

## **Adult Disability Payment Mobility Consultation**

### **Introduction**

There are over 50,000 people living in Scotland with Crohn's Disease and Ulcerative Colitis, the two main forms of Inflammatory Bowel Disease. These are lifelong, immune-mediated diseases of the gut. There is currently no known cure.

The symptoms of Crohn's and Colitis include urgent and frequent diarrhoea, rectal bleeding, pain, profound fatigue, anaemia and inflammation of the joints, skin, liver and eyes. Three in four people with Crohn's and Colitis experience bowel incontinence<sup>i</sup>, which is an unpredictable and urgent need to pass stools. People living with Crohn's may also experience strictures (narrowing) of the bowel resulting in abdominal pain caused by partial blockage, and anal fissures, tags, abscess and fistulas<sup>ii</sup>. Furthermore, people with Crohn's and Colitis are more likely to develop osteoporosis and fragile bones<sup>iii</sup>.

Crohn's and Colitis follow a relapsing and remitting disease course. Relapses (or 'flare-ups') often occur suddenly and unpredictably throughout a person's lifetime. There is also significant variation in the pattern and complexity of the symptoms both between people and in the individual at different times in their life<sup>iv</sup>. The combination of symptoms can make walking any distance and undertaking journeys safely very difficult. In a survey of 4,000 people with Crohn's and Colitis, 70% stated that their condition means they cannot undertake any journey without the threat of considerable harm to their safety<sup>vi</sup>.

### **Section 1: The moving around activity**

#### **1. Do you agree or disagree that the moving around activity criteria for Adult Disability Payment are easy to understand?**

Don't know

#### **1 (a). Please give reasons for your answer, outlining which parts you think are easy or difficult to understand and why.**

Whilst we acknowledge that the concept of prescribed distances might be straightforward to understand from a technical standpoint, in reality, people don't think about their mobility in precise distances and find it difficult to imagine what 20, 50 and 200 meters might look like, and how this is applicable to their day to day mobility challenges.

#### **2. Are there any other issues with the moving around activity that we have not captured above?**

Yes

#### **2(a). If you said "yes," what other issues with the moving around activity do you think need to be considered?**

We agree and recognise the points outlined in the research and consultation findings section. Of particular relevance for people with Crohn's and Colitis are the concerns

raised regarding the arbitrarily set distances, which are not grounded in the reality of a person's mobility issues and do not adequately cover progressive or fluctuating conditions. We are also concerned that the moving around activity in its current form does not sufficiently recognise anxiety, bowel urgency and incontinence and how this impacts someone's ability to move around.

**3. How effective do you think the moving around section of the application form is at helping us understand a person's mobility needs?**

Somewhat effective

**Please give reasons for your answer**

We welcome the use of visual aids to represent the key concepts of the moving around activity and the qualifying distances. However, the pictures of the qualifying distances in Figure 2 are unclear. An overhead perspective may be better at demonstrating how far the distances are, accompanied by written commentary to further support the interpretation of the criteria.

We also welcome the prompts of tiredness, breathlessness and pain as shown in Figure 4, which are likely to support individuals to provide further information on the impact of walking certain distances. Prompts regarding pain and fatigue are of particular relevance to people with Crohn's and Colitis. Research shows 86% of people with these conditions experience fatigue and, even in remission, 40% say fatigue is their primary symptom<sup>vii</sup>. Furthermore, joint pain or pain and swelling of the joints are the most common symptoms of Crohn's and Colitis outside the gut, experienced by 1 in 3 people<sup>viii</sup>. **We recommend that guidance is issued to assessors to ensure a holistic view of pain is considered.**

**We also recommend that the prompts shown in Figure 4 include mental health/anxiety and bowel incontinence.** Experiencing an episode of incontinence in public is profoundly embarrassing. The fear of incontinence or of being unable to locate a toilet can have a significant impact on mental wellbeing and lead to heightened anxiety, even when travelling short distances, such as from a parking space to a shop. The addition of these prompts would ensure a holistic approach to mobility issues and allow for people with Crohn's and Colitis to provide a nuanced response to how their condition impacts their ability to move around.

