

Homecare Medicines Services

Submission from Crohn's & Colitis UK

1. About this submission

1.1. Crohn's & Colitis UK is the leading charity for Crohn's and Colitis: lifelong conditions affecting over 500,000 people in the UK. We provide information, campaign and work to reduce the stigma around the conditions and symptoms. We want to improve the lives of the people who come to us for support, and we fund vital research towards the long-term goal of a world free from Crohn's and Colitis.

1.2. When homecare medicine services work well they offer people the opportunity to continue their treatment in the comfort of their own home, reducing the costs of travelling back and forth to hospital and the impact on work or education. However, evidence from people living with Crohn's and Colitis and clinicians highlight deep, systemic and long-standing failures in homecare medicine services. These go beyond issues experienced by just one provider.

1.3. These failures are causing harm to patients and increasing the burden on clinicians and the wider NHS. Therefore, we welcome the Public Services Committee's inquiry.

1.4. Our recommendations:

1.4.1. Improved accountability of homecare services with national KPIs that are monitored with reports published publicly on a regular basis. Government should conduct a review of homecare medicine services KPIs and develop a framework of metrics that is coproduced with patients and clinicians with a transparent reporting mechanism. The KPIs should include: patient choice, patient involvement in procuring, operational delivery and service monitoring, clear information and communication to patients.

1.4.2. Stronger enforcement. Given the scale and the severity of issues affecting patient care and clinical teams, it is important that there is clear and transparent regulation of homecare services. There needs to be financial penalties for failures in services that cause additional burden on the NHS.

1.4.3. A streamlined and transparent complaints process that reduces the administrative burden on the NHS teams and makes it easier for both clinicians and patients to track the progress of their cases. This is crucial as we are hearing from both patients and IBD nurses that patients are losing trust in their IBD service and clinical teams due to failures in homecare services.

1.4.4. Improved communication with patients. It is hugely worrying that patients cannot contact homecare medicine services when they do not receive their medication or receive the wrong medication. It is completely unacceptable for NHS services to have to use NHS staff resource to deal with the resulting high rate of enquiries.

1.4.5. Addressing the interoperability of IT systems between secondary care and homecare services. Access to shared records and electronic prescribing is not currently standard, and this causes prescriptions not to be processed on time.

2. About Crohn's and Colitis and Homecare Medicine Services

2.1. Over 500,000 people in the UK live with Crohn's Disease and Ulcerative Colitis, the two main forms of Inflammatory Bowel Disease (IBD). These are immune-mediated, chronic diseases of the gut, for which there is no known cure.

2.2. Around 1 in 4 people with Crohn's and Colitis are diagnosed before they are 30, which means many live most of their lives with the conditions, and will require ongoing specialist treatment and healthcare, managed in secondary care, at significant cost to the NHS.¹

2.3. When homecare medicine services work well, they play an important role in personalised care. Studies indicate a strong preference for taking medication at home. One study found 67% of people living with Crohn's or Colitis preferred receiving an injection at home rather than having an infusion in hospital.²

2.4. One of the most common group of drugs supplied via homecare medicine services for people with Crohn's and Colitis are subcutaneous injections of biologics, but some newer oral therapies are also supplied via this route. Currently, there is no publicly available data on the number of IBD patients subscribed to homecare medicines services.

2.5. Missing IBD medications is strongly associated with loss of response to treatment, leading to flares, dose intensification or discontinuation, surgery or hospitalisation. It is important to note that the range of options available for treating IBD remains limited and once current medicines fail to alleviate symptoms, surgery may remain the only option. For many patients the prospect of surgery is one they face with considerable anxiety, and it can bring with it a range of potential complications, which may require further treatment and ongoing management. There can also be an associated profound psychological and social impact, for example, in terms of body image and self-esteem.

3. What problems are there, if any, relating to homecare medicines services? What is the prevalence of any problems? Please share any relevant analysis.

