

Crohn's & Colitis UK's response to the '[Shaping future support: the health and disability green paper](#)'

October 2021

Crohn's & Colitis UK welcomes the opportunity to provide input into the Government's consultation on '[Shaping future support: the health and disability green paper](#)'.

1. Crohn's & Colitis UK are the leading charity for 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. Inflammatory Bowel Disease (IBD), the two main forms of which are Crohn's Disease and Ulcerative Colitis, affects over 500,000 children and adults in the UK. They are lifelong, often debilitating conditions, with no cure. You can develop IBD at any age, but most people are diagnosed between the ages of 15 and 40, which means it has a significant impact on their working life. IBD requires tight monitoring and management, with care managed across primary and secondary care, often with high-cost medications or surgery, or a combination of both. Delayed diagnosis increases the likelihood of surgery or more expensive treatments and may result in a poorer prognosis.² If left untreated, poorly managed or in cases of severe disease, Crohn's and Colitis can cause serious complications, which require emergency medical and/or surgical intervention. The annual cost of treating a flare (relapse) is up to six times greater than treating a patient in remission.³ The cost impact of Crohn's and Colitis on the NHS is increasing year on year and average per patient cost is comparable to cancer and heart disease.⁴ Social functioning can be impaired - leading to an inability to work, attend school and/or participate in leisure activities, with consequences on relationships, everyday responsibilities and achievement of life goals.
3. Crohn's & Colitis UK is a member of the Disability Benefits Consortium (DBC) and endorses the wider recommendations made in their submission.

Summary points:

- The Department for Work and Pensions (DWP) must do more to recognise the nature and impact of fluctuating conditions throughout its work to ensure that people with IBD can access benefits when they require them and to increase employment opportunities
- Personal Independence Payment (PIP) needs to be reformed and benefits assessors must have appropriate understanding of fluctuating long-term conditions
- Access to Work and Disability Confident schemes should be expanded, and take-up increased, ensuring greater inclusivity for people with invisible conditions
- Work coaches must have a good understanding of IBD

¹ www.crohnsandcolitis.org.uk

² Mozdiak E, O'Malley J, Arasaradnam R (2015). Inflammatory bowel disease. *BMJ*. 351: h4416. [Inflammatory bowel disease | The BMJ](#)

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

⁴ Luces C, Bodger K (2006). Economic burden of inflammatory bowel disease: A UK perspective. *Expert Review of Pharmacoeconomics & Outcomes Research*. 6: 471-482.

- Employment information and support needs to be provided by health services, with joined-up working between government departments, health systems and the voluntary sector - we would advocate the vocational model for IBD that is described and case management approaches
- Support needs to be increased for young people with IBD moving out of education and into work

A benefits system that recognises fluctuating long-term conditions

4. There are hundreds of thousands of people who live with fluctuating long-term conditions, which include Crohn's Disease, Ulcerative Colitis, arthritis, multiple sclerosis, Parkinson's and lupus. The fluctuating nature of these health conditions can be extremely challenging for those who live with them. At only three points in the Green Paper are there references to fluctuating long-term conditions (pages 50, 51 and 70). In contrast, there are 609 mentions of 'disability' or 'disabled'. This albeit simple numerical disparity tends to reinforce the established belief that the support available through the current benefits system is largely built on a concept of a disabled person with a 'permanent and substantial' impairment or on the person with a long-term health condition which is likely to degenerate. There appears to be little recognition of the person who has a long-term, fluctuating health condition and the adverse effects this has on the person's ability to work, undertake education and maintain their physical and mental health.⁵
5. Unlike its predecessor, Disability Living Allowance (DLA), eligibility for PIP is based upon an external assessment with regular assessments of continuing eligibility. Eligibility is based upon a series of tests that include preparing and eating food, managing medication, maintaining personal hygiene and making day-to-day decisions. Points are awarded for each activity and the level of benefit determined upon the score achieved. Claimants are required to have needed assistance for more than three months to qualify and the expectation is they are likely to maintain that requirement for at least nine months into the future. **This basic description of the claim process clearly suggests that it has been designed to suit either stable conditions or those whose course is exemplified by ongoing deterioration.**

