

# Crohn's & Colitis UK evidence submission: Accessible transport: legal obligations

## 1. About this submission

- 1.1. **Crohn's & Colitis UK**<sup>1</sup> is the leading charity for people affected by Crohn's and Colitis in the UK. We work to improve diagnosis, treatment, and care, to fund research into a cure, to raise awareness, and to provide information and support.
- 1.2. Over 500,000 people in the UK have Inflammatory Bowel Disease (IBD), the two main forms of which are Crohn's Disease and Ulcerative Colitis<sup>2</sup>. These are lifelong diseases of the gut. They can affect almost every part of the body and every aspect of life: from digestion and joints to energy levels, mental health, education and the ability to work. There is no known cure.
- 1.3. Crohn's and Colitis cause the intestines to become swollen, ulcerated and inflamed. Symptoms include significant abdominal pain, nausea, extreme fatigue and chronic joint pain. People also have to live with bowel incontinence, an unpredictable, frequent and urgent need to access a toilet because of multiple bouts of diarrhoea (sometimes with blood and mucous). Consequently, the symptoms of Crohn's and Colitis can make walking any distance and undertaking journeys safely, very difficult.
- 1.4. One of the key characteristics of Crohn's and Colitis is that the disease severity fluctuates over a lifetime with periods of remission and relapse ("flare up") of symptoms. The pattern of relapse and remission is complex and unpredictable and varies from person to person.
- 1.5. Approximately 6.5 million people in the UK have problems with their bowels. A range of disabilities and long-term health conditions present with bowel urgency and incontinence that require people to have quick access to suitable toilet facilities.
- 1.6. Three in four people with Crohn's or Colitis experience bowel incontinence. Incontinence is sometimes debilitating, often embarrassing and can be a life-changing problem, affecting all parts of daily life, including travel. Understandably, this incapacitating symptom is accompanied by a continuous anxiety about suddenly needing the toilet and having very little time to find one.
- 1.7. Experiencing an episode of incontinence in public is profoundly embarrassing. Concerns with access to toilets, especially in unfamiliar environments, can severely limit the journeys that people living with IBD take. For many individuals, the result of poor access to a toilet has a devastating impact on their ability to engage in regular activities away from home such as going to work, shopping or socialising and lead to periods of isolation.

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<sup>1</sup> [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk)

<sup>2</sup> Crohn's & Colitis UK (2022). [New research shows over 1 in 123 people in UK living with Crohn's or Colitis \(crohnsandcolitis.org.uk\)](https://www.crohnsandcolitis.org.uk/news/new-research-shows-over-1-in-123-people-in-uk-living-with-crohns-or-colitis)

- 1.8. Our research tells us that:
  - 1.8.1. Almost 9 in 10 people (87%) with Crohn's or Colitis plan journeys based on access to toilets.
  - 1.8.2. 72% reported that they feel their IBD limited their travel some or all of the time.
  - 1.8.3. 70% of people with Crohn's or Colitis worry about toilet facilities whilst travelling.
  - 1.8.4. 63% of people with Crohn's or Colitis worry about toilet facilities at their travel destination.
- 1.9. Train transport is particularly important for people living with Crohn's or Colitis, especially when long distance journeys are being planned as part of work or for leisure, due to the presence of accessible toilets and toilet facilities on this mode of transport.
- 1.10. This response highlights the experiences of people living with Crohn's and Colitis when planning to travel, at stations, and on different modes of transport, outlining the need for greater staff awareness on hidden disabilities, better data and greater transparency, and improved passenger information and access to toilets.