3.1. There are deep, systemic and long-standing failures in homecare medicines services, which go beyond issues experienced by just one provider. To illustrate the scale of the problem:

3.1.1. Nearly two thirds (62%) of people living with Crohn's and Colitis who responded to a recent charity survey told us that they have experienced problems with their homecare medicine service in the last six months.³

¹ Crohn's & Colitis UK (2022). New research shows over 1 in 123 people in UK living with Crohn's or Colitis (crohnsandcolitis.org.uk)

² Van Deen, W.K. *et al.* (2020) 'S0812 Patients' Preferences for Subcutaneous or Intravenous Administration Methods in Inflammatory Bowel Diseases', *Official journal of the American College of Gastroenterology | ACG*, 115, p. S417. Available at: <https://doi.org/10.14309/01.ajg.0000705296.17553.49>.

³ Based on 711 respondents. The survey was carried out between 8-11 May 2023.

- 3.1.2. Nearly half (43%) of IBD nurses who responded to a recent charity survey reported that more than 40% of their patients on homecare medicine services had an issue in the last six months.⁴
- 3.1.3. The same survey found that IBD nurses assist on average eight patients with homecare medicine services issues a week. However, there are huge variations across the country, with some reporting supporting 50-60 patients in a typical week.
- 3.2. Crohn's & Colitis UK's surveys with IBD nurses and patients reveal that there are a wide range of issues with homecare medicine services including:
 - 3.2.1. Medicine deliveries or homecare nurse visits being delayed or cancelled at short notice, with little to no communication from homecare medicine services. A third (30%) of people living with Crohn's and Colitis report they have had these sorts of problems in the last six months.
 - 3.2.2. Homecare medicine services sending the incorrect medication, out of date drugs or incorrect dosage to patients.
 - 3.2.3. Issues related to processing prescriptions, such as paperwork being signed as received by the homecare medicine service and then going missing and delays in the provider pharmacists approving the prescriptions.
 - 3.2.4. Homecare medicine services not contacting hospital-based homecare teams when a repeat prescription is due as per their commissioned prescription management service. Instead it is frequently being left to patients to alert their IBD teams.
- 3.3. We understand that IBD patients on Adalimumab (Humira/Imraldi) are particularly impacted as this requires administration every two weeks, leaving very little room for error for administrative errors. In one incident an IBD nurse told us that the medicine was delivered 6 weeks after it was due to be administered to the patient. In another, the delivery was cancelled on the day it was meant to be delivered and rebooked for 8 weeks later.
- 3.4. We have also heard from clinicians that young people attending university or college away from home experience particular difficulties as homecare medicine services do not effectively deal with individuals with two addresses (home and university). We have heard about one patient who needed to travel from London to Newcastle to be able to pick up their medication over the summer, and he ended up in A&E as a result of missing a dose.
- 3.5. These problems are compounded by serious communication issues whereby both patients and IBD teams have great difficulty in contacting homecare medicine services to report and investigate issues. Over a quarter of (26%) patients responding to our survey told us they found it difficult to get hold of someone at the homecare provider.

⁴ Based on 86 respondents (We estimate there are 300 IBD nurses in England). The survey was carried out between 8-11 May 2023.

3.6. Our survey of IBD nurses show that homecare services are not improving: 51% told us that problems with homecare medicine services have worsened in the last six months and 41% said they have remained the same.