"I applied but was turned down due to "not being ill enough". My experience of the benefit process was incredibly negative". (Female, 25-34; Midlands)⁶

Assessment

6. Approximately 10,000 people with Crohn's or Colitis receive PIP, around 2% of the total population with IBD.⁷ Issues related to PIP remains the most frequently cited reason for people contacting the Crohn's & Colitis UK Helpline with benefit-related queries.⁸ Over a period of years, the greatest number of complaints to the Crohn's & Colitis UK's Benefit Support line have concerned the face-to-face assessment and lack of knowledge that assessors have of IBD. This lack of condition-specific knowledge has been echoed on many occasions in the discussions of the DBC.
7. Crohn's Disease and Ulcerative Colitis are often described as invisible or hidden conditions because the symptoms are often not externally evident. Consequently, where

⁵ Elizabeth Price, Liz Walker & Sara Booth (2020) Feeling the benefit? Fluctuating illness and the world of welfare, *Disability & Society*, 35:8, 1315-1336, doi: 10.1080/09687599.2019.1680346

⁶ Price et al. Op. cit. Pg. 12

⁷ Stat-Xplore DWP benefit statistics

⁸ Crohn's & Colitis UK internal data analysis. Sept 2021.

levels of awareness and understanding are low amongst assessors, and the system is not designed around the condition, wrong assumptions can be made and misunderstandings can arise, which can add to an individual's distress.

8. The assessment requires understanding and sensitivity, as well as assessors skilled in drawing out what a real day for a person with IBD looks like. This can be a challenge as people with IBD 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. During a 'flare' of the condition, people with IBD often report requiring the toilet more than 20 times a day. Additional manifestations such as profound fatigue, even present when the condition is in remission, are not captured
9. People with IBD frequently express concerns that assessors do not understand the true disabling nature of the condition, its fluctuating nature, and its effect on their ability to maintain employment, relationships, education and engage in day-to-day activities. They feel that assessors prejudge eligibility based on their physical capability within a face-to-face assessment, rather than asking questions that are relevant to their lives with IBD. It is imperative that more is done to ensure that people with IBD are seen by health professionals who understand the nature of the diseases they are assessing.
10. In the case of PIP specifically, decisions are made based on blunt and inflexible measures such as whether a person can complete a specified task to an acceptable standard, repeatedly and within a given time frame.⁹ To qualify for the benefit, the person must be unable to perform these specified activities for 50% of the time. This is essentially a 'snapshot' taken by an assessor which may or may not be taken on what the person may feel is either a 'good' or 'bad' day. The current assessment also fails to consider the long-term, cumulative effect of living with a health condition such as IBD, the key symptoms of which may include severe pain, surgery, debilitating fatigue, and mental health/anxiety issues.
11. The continued and widely held view of those undergoing assessments is that health professionals have low awareness of IBD, are unsympathetic, and claimants often feel very distressed, intimidated and undervalued by the whole process. People living with IBD have told us:

"It was a very poor and distressing experience. Assessor was impersonal, dismissive, hurried my answers, ignored my explanations, and recorded false information. The report was completed entirely of standard system phrases with different sections contradicting one another. I complained about my experience and the points score awarded and this was reconsidered."

"Shocking, she knew nothing about my illness (that was evident) and was found fit for work when I knew I was nowhere near."¹⁰

12. This negative experience is not limited to people with IBD. As Price et al point out in their research with people who have lupus, this approach '*fundamentally disadvantages people living with fluctuating conditions, meaning they may, or may not, depending on their ability on a particular day, be able to meet the criteria*'.