However, it is unclear how the information provided by the impact prompts will support an individual's application. We are concerned that the current guidance does not provide advice on how the current point system will differentiate between two individuals who can walk the same distance but one experiences incapacitating pain and fatigue for several days afterwards, compared to the other who only experiences mild symptoms. **We recommend that this distinction is made clear.**

**4. What impact do you think the changes to how we make decisions on the moving around activity have on understanding a person's mobility needs?**

Neither positive nor negative

**Please give reasons for your answer**

There are several encouraging changes that Social Security Scotland have made to their decision-making process regarding the moving around activity. However, these changes relate less to how assessors may understand a person's mobility needs and more to how a claimant may experience the application process.

We welcome limiting the use of consultations to when there is no other practicable way to understand a person's need. We have heard from many people with Crohn's and Colitis that assessments on any given day, due to the unpredictable and fluctuating nature of the conditions, may not give an accurate reflection of incapacitation. However, we would like to see greater clarity on what 'no other practicable way' means and how this will be communicated with claimants. Assessors should always exhaust all possible avenues to gather reliable evidence from the claimant, people who know them and their medical professionals to allow for a correct decision to be made, first time.

We also welcome the changes proposed to informal observations when consultation is necessary, in particular giving claimants the opportunity to respond to observations during the consultation. People with Crohn's and Colitis tell us that they feel assessors prejudge eligibility based on their physical/mobility capability within a face-to-face assessment, rather than asking probing questions that are relevant to their lives. The opportunity to respond to observations facilitates a two-way exchange that will allow claimants to fully explain how the condition affects their mobility.

We also welcome the commitment to increase training requirements for Social Security Scotland staff conducting consultations and urge that such staff are given professional training in specific health conditions and disabilities. It is imperative that Social Security Scotland staff understand that the effects of Crohn's and Colitis are not restricted to the gut but can also include the liver, eyes, and joints as well as energy levels, pain, and mental health.

We agree that starting from a position of trust during a consultation is essential but will require Social Security Scotland staff to be trained in soft skills including good communication, active listening and facilitation, to draw out what a real day for a person with Crohn's or Colitis looks like. These skills will be crucial because people with the conditions may find it very difficult or embarrassing to talk about their experience, especially given both the lack of awareness of the condition and the nature of the symptoms, such as urgent and uncontrollable diarrhoea. These skills and condition knowledge should be reviewed in regular supervision.

Finally, we welcome the need for only one piece of supporting information to be submitted alongside Adult Disability Payment claims. **We recommend clarifying the fact that supporting information may be supplied by clinicians or nurses in the secondary care settings.** This is particularly important as there are known issues in information sharing between primary and secondary care settings. For people with Crohn's or Colitis, their GP may not be the best placed health professional to provide suitable information about the true debilitating effects of a person's condition. In this instance, a Gastroenterologist or IBD Nurse who will be overseeing the management of an individual's

disease within secondary care, will be best placed to provide supporting information for people with Crohn's and Colitis.

**5. If there was an opportunity to change the moving around activity criteria, what changes would you make (if any)?**

Although we welcome efforts to incorporate impact prompts and a more dignified approach the application process, we are disappointed that the recommendations from ourselves, multiple patient organisations and the ALLIANCE regarding removing the 20 meter and 50% rules have not been considered by Social Security Scotland.

We do not believe that the current strict and arbitrary measurements of distance are the best way to determine a person's mobility needs, regardless of their disability. A more flexible approach should be taken, which is grounded in a person's reality, and considers a person's ability to move around their own home, local area, and other places they may frequent in daily life (e.g. school, workplace, shopping and leisure facilities, and healthcare services). This approach should consider not only the physical ability to travel within these areas but also the impact on doing so on pain, exhaustion and mental health/anxiety and other symptoms. We support the ALLIANCE's suggestion of what such criteria could include.

**We recommend that a review and design exercise should be carried out with disabled people including people with Crohn's and Colitis, patient charities, academics and healthcare professionals to design an agreed appropriate alternative to the current mobility criteria.**

**5(a). If you proposed changes, what positive impacts could these have, and for who?**

The changes proposed would enable people with Crohn's and Colitis and other disabilities to more accurately describe how the conditions impact their mobility, supporting a more personalised and holistic approach to the application process. More relevant criteria may also result in them being correctly awarded the appropriate rate of payment, which is likely to improve quality of life.