4. What impact do any problems in homecare medicines services have on individuals, clinicians, and the wider NHS?

Impact on patients

- 4.1. There is currently no medical or surgical cure for IBD and current available treatments are aimed at inducing and maintaining remission and improving quality of life. IBD requires careful monitoring and management, often over several decades from the age of diagnosis. If left untreated or poorly managed, this condition can cause serious complications, which require emergency medical and/or surgical intervention.
- 4.2. Timely delivery of medicines is vital in the management of Crohn's and Colitis. Variation in treatment protocols can lead to anti-drug antibody formation and/or reduced effectiveness of medicines, increasing the risk of flares (i.e. relapse in symptoms). One of the main reasons patients report for not taking medication is running out of medications.^{5 6}
- 4.3. Missing IBD medications is strongly associated with loss of response to treatment, leading to flares, dose intensification or discontinuation, surgery or hospitalisation. There is anecdotal evidence from IBD pharmacists that an increasing number of patients are switching drugs because they are not able to receive them from their homecare companies. Losing efficacy therefore seriously limits people's options and increases the risk of surgery.
- 4.4. The range of options available for treating IBD remains limited and once current medicines fail to alleviate symptoms, surgery may remain the only option. For many patients the prospect of surgery is one they face with considerable anxiety, and it can bring with it a range of potential complications, which may require further treatment and ongoing management. There can also be an associated profound psychological and social impact, for example, in terms of body image and self-esteem.
- 4.5. Patients taking subcutaneous biologics for Crohn's or Colitis (i.e. those who are on homecare medicine services) have a significantly increased risk of flare and hospitalisation, even compared to the wider IBD population, if their medication is delayed. For example, a study of biological adherence in IBD patients found that those who delayed refills of their subcutaneous biologics by more than two days on a fortnightly basis, had a significantly increased risk of flare.⁷ In these circumstances, IBD teams need to react quickly to control inflammation by prescribing a course of

⁵ Feagins LA, Iqbal R, Spechler SJ. Case-control study of factors that trigger inflammatory bowel disease flares. *World Journal of Gastroenterology*. 2014 Apr 21;20(15):4329-34.

⁶ van der Have M, Oldenburg B, Kaptein AA, Jansen JM, Scheffer RC, van Tuyl BA, van der Meulen-de Jong AE, Pierik M, Siersema PD, van Oijen MG, Fidder HH. Non-adherence to anti-TNF therapy is associated with illness perceptions and clinical outcomes in outpatients with inflammatory bowel disease: results from a prospective multicentre study. *Journal of Crohn's and Colitis*. 2016 May 1;10(5):549-55.

⁷ Govani SM, Noureldin M, Higgins PDR, et al. Defining an Optimal Adherence Threshold for Patients Taking Subcutaneous Anti-TNFs for Inflammatory Bowel Diseases. *Am J Gastroenterol*. 2018;113(2):276-282. doi:10.1038/ajg.2017.438

steroids, increasing the dose of the medicine or discontinuing it, or by doing surgery, at considerable cost to both patients and the NHS.

4.6. A relapse in symptoms can have a profound and devastating impact on all aspects of a person's life. Frequent diarrhoea, blood or mucus in stools, abdominal pain, strictures, fatigue, mental health deterioration plus extra-intestinal manifestations such as joint, skin and eye problems, all affect an individual's ability to work, study, socialise, participate in leisure activities or have intimate relationships.

4.7. Our survey of people living with Crohn's and Colitis revealed that as a result of failures in homecare medicine services:

- Nearly half (47%) experienced a flare
- 1 in 11 (9%) needed to have a new treatment plan
- 1 in 13 (8%) needed to be reloaded with induction doses of biologics, requiring them to travel to hospital for their infusion, needing time off work and incurring travel costs
- 1 in 8 (13%) said they had their steroid course extended. Two thirds (65%) of IBD nurse respondents said they had patients who had their steroid course extended due to a failure of the delivery of their biologic
- 1 in 9 (12%) ended up in A&E
- 1 in 20 (5%) required surgery.

4.8. Additionally, more than half (51%) of patients reported that the issues with homecare medicine services had affected their mental health, whilst over a third (35%) found it difficult to go to work or school. One in six (16%) have faced financial problems.

"It makes me mad, frustrated, but mostly it's heartbreaking seeing my child suffering - and feeling helpless. [Homecare provider] has added so much unnecessary stress to our lives, when we were already struggling with accepting our daughter's diagnosis." Parent of an 7 year old female with Crohn's Disease.

Impact on clinicians and the NHS

4.9. Failures in homecare medicine services which result in a relapse of symptoms, flares, emergency treatment or surgery increase costs to the NHS and add resource pressures on already stretched IBD services.

4.10. Not only do IBD teams need to react quickly to treat flares, patients who have difficulty in contacting homecare medicine services to report and investigate issues, turn to their IBD service, specifically their IBD nurses, for help. Half (49%) of the nurses responding to our survey told us they spend at least half a day every week supporting patients having difficulties with their homecare medicine service with 12% spending a day or more.