"I have been told I am too healthy to claim benefit for my lupus. This is despite the fact that some days I am incapacitated by migraines, fatigue and joint pain. I do not

⁹ Price et al. Op. cit. Pg. 7

¹⁰ DBC, Big Benefits Survey 2015-16, January 2016

experience these symptoms enough apparently to warrant government support”.
(Female, 25-34; London)¹¹

13. However, when assessments are undertaken by knowledgeable and compassionate health professionals, the assessment can be a positive experience. One person told us:

“They were fantastic, I got to speak to a doctor that truly understood, saw my condition and was able to make an informed decision on my health.”¹²

14. There have been positive steps taken in some areas within the scope of this Green Paper, and which indicate both a willingness and ability to accommodate and support people whose long-term medical conditions fluctuate in severity. These developments are welcomed by Crohn’s & Colitis UK. In particular, changes to the Access to Work scheme have resulted in some people with Crohn’s and Colitis being made an award which has helped them remain in employment. This assistance includes, for example, an award to help a person with IBD pay for a taxi to get to work when their condition is ‘flaring’ and they were unable to use their usual method of public transport due to a potential urgent need to access a toilet en route. This is a very positive step and signals a greater willingness to work alongside the person with the long-term fluctuating illness and, importantly, to trust that person’s description of their need, alongside any supporting medical evidence, at any given time.

15. This willingness to trust and respect a person’s description of the effects of their illness, alongside medical evidence, is very often lacking in the benefits system notably in this case, in the assessments for PIP.

“Horrible. The woman was very nasty and not understanding at all. I felt intimidated. When asked if I soil myself, I said ‘yes on occasion’ but because I haven’t seen an incontinence nurse, she said I was lying. She didn’t understand that every day is different and that there are good and bad days.”

“Unduly exhausting! Made to go through an intense interview for over an hour, after journeying there, all whilst being extremely unwell and carrying out this made my symptoms worse, and bed bound for days afterwards.”¹³

16. Recommendation

Within the current assessment system, assessors must have comprehensive knowledge of the needs of people with long-term health conditions and undertake condition-specific training on IBD and other fluctuating conditions, which is overseen and quality assured by DWP.

17. Recommendation

In response to the consultation questions at point 243 onwards, and considering the wider reform of PIP, Crohn’s & Colitis UK recommends that the DWP establish a task and finish group to investigate how PIP could be improved for people with fluctuating conditions. This working group should include people with fluctuating conditions and those with experience of the current benefits system. This comprehensive and inclusive approach would be preferable to a more ‘piecemeal’ attempt at change based on individual responses to this consultation.

¹¹ Price et al. Op.cit. Pg. 12

¹² DBC, Op. Cit

¹³ Crohn’s & Colitis UK, Helpline feedback 2018

- The working group should pay particular attention to how the PIP and related assessments could be revised to better reflect the experience of people with IBD and other fluctuating conditions.
- The group should also consider whether the underlying ethos of PIP could be re-focused and used not only to reflect the additional costs of disability but also to support people with fluctuating conditions to remain in the workplace, at a level which reflects their abilities, and which promotes economic security. This would be wholly in line with the Departmental aim set out in point 34 in the consultation document: *'We want to make sure that money spent on supporting disabled people and people with health conditions has a positive impact on their lives'*.

18. Crohn's & Colitis UK are not recommending that assessment for PIP be tied to a person's ability to work. The DWP could, as has been the case with the development of the Access to Work scheme, view PIP as another supportive tool that promotes work. Where appropriate, PIP could support interventions that enable individuals to remain in work by, for example, reducing their hours to better manage their condition and retain a level of financial security. This approach would be in line with the Department's key priority for change - 'Improving employment outcomes' and would be a targeted investment in people's wellbeing.

Alternative approaches

19. Other countries within Europe support people with fluctuating conditions in a range of different ways. For example, some Scandinavian countries have adopted the concept of 'partial sick leave', whereby state benefits are paid to people with long-term conditions and disabilities to help them remain in employment. Trials in Finland demonstrated that people on such a scheme had 20% fewer additional 'sickness' days than people on the standard scheme and were able to remain in employment. "Partial sick leave allows people with reduced workability to work part time. Thereby, a full-time sick leave can be avoided, and the partial sick listed person will maintain his or her connection to the labour market, which should make a full time return to work more likely at a later point". It may prove informative to look at this more supportive approach to welfare benefits and employment in greater detail.¹⁴
20. The Department will also be aware that the Scottish Government is currently in the process of replacing PIP with the Adult Disability Payment (ADP). As part of this process, Crohn's & Colitis UK has been engaged with Social Security Scotland over an extended period and on several levels to ensure that the new system meets the needs of people with Inflammatory Bowel Disease and other fluctuating conditions. This has included:
- Involvement in all general consultations on the overall development of the payment
 - Contributing to the development of the equivalent of the 'descriptors' to ensure that they do not unintentionally exclude people with fluctuating conditions
 - Inviting people with Crohn's and Colitis to complete the draft forms alongside their developers to explain how the forms and wider process might be improved for people with long-term fluctuating conditions.
21. The experience of Crohn's & Colitis UK to date has been that the approach taken during the development of the ADP by the Scottish Government has been positively focused on

