

## **Crohn's & Colitis UK evidence submission: Consultation on legislation to implement rail transformation**

[July 2022]

### **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, extreme fatigue and nausea. People also have to live with bowel incontinence, an unpredictable, frequent and urgent need to access a toilet because of multiple bouts of diarrhoea. In addition, many people experience chronic joint pain. The nature of these symptoms means that Crohn's and Colitis is classified as an invisible disability and can make walking any distance and undertaking journeys safely, very difficult.
- 1.4. This submission outlines our response to the Department of Transport's consultation on legislation to implement rail transformation. This submission focuses on the questions 14 and 21 on improving accessibility on the railways.

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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](https://www.crohnsandcolitis.org.uk/news/new-research-shows-over-1-in-123-people-in-uk-living-with-crohns-or-colitis) ([crohnsandcolitis.org.uk](http://crohnsandcolitis.org.uk))

## 2. Summary of key points and recommendations

- 2.1. Approximately 6.5 million people in the UK have problems with their bowels.
- 2.2. 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. These include Crohn's and Colitis.
- 2.3. 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. Consequently:
  - Almost 9 in 10 people (87%) with Crohn's or Colitis plan journeys based on access to toilets.
  - 70% of people with Crohn's or Colitis worry about toilet facilities whilst travelling.
  - 63% of people with Crohn's or Colitis worry about toilet facilities at their travel destination.
- 2.4. 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.
- 2.5. We welcome the introduction of the Accessibility Duty as a core part of the Great British Railways Licence. The Accessibility Duty must refer to a definition of non-visible disabilities and long-term health conditions with symptoms such as debilitating pain, fatigue, dizziness which may impact daily activities including travel.
- 2.6. We agree that the expansion of the role of the Disabled Persons Transport Advisory Committee (DPTAC) to act as a statutory advisor to Great British Railways will have a positive impact.
- 2.7. We appreciate DPTACs recognition of non-visible disabilities and the impact of incontinence, however believe that Crohn's and Colitis must be recognised in any list of non-visible disabilities. It is essential that people with these conditions and the organisations that represent them, are consulted to shape accessibility policies and subsequent service provision.

## 3. Do you agree with the proposal for Great British Railways' new duties to be captured in the licence? (Question 14)

- 3.1. 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. These health conditions include Crohn's and Colitis, as well as diabetes, Parkinson's disease, Multiple Sclerosis, and Muscular Dystrophy. In some cases, bowel incontinence may result from a health condition such as dementia or a severe learning disability that causes the person to lose bowel control. These conditions cut across all genders and ages.
- 3.2. Three in four people with Crohn's or Colitis experience bowel incontinence. Incontinence is sometimes debilitating, often embarrassing and it can be a life-changing problem, affecting all parts of daily life including travel.

*“As someone with Ulcerative Colitis, I fully rely on public toilets in order to leave my house.”*

*“I suffer from Crohn's disease and need access to public toilets in order to carry out my everyday life.”*

- 3.3. Understandably, people experiencing incontinence often suffer from considerable anxiety about using transport, limiting their destinations to places close to an accessible toilet, or allowing time for toilet stops along a journey. The vast majority (87%) of people with Crohn's or Colitis told us that they plan their journeys based on access to toilets and admitted not starting a journey due to fear of not being able to reach a toilet in time.<sup>3</sup> Furthermore, 70% of people living with these conditions worry about toilet facilities whilst travelling and 63% worry about toilet facilities at their travel destination.<sup>4</sup>

*“I struggle to go on journeys like I'd want to without having to worry about when I'll have to go to the toilet again.”*

- 3.4. We believe that people living with Crohn's and 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.
- 3.5. Crohn's & Colitis UK therefore welcomes the focus on accessibility in the new licence for Great British Railways, and the inclusion of this duty in primary legislation to ensure delivery for passengers.
- 3.6. We believe that accessibility must cover all stages of a journey from booking to journey end. Therefore, we welcome the integration of responsibilities across track,

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<sup>3</sup> Toilet Consortium UK survey (2018). Survey size was 989 participants.

<sup>4</sup> Crohn's & Colitis UK (2017). *Travel with IBD survey*. Survey size was 1,776 participants.

train and stations providing greater clarity of what passengers can expect and where responsibility lies.

- 3.7. We further welcome the requirement set out in the licence to develop, publish and adhere to an accessibility policy. We believe it is essential that people with Crohn's and Colitis and the organisations that represent them are consulted to shape such policies and subsequent service provision.

#### **4. Do you support the proposal to expand DPTAC's remit to become a statutory advisor to Great British Railways, as well as to the Secretary of State, on matters relating to disability and transport? (Question 21)**

- 4.1. We welcome the condition in the Great British Railways Licence for consultation with disabled passengers and those with additional needs, directly and through representative organisations.
- 4.2. We appreciate DPTACs recognition of non-visible disabilities and the impact of incontinence, however believe that Crohn's and Colitis must be recognised in any list of non-visible disabilities.
- 4.3. We agree that the expansion of the role of the Disabled Persons Transport Advisory Committee (DPTAC) to act as a statutory advisor to Great British Railways, in addition to the UK Government, will have a positive impact.

This submission has been written by Chloe Hutchinson, Policy Lead at Crohn's & Colitis UK. For further information, please write to [policy@crohnsandcolitis.org.uk](mailto:policy@crohnsandcolitis.org.uk)