"We are getting more calls on our advice line regarding delays in homecare deliveries and nurse visits, which obviously is increasing our workload. One of the major issues we have is that there is no way to contact the nursing service at [Homecare provider] apart from emailing their manager, or calling the customer service team and getting them to pass a message on. Unfortunately, we have had a handful of patients that don't complain so we haven't found out until much later on that they have received their injections months after they should have. We have

had to re-load several Ustekinumab patients with the induction doses because of such big gaps between doses.” Crohn's & Colitis UK IBD nurse specialist

4.11. Homecare issues have a significant impact on pharmacy teams too. One IBD pharmacist told us in a typical week their advice lines spend 15 hours dealing with calls from patients who are unable to get the support they need from homecare medicine services and told us that *“patients should be supported as per service level agreement, but they end up calling our advice lines because nobody answers their calls”*.

4.12. Contextualising our survey results described in section 3.3 from a health economics perspective, we have reason to believe that delays to treatment caused by homecare delivery delays could be incurring a substantial cost to the NHS. For example,

- Each patient with Crohn's or Colitis who is admitted to A&E with stomach pain costs the NHS between £168-184.⁸
- A patient on biologics who experiences a moderate flare costs the NHS £1,700-2,900.⁹
- Each IBD related surgery costs the NHS over £9,400.¹⁰
- Biologic medicines are expensive and therefore reloading patients with induction doses is likely to come at a significant cost.

5. How robust, and how effective are the relevant performance indicators? How easy are they to find and use?

5.1. Whilst we know that the National Medicines Homecare Committee publish 61 KPIs, there is no transparent way of monitoring performance against these KPIs. We have found no publicly available data on the number of patients with Crohn's and Colitis on the system, and how they are served by the homecare services, or any broad indicators across the system on the performance of homecare medicine services. It is currently impossible to ascertain a clear picture of the reliability and safety of services provided.

5.2. **Recommendation: Government should conduct a review of homecare medicine services KPIs and develop a framework of metrics that is coproduced with patients and clinicians with a transparent reporting mechanism. The KPIs should include: patient choice, patient involvement in procuring, operational delivery and service monitoring, clear information and communication to patients.**

6. Do you have comments on the amount of information that is available to the public; or to relevant professionals?

6.1. Communication between patients, IBD teams and homecare medicine services is poor, which leaves patients in the dark about when they will receive their medication and IBD teams burdened with additional administrative workload.

⁸ Based on draft Rightcare scenario for IBD

⁹ Ghosh N, Premchand P. A UK cost of care model for inflammatory bowel disease. *Frontline Gastroenterol.* 2015 Jul;6(3):169-174.

¹⁰ Based on draft Rightcare scenario for IBD

- 6.2. Despite the catalogue of problems dealt by patients and IBD nurses, the number of ‘formal complaints’ to the homecare services are relatively small. In a survey of IBD nurses, we found that on average nurses raised 5 official complaints in the last six months. One nurse told us “*for every formal complaint, you can assume at least 10 very serious issues that should be dealt with as a formal complaint*”. It is hugely important that we reduce the burden on clinicians, so that the complaint numbers reflect the scale and the severity of problems experienced by patients.
- 6.3. Both nurses and pharmacists tell us that the process for raising complaints is too long and complex, and that they cannot afford to spend more time filling out forms especially after having spent hours supporting patients with homecare deliveries.
- 6.4. **Recommendation: There should also be streamlined complaints reporting and resolution processes in place, ideally digitally, that resolve patient/clinician concerns, whilst reducing the extensive administrative burden on clinical teams.**
7. **Where services may be failing to meet required standards, how effective are enforcement mechanisms?**
- 7.1. There is a lack of clarity regarding accountability and enforcement of standards in relation to the quality, cost effectiveness, safety, and reliability of homecare medicines services at a national, regional and local level.
- 7.2. **Recommendation: Government should commit to reviewing, streamlining and establishing clear lines of accountability that include greater enforcement mechanisms to improve the overall safety, efficiency and effectiveness of homecare medicine services.**

For further information, please contact policy@crohnsandcolitis.org.uk