¹⁴ Nordic Social Statistical Committee, Copenhagen (2015). Sickness Absence in the Nordic Countries. [FULLTEXT06.pdf \(diva-portal.org\)](#)

ensuring that the new benefit provides support not only for disabled people, but also for those people with a long-term health condition who may or may not regard themselves, or be regarded by others, as being ‘disabled’.

22. The development process has shown an understanding that the ‘costs’ of disability or having a long-term health condition are not only financial, but also include the cumulative adverse effects arising from long-term exposure to pain, fatigue and anxiety. ADP is not being viewed, as one person involved in the consultation put it, as a “reward for inability”, but as part of a wider system aimed at supporting working age disabled people.
23. The following is taken from the Social Security Scotland website and indicates an approach based significantly on partnership and the use of existing background information to reduce the need for face-to-face assessments which have been the source of considerable dispute and anxiety over an extended period with PIP.

Social Security Scotland will make decisions about entitlement for Adult Disability Payments using the applicants account of their circumstances and existing supporting information, where possible.

Examples of supporting information include:

- *a social care needs assessment*
- *a report from a community psychiatric nurse*
- *information from a carer*

We will significantly reduce the number of [face-to-face assessments](#) and will only ask someone to undertake a face-to-face assessment when it is the only practicable way to make a decision.¹⁵

24. Recommendation

Crohn’s & Colitis UK recommends that the DWP examine the approach taken by the Scottish Government in the development of the Adult Disability Payment in terms of:

- **The inclusive nature of the development and proposed review process**
- **The overt focus on supporting the applicant’s application through engagement with others who can provide supporting information**
- **The employment of a range of professionals within Social Security Scotland who can assist in the determination of an award, including mental health nurses and social workers**
- **The acknowledgement that the ADP can play a significant role in promoting financial security for disabled people and hence improving their overall quality of life**

Crohn’s & Colitis UK notes the suggestion that part or all of PIP payments could be swapped for the direct provision of aids or equipment.

25. Recommendation

Crohn’s & Colitis UK does not support the proposal to swap part of a person’s Personal Independence Payment for the direct provision of aids, appliances, and services. This proposal is contrary to the general direction of a range of other policies within the field of health and social care which are increasingly designed to give the person concerned greater control of discretionary spend.

¹⁵ [Social security: Disability Assistance - gov.scot \(www.gov.scot\)](http://www.gov.scot)

This section includes: the Access to Work (ATW) and Disability Confident schemes; the Work Capability Assessment (WCA); the role of Work Coaches; the role of local organisations in supporting disabled people and people with health conditions into employment; support in health settings; support provided digitally; and the transition from education to the labour market.

The key challenges lay in not just increasing and retaining more people disabled people and people with long-term conditions in work, but making sure that work is meaningful, competitively paid and high quality.

Improving understanding and work opportunities for disabled people

26. We agree with the Government that more can be done by employers to improve work opportunities for both disabled people and those with long-term conditions. We believe this is true for those people with IBD who fall within, as well as those who fall outside, current disability legislation. There will be people with IBD who will come within the definition of the law but do not necessarily see themselves as disabled, and those who fall outside the definition but self-identify as disabled due to the impact of the condition on their everyday lives. For some, the fluctuating nature of their condition will cause them to move in and out of definition of the legislation's protections and support available to them.
27. Crohn's & Colitis UK would like to see activity in three areas:
- 1) Education of employers about the law and, in particular, increasing understanding that the legislation includes people with fluctuating and invisible disabilities and health conditions
 - 2) Increased awareness and expansion of support
 - 3) More research into IBD and employment to inform advice, support and more effective interventions