**5(b). If you proposed changes, what negative impacts could these have, and for who?**

We do not foresee any negative impacts arising from such changes.

**Section 2: The planning and following journeys activity**

**6. Do you agree or disagree that the planning and following journeys activity eligibility criteria is easy to understand?**

Don't know.

**6(a). Please give reasons for your answer, outlining which parts you think are easy or difficult to understand and why.**

The planning and following journeys activity is easier to understand than the arbitrary criteria of the moving around activity. However, as we describe in Question 7a we believe that people with Crohn's and Colitis will experience considerable challenges articulating the full range of journey planning difficulties that they may face under this current eligibility criteria.

**6(b). How could we make the planning and following journeys activity eligibility criteria easier to understand?**

Please see our answer to Question 10.

**7. Are there any other issues with the planning and following journeys activity that we have not captured above?**

Yes

**7(a). If you said "yes", what other issues with the planning and following journeys activity do you think need to be considered?**

We believe that the current planning and following journeys activity eligibility criteria do not properly articulate the full range of journey planning difficulties that people with Crohn's and Colitis face. Many people with these conditions will likely have the mental capacity to plan their journey but will have considerable difficulty doing so because of a) limited toilet access on their journey route and b) limited information on where toilets are located along their journey to facilitate planning.

Bowel incontinence, the sudden and uncontrollable need to use the toilet, is a real and recognised symptom of Crohn's and Colitis and not just exaggerated anxiety on the part of the individual. Quick access to suitable toilet facilities is crucial, either to prevent or act should an accident occur. The prospect of having an accident in public can have a profound effect on someone's ability to undertake everyday activities involving traveling.

A survey of people with Crohn's and Colitis found that 8 in 10 plan their journeys based upon access to toilets, whilst 7 in 10 worry about toilet facilities whilst travelling and 6 in 10 worry about toilet facilities at their travel destination<sup>ix</sup>.

Additionally, some people living with Crohn's and Colitis have stoma bags and may require extra space to change and dispose of equipment comfortably, hygienically and in privacy. This requires a fully enclosed cubicle with access to a sink and disposal facilities. Six in 10 people with Crohn's and Colitis regularly use accessible toilets<sup>x</sup>.

Many people with the conditions rely on taxis or private hire vehicles to undertake journeys, at considerable cost. This is due to a dearth of publicly available real-time information on toilet facilities on transport and travel hubs including toilet location, description of the facilities, opening and closing times, cost and payment options. Unexpected toilet closures or bus replacement services that often do not have toilet facilities can cause profound distress and impact a person with Crohn's or Colitis from completing their journey.

There are other issues that people with Crohn's and Colitis face that impact their ability to undertake a journey, which is currently not covered within the eligibility criteria. Journeys can often take a lot longer than average. People with these conditions may have to start and stop a journey on a number of occasions or may have to make a couple of attempts to complete a journey due to a loss of bowel control or pain management.

Furthermore, the exclusion of speech as a form of assistance disadvantages people with Crohn's and Colitis. When out in public and in particular urgent need, a person with these conditions may resort to asking to use the toilet in a shop or hospitality venue. However, a survey of 1,370 people with Crohn's and Colitis revealed that 1 in 2 have experienced discrimination for using an accessible toilet, with over 60% of these instances including either verbal and or physical abuse<sup>x1</sup>. This can lead to heightened anxiety, which impacts on a person's ability to leave the house.

**We strongly recommend that Social Security Scotland take a more holistic approach to the development of the planning and following journeys eligibility criteria. This approach should recognise the systemic barriers to journey planning that people with Crohn's and Colitis face, such a public toilet closures and a lack of publicly available information on toilet location, and the subsequent impact on mobility.**

**8. How effective do you think the planning and following journeys section of the application form is at helping us understand a person's ability to plan and follow journeys?**

Not very effective

**Please give reasons for your answer**

For reasons stated in our answer to Question 7a, we do not believe that the application form has been designed to enable a person with Crohn's and Colitis to fully explain how the condition impacts their ability to plan a journey. Furthermore, the binary Yes/No answer for the question "can you leave your home at all?" is not sufficiently nuanced for people living with a condition that is unpredictable and fluctuating. It is currently unclear how fluctuating conditions are captured in this section, which may impact on an assessors ability to fully understand how people with Crohn's and Colitis are able to plan and follow journeys.

