act as a barrier to treatment and adherence, we could not support guidance, which would act to restrict access to vital medicines for people with long-term conditions.

The NHS Constitution states that "Access to NHS services is based on clinical need, not on an individual's ability to pay".

We believe a fair and sustainable system that enables people with long-term conditions to access the medication they need to stay well will be of far greater benefit to the NHS and wider economy than any apparent short-term financial gain from charging.

We would welcome the opportunity to discuss our response in more detail with NHS England and are happy to answer any questions or requests for further information.

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