

Mobility as a Service Code of Practice

Submission from Crohn's & Colitis UK

Crohn's Disease and Ulcerative Colitis

Over 500,000 people in the UK have Inflammatory Bowel Disease, the two main forms of which are Crohn's Disease and Ulcerative Colitis. Crohn's and Colitis are lifelong diseases of the gut that affect adults and children of all ages. They are painful, debilitating and widely misunderstood. There is no known cure. Crohn's and Colitis don't just affect the gut. They can affect almost every part of the body and every aspect of someone's life: from digestion and joints to energy levels and mental health.

Crohn's and Colitis causes the intestines to become swollen, ulcerated and inflamed. Symptoms include significant abdominal pain, extreme fatigue and nausea. People also have to live with the problem of an unpredictable, frequent and urgent need for access to a toilet because of multiple bouts of diarrhoea. In addition, many people experience chronic joint pain. The combination of symptoms can make walking any distance and undertaking journeys safely very difficult.

Crohn's & Colitis UK

Crohn's & Colitis UK is the UK's leading charity for Crohn's Disease and Ulcerative Colitis. We're working to improve diagnosis and treatment, and to fund research into a cure; to raise awareness and to give people hope, comfort and confidence to live freer, fuller lives.

We gather information about the experience of patients through:

- the Crohn's & Colitis UK helpline
- local networks
- calls for evidence via our website and social media
- one to one discussion with people with IBD, clinicians, and the wider IBD community; and
- research - our own and that of external organisations.

We would like to use our evidence and the voices of people with Crohn's and Colitis to respond to the questions detailed in *Section 4: Accessibility and Inclusion* of the Mobility as a Service Code of Practice consultation.

Summary of key points and recommendations

- Problems with the bladder affect more than 14 million people in the UK and approximately 6.5 million have bowel problems. In addition, 900,000 children and young people reportedly suffer from bladder and bowel dysfunction.
- A range of disabilities and long-term health conditions present with urinary and bowel urgency and incontinence that require people to have quick access to suitable toilet facilities.
- Incontinence is sometimes debilitating, often embarrassing and it 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 and 63% worried about toilet facilities at their travel destination.
- 92% people with Crohn's or Colitis have difficulty finding public toilets.
- To improve access and inclusion of children and adults with disabilities and older people (aged 65+), MaaS platforms should be designed to enable users to plan their journey based upon toilet accessibility.
- To ensure the systems that MaaS platforms provide are accessible and inclusive to all users, providers should consult with people with disabilities and the organisations and/or charities who represent them in the development and user acceptability testing of MaaS platforms and their code of practice. This group must include those with invisible disabilities, such as Crohn's and Colitis.

Section 4: Accessibility and Inclusion

Problems with the bladder affect more than 14 million people in the UK and approximately 6.5 million have bowel problems. It is estimated that more than 3 million people over 65 in the UK experience urinary incontinence, alongside mobility issues. This is also a group known to experience social isolation and loneliness.¹ In addition, 900,000 children and young people reportedly suffer from bladder and bowel dysfunction.²

A range of disabilities and long-term health conditions present with urinary and bowel urgency and incontinence that require people to have quick access to suitable toilet facilities. These health conditions include Crohn's and Colitis, Diabetes, Parkinson's, disease, Multiple Sclerosis, and Muscular Dystrophy. In some cases, urinary and bowel incontinence may result from a health condition such as dementia or a severe learning disability that causes the person to lose bowel control.

Incontinence is sometimes debilitating, often embarrassing and it can be a life-changing problem, affecting all parts of daily life including travel. Three in four people with Crohn's or Colitis experience bowel incontinence. Therefore, quick access to suitable toilet facilities is crucial, either to prevent or act should an accident occur.

"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."

Understandably, people experiencing these distressing symptoms often suffer from considerable anxiety about using public 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.³ Furthermore, 70% of people living with these conditions worry about toilet facilities whilst travelling and 63% worry about toilet facilities at their travel destination.⁴

¹ Age UK (2022). Bladder and bowel problems. https://www.ageuk.org.uk/globalassets/age-uk/documents/information-guides/ageukig15_bladder_bowel.inf.pdf

² NHS (2015). New guidance to improve services and lives for people living with bladder and bowel problems. <https://www.england.nhs.uk/2015/11/continence-care/>

³ Toilet Consortium UK survey (2018). Survey size was 989 participants.

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

“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.”

Unsurprisingly, knowing the location and the opening and closing times of publicly available toilets is essential for planning travel journeys. However, 92% of people with Crohn's or Colitis told us that they have found public toilets difficult to find.⁵ Knowing the type of toilet available is also important as most people (60%) living with these conditions regularly use accessible toilets.⁶ Some have [stoma bags](#) and may require extra space to change and dispose of equipment comfortably, hygienically and in privacy.

To improve access and inclusion of children and adults with disabilities, and older people (aged 65+), MaaS platforms should be designed to enable users to plan their journey based upon toilet accessibility.

MaaS platform should therefore include:

1. Functionality that allows users to filter and select journeys based upon access to toilets, whether that be on the mode of transport itself, in transport hubs (i.e. bus/train stations, taxi ranks etc) or in businesses who have signed up to a local council's [Community Toilet Scheme](#).
2. Functionality that enables users to reserve their travel seats based upon toilet accessibility free of charge, where applicable.
3. Functionality that enables users to map toilet provision⁷ across their journey with real time information on the following:
 - a. The location of toilets including whether they are past ticket barriers or turnstiles
 - b. The cost of accessing the toilets and whether cash and/or card are accepted
 - c. Toilet opening and closing times
 - d. A description of the facilities (i.e. a regular or an accessible toilet).

To ensure the systems that MaaS platforms provide are accessible and inclusive to all users, providers should consult with people with disabilities and the organisations and/or charities who represent them in the development and user acceptability testing of MaaS platforms and their code of practice. This group must include those with invisible disabilities, such as Crohn's and Colitis.

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

⁵ Toilet Consortium UK survey (2018).

⁶ Ibid

⁷ Using existing toilet maps: [The Great British Toilet Map: Find Toilet](#), [ToiletMap \(uktoiletmap.org\)](#), [Public Toilet Info](#), [Find wheelchair-accessible toilets & parking near you \(coloplast.co.uk\)](#) or partnering with existing applications [Find the Nearest Public Toilets with these Mobile Apps | WC Portables](#)