**9. What impact do you think the changes to how we make decisions on the planning and following journeys activity has on understanding a person's ability to plan and follow journeys?**

Neither positive nor negative

**Please give reasons for your answer**

As per our response to Question 4, we welcome the improvements that Social Security Scotland propose regarding the role and training of their practitioners. However, these changes relate less to how assessors may understand a person's ability to plan a journey and more to how a claimant may experience the application process. For an assessor to

fully understand a person with Crohn's and Colitis's ability to plan and follow a journey, our recommendations in Question 10 would need to be embedded.

**10. If there was an opportunity to change any specific aspects of the planning and following journeys activity, what changes would you make (if any)?**

We believe that Social Security Scotland should take the opportunity to design a more progressive and holistic approach which is based on the social and rights-based models of disability, which sees people as being disabled because of society's social and other structural barriers, which infringe their rights.

The changes to the planning and following journeys activity eligibility criteria should include a consideration of:

1. What extent the information that people require in order to plan and safely undertake a journey exists.
2. The amount of time and energy planning a journey takes and the toll this takes on a person's mental health.
3. The impact changes (i.e. toilet closures, mode of transport, transport delays and diversions) have on a person's ability to complete their journey as originally intended.
4. The additional costs that a person may incur (i.e. by taking taxis or private hire vehicles, or buying incontinence products) due to the lack of reliable information they need in order to undertake a journey safely or a journey taking longer than originally intended due to incontinence or pain.

**We recommend that a review and design exercise should be carried out with disabled people including people with Crohn's and Colitis, patient charities, academics and healthcare professionals to design an agreed appropriate alternative to the current mobility criteria.**

**10(a). If you proposed changes, what positive impacts could these have, and for who?**

The changes proposed would enable people with Crohn's and Colitis to more accurately describe how the conditions impact their mobility, supporting a more personalised and holistic approach to the application process. More relevant criteria may also result in them being correctly awarded the appropriate rate of payment, which is likely to improve quality of life.

**10(b). If you proposed changes, what negative impacts could these have, and for who?**

We do not foresee any negative impacts arising from such changes.

**Section 3: Support for people with fluctuating conditions**

**11. Do you agree or disagree that the criteria for fluctuating conditions is easy to understand?**

Disagree

**11(a). Please give reasons for your answer, outlining which parts you think are easy or difficult to understand and why.**

We believe that the eligibility criteria is very challenging to understand and not grounded in a person's reality where their condition not only fluctuates, but it unpredictable. It is unclear what the timeline for '50% of days' is, for example does this mean 50% of days in a week, month or year? It is also unclear from the consultation paper how the information on fluctuating conditions will be sufficiently gathered and articulated by the claimant to support assessor understanding.

**11(b). How could we make the fluctuating conditions criteria easier to understand?**

Please see our answer to question 14.

**12. Are there any other issues with the fluctuating conditions criteria that we have not captured above?**

Yes

**12(a). If you said "yes", what other issues with the fluctuating conditions criteria do you think need to be considered?**

Please see our response to question 11a.

Furthermore, we are pleased to see the point made around not relying on the 50% marker and using a worst day description but would like to see Crohn's and Colitis used as an example of fluctuating condition due to its unique nature. Crohn's and Colitis are conditions with incredibly unpredictable symptoms, and it can be often impossible to plan your life based on when the symptoms may present. The impact of symptoms can come on suddenly and can change drastically during the course of a day. People with Crohn's and Colitis will have a unique experience with disability benefits in Scotland and we would like to see this represented.

**13. How effective do you think the fluctuating conditions section of the application form is at helping us understand the needs of people with fluctuating conditions?**

Not very effective

**Please give reasons for your answer**

It is difficult to answer this question when the definitions and guidance on how the eligibility criteria is applied has not been included in the consultation document for review. We do not believe that the current format on the application form will enable claimants to sufficiently explain how the fluctuating and unpredictable nature of their condition impacts on their mobility.



**14. Thinking about the changes we have made to how we make decisions about fluctuating conditions, what impact do you think this is having on understanding the impact of a person's fluctuating conditions?**

Neither positive nor negative

**Please give reasons for your answer**

Whilst we welcome the suggested changes to decision making, in particular to the role of the practitioner, these positive changes relate less to how assessors may understand the fluctuating nature of a person's condition and more to how a claimant may experience the application process. For an assessor to fully understand the impact of a fluctuating condition, our recommendations in Question 15 would need to be embedded.