## 2. The impact of current legislation on delivering accessible transport

- 2.1. Current legislation relating to transport for disabled people does not fully meet the needs of people with Crohn's and Colitis and is not enforced sufficiently to prevent them from experiencing significant barriers to using public transport, including the inadequate provision of:
  - 2.1.1. Adequate toilet facilities on public transport and in stations.
  - 2.1.2. Assistance from staff, who fail to recognise hidden disabilities and their impact on the ability to travel.
  - 2.1.3. Information to support people in planning their journeys, including on the toilet facilities available.
- 2.2. As points 2.1.1 - 2.1.3 show, the principles of "reasonable adjustment" and "indirect discrimination" within the Equality Act 2010 are not being sufficiently enforced for people with Crohn's or Colitis, which is rendering public transport inaccessible.
- 2.3. Furthermore, in a direct contravention of regulation (EU) No 1107/2006<sup>3</sup> members have reported difficulties in receiving assistance when booking airline tickets. One member told us:

*"I was told off down the phone for contacting the helpline for passengers with disabilities when I wasn't registered disabled, was told I couldn't request a seat*

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<sup>3</sup> Which states that "In order to give disabled persons and persons with reduced mobility opportunities for air travel comparable to those of other citizens, assistance to meet their particular needs should be provided at the airport as well as on board aircraft, by employing the necessary staff and equipment."

*near the toilet and that I couldn't have any extra hand luggage allowance for my medication”.*

### **3. How can existing legislation be better enforced to make accessible transport a reality?**

- 3.1. The better enforcement of legislation around accessible transport should be well supported by data collection and publication across the transport system, so that issues and patterns can be better identified and raised.
- 3.2. This data should include:
  - 3.2.1. Number of train and coach services that run where the toilet is out of order.
  - 3.2.2. Information about toilet closures at stations.
  - 3.2.3. Number of complaints involving access to toilets.
  - 3.2.4. The number of people with Crohn's and Colitis who apply and are awarded a blue badge.

### **4. Best practice: toilet facilities**

- 4.1. With almost 9 in 10 people (87%) with Crohn's or Colitis reporting that they plan journeys based on access to toilets, it is essential that there is good access, adequate facilities and reliable information across services and around the country for public transport to be accessible. However this is currently not the case, with particular issues relating to:
  - 4.1.1. The availability of easily accessible and up to date information about toilet facilities.
  - 4.1.2. The cost of toilet facilities.
  - 4.1.3. Unexpected closures.
  - 4.1.4. Rail replacement services and provision on buses and coaches.
- 4.2. These issues put those with Crohn's and Colitis at a disadvantage as stated by the “indirect discrimination” provisions in the Equalities Act 2010 legislation.
- 4.3. Initiatives such as the ‘Great British Public Toilet Map’<sup>4</sup> are incredibly useful when planning journeys, however information may be incomplete or out of date, with some entries last updated in 2016.

*“There seems to be a good provision of toilets at the rail stations I use. However, if the toilets are closed or removed due to maintenance or even building work then I cannot be reliant on them. It can also be embarrassing and distressing when the toilets are not maintained well, for example broken flushes and door locks.*

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<sup>4</sup> <https://www.toiletmap.org.uk/>

*Also, when you have to ensure you have a specific amount of cash change for certain train station toilets, this can be difficult when you suffer from urgency.”*

4.4 Live information on toilet availability at bus and train stations should be easily available alongside booking tickets and checking whether the service is running on time, allowing people with Crohn’s and Colitis to travel with confidence. This should include information on whether the toilets in the station are available, their opening times, where they are located in the station (i.e. before or after the ticket gates), whether there is a cost to use them and if so, how much, and whether there are toilets available on the train itself.

4.5 People living with Crohn’s and Colitis need to access toilets more frequently than the general population. We therefore believe that publicly accessible toilets in travel hubs (e.g train stations, bus stations) should be free of charge. In the instances where this is not possible, the medical need for a toilet should be charged for under disability legislation in the same way that the provision for many others areas of medical disability is free within the transport system (e.g ramps for wheelchair users).

*“The time spent searching in your purse for the correct change (or trying to obtain some change if you don’t have any) and then queuing to go through the turnstile could make the difference as to whether or not you reach the toilet in time”.*

4.6 Train transport is particularly useful for people with Crohn’s and Colitis, especially when long distance journeys are being planned as part of work or for leisure, due to the presence of accessible toilets and toilet facilities on these trains. Therefore, should the rail section of a person’s journey be unexpectedly replaced with road transport, it is imperative that users are informed of toilet access on all alternative modes of travel (e.g. bus replacement services) and refunds provided should such facilities not be provided.