**15. If there was an opportunity to change any specific aspects of the fluctuating conditions criteria, what changes would you make (if any)?**

**Along with the ALLIANCE and other patient organisations, we strongly believe that the 50% rule should be scrapped and replaced with a process that seeks to understand how people are impacted on their worst day.** Thinking more broadly in this way will present a more holistic picture of a person's needs and abilities. We believe that Social Security Scotland should put trust in claimants to be able to describe what their worst days look like.

The current time period for 50% of the time is not clear and disadvantages people with Crohn's and Colitis. Over a lifetime, we estimate at least 54% of people diagnosed with Crohn's and 44% of people diagnosed with Colitis would be severely impacted. However, the nature of the condition means that it is impossible to predict when a flare may occur or escalate and it may be the case that symptoms suddenly present during the course of a day. This means that someone could be well in a morning and incredibly ill in an afternoon. Similarly, they might have a period of remission with few symptoms, and severe relapse which require hospitalisation. Although people with Crohn's and Colitis may not be experiencing symptoms constantly, the unpredictability of when they might have a bad day means that they need additional support and face financial hardship due to their disability.

**15(a). If you proposed changes, what positive impacts could these have, and for who?**

The changes proposed would enable people with Crohn's and Colitis to more accurately describe how the fluctuating nature of their condition impact their mobility, supporting a more personalised and holistic approach to the application process. More relevant criteria may also result in them being correctly awarded the appropriate rate of payment, which is likely to improve quality of life.

**15(b). If you proposed changes, what negative impacts could these have, and for who?**

We do not foresee any negative impacts arising from such changes.

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<sup>i</sup> Norton, C *et al* (2013). Faecal incontinence in inflammatory bowel disease: Associations and effect on quality of life, *Journal of Crohn's and Colitis*, 7(8), Pages e302-e311, Norton, C *et al*, Asking about bowel control problems in IBD: results of face-to-face screening versus self-reporting. *Gut* 67 (2018)

<sup>ii</sup> Pogacnik and Salgado (2019). Perianal Crohn's Disease, *Clin Colon Rectal Surg*, 32(5): 377-385. CKS. Crohn's disease: complications. <https://cks.nice.org.uk/topics/crohns-disease/background-information/complications/> (2020).

<sup>iii</sup> Baban *et al* (2021). Osteoporosis Complications in Crohn's Disease Patients: Factors, Pathogenesis and Treatment Outlines, *Cureus*, 13(12): e20564.

<sup>iv</sup> Solberg *et al* (2009). Clinical course during the first 10 years of ulcerative colitis: results from a population-based inception cohort (IBSEN Study). *Scand J Gastroenterol*, 44(4):431-40.

<sup>v</sup> Solberg *et al* (2007). Clinical course in Crohn's disease: results of a Norwegian population-based ten-year follow-up study. *Clin Gastroenterol Hepatol*, 5(12):1430-8.

<sup>vi</sup> Crohn's & Colitis UK (2018). Blue Badges - Your View Matters. Unpublished.

<sup>vii</sup> Borren, N. Z, van der Woude, C. J. & Ananthakrishnan, A. N. Fatigue in IBD: epidemiology, pathophysiology and management. *Nature Reviews Gastroenterology and Hepatology* vol. 16 (2019)

<sup>viii</sup> Tindell A, Johnsson H, McInnes IB. Arthritis, Arthropathy, and Osteoporosis in Inflammatory Bowel Disease. In: *Crohn's Disease and Ulcerative Colitis* [Internet]. Cham: Springer International Publishing; 2017 [cited 2018 Aug 20]. p. 571–83. Available from: [http://link.springer.com/10.1007/978-3-319-33703-6\\_55](http://link.springer.com/10.1007/978-3-319-33703-6_55)

<sup>ix</sup> Crohn's & Colitis UK (2017). Travel with IBD survey. Unpublished

<sup>x</sup> Toilet Consortium UK survey (2018). Unpublished.

<sup>xi</sup> Toilet Consortium UK survey (2018). Unpublished.