4.7 For coaches and buses, we strongly recommend that in any tendering criteria developed for contracts to provide replacement road services that:

4.7.1 The presence of toilet facilities onboard coaches and buses is made a mandatory requirement

4.7.2 Where rail replacement services are advertised in advance, access to toilet facilities on replacement vehicles should be clear on all information boards / posters etc. This will help ensure people with Crohn’s or Colitis feel confident to travel on these days, instead of staying at home due to concern over access to toilets.

4.7.3 On the day of rail replacement services toilet facilities are again advertised on information boards and when announcing bus destinations etc, rail staff should include mention that toilets are onboard.

4.8 Another serious concern of people with Crohn’s and Colitis, is the availability of toilet facilities on the London Underground network, and in particular, the

provision of information about the location of toilet facilities. In the event of an urgent need to use the toilet while travelling on the tube, it is difficult for people with Crohn's and Colitis to know whether an approaching underground station contains facilities, or whether it is better to leave the station and find a toilet outside. This lack of information can cause unnecessary distress and delay in the event of an urgent need to use the toilet.

- 4.9 Although Transport For London does produce a map of stations with toilet facilities<sup>5</sup> this is downloadable only, unlike notifications of wheelchair accessible stations, which appear on the standard tube map. It is also potentially difficult to download the map while underground.
- 4.10 The lack of easily accessible information about the location and provision of toilet facilities on the London Underground network is a breach of "reasonable adjustment" requirements, as the practice of making the toilet map downloadable only clearly puts, "a disabled person at a substantial disadvantage in relation to a relevant matter in comparison with persons who are not disabled", in the words of the legislation.

## 5. Best practice: Staff training and awareness

- 5.1. Crohn's and Colitis UK members have told us that there is a serious problem in terms of the perception of disability from public transport staff, which is disproportionately focused on physical disabilities such as wheelchair access, despite the fact that Crohn's and Colitis is equally debilitating.

*"People like myself who suffer from a chronic illness such as IBD also need use of disabled seating at times, as it is difficult to hold yourself up and stand for long periods of time when suffering from symptoms such as extreme fatigue, abdominal pain, joint pain and sometimes dizziness. It is frowned upon by public transport staff when those with a non-visible disability use this seating."*

- 5.2. There is still a lack of awareness of invisible conditions and disability assistant schemes do not always recognise them.
- 5.3. Education on invisible conditions is needed with staff trained to support passengers in a helpful, discreet, and understanding way. This should be offered as widely as possible so that all passenger facing staff, including temporary agency staff, are included.
- 5.4. Not Every Disability is Visible accessible toilet signs should be a requirement across the transport systems. This will help change public perceptions of disability, end stigma and ensure everyone who needs to use an accessible toilet can.

## 6. Summary of recommendations

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<sup>5</sup> <http://www.tfl.gov.uk/assets/downloads/toilets-map.pdf>

- 6.1. People living with Crohn's or Colitis have a right to feel confident and comfortable when travelling on public transport, just like everyone else. This is a matter of personal and public health, equality and social inclusion. However, current legislation and its enforcement does not currently deliver this.
- 6.2. To effectively enforce legislation on accessible transport, the appropriate data needs to be collected, and preferably published so that issues can be identified.
- 6.3. Reliable live information about toilet facilities, both in stations and on services, needs to be easily available across the transport network.
- 6.4. Tendering criteria developed for contracts to provide replacement road services should include requirements around toilet access and the advertisement of these facilities
- 6.5. Toilets should be labelled on the London Underground map so that the information is easily accessible within all stations, not just online.
- 6.6. All passenger facing staff should be trained on invisible conditions to support passengers in a helpful, discreet, and understanding way.
- 6.7. Not Every Disability is Visible accessible toilet signs should be a requirement across the transport systems.

For further information, please write to [policy@crohnsandcolitis.org.uk](mailto:policy@crohnsandcolitis.org.uk)