Expansion and increased take up of Access of Work and Disability Confident schemes for people with IBD and invisible conditions

28. We welcome the Government's commitment to increasing awareness of Access to Work and Disability Confident. We would welcome a communication campaign that markets to employers beyond the Department's social media channels, Access to Work pages on the JobHelp website and on gov.uk.¹⁶ We would like to see tailored communications activity that increases employers' understanding of fluctuating and invisible conditions to improve work opportunities for all disabled people and people with long-term conditions. This could be in form of a discrete campaign with case studies and examples of best practice and/or be incorporated into future campaigns identified in the Disability Strategy.

“Respondents frequently described a lack of belief and dismissive attitudes as contributing to a sense of stigma: “I have had multiple managers who completely discount asthma as a disability or something that could affect my everyday life, dismissed my experience of living with it. I’ve had to fight for adjustments over how I am treated over it.”¹⁷

¹⁶ [Written questions and answers - Written questions, answers and statements - UK Parliament](#)

¹⁷ [DHIWsurveyreportEng.pdf \(tuc.org.uk\)](#)

29. In 2021, Crohn's & Colitis UK launched a campaign aimed at employers to increase understanding of fluctuating and invisible disabilities and health conditions. The Are You IN?¹⁸ campaign is based on the learning from our earlier Not Every Disability Is Visible (NEDIV) campaign. NEDIV was launched in 2016 to raise awareness about invisible disabilities and to educate the public that not everyone needing to use an accessible toilet might use a wheelchair or have an obvious visible disability.¹⁹
30. Our NEDIV campaign worked with restaurants, transport companies and businesses to improve signage on public toilets and train their staff on invisible conditions. This included challenging stereotypes and tackling misconceptions around IBD, as well as bringing attention to the Can't Wait Card.²⁰ We also supported airports to promote awareness of the invisible disability lanyard amongst airport staff and to people with IBD and other invisible conditions. Following the campaign, over 80% of people with Crohn's or Colitis said they felt more comfortable visiting a venue with the Not Every Disability is Visible sign installed.²¹
31. Taking this concept further, the Are You IN? campaign invites employers to sign up to pledges,²² showing their commitment to making the workplace more inclusive for people living with invisible conditions and disabilities. Employers have access to a range of tools and resources to support them to do this. The campaign also encourages workplaces to nominate Invisible Condition Reps and put in place appropriate line manager awareness training. Employers can sign up to either silver or gold pledges (see Appendix) - however the emphasis of the campaign is on starting the journey. We don't expect companies to implement all the pledges straight away, but to realise what they can do and to have a clear plan for considering the rest of the pledges over a longer period.
- The silver pledges - appointing, empowering and informing - support employers to put in place the right structures and support to make the workplace more inclusive, with staff feeling more informed and empowered to approach conversations around invisible disability
 - The gold pledges focus on taking employer commitment one step further. A gold employer is expected to offer its employees with invisible conditions the highest level of support and to increase awareness of the campaigns aims internally and externally.
32. Since its launch early this year, over 41 employers/companies have signed up, including an NHS trust, local councils, universities, and private companies such as national law firms, PR agencies and a range of local businesses. Approximately 145,000 employees across the UK are now working in organisations signed up to the campaign. And we have expressions of interest from over 350 companies or their employees to get involved with the campaign - outlining a clear need for more support for companies and employees around invisible conditions and disabilities.

33. **Recommendation**

Increase promotion of the Access to Work and Disability Confident schemes amongst employers. Working with the voluntary sector, explore how aspirations and expectations of those employers who sign up to the Disability Confident scheme can be raised. We would like to see a clear plan of action setting out how the

¹⁸ [Not Every Disability is Visible | Not Every Disability is Visible |...](#) (last accessed on 27/9/21)

¹⁹ [Not Every Disability is Visible campaign celebrates 4th birthday in style! | Crohn's & Colitis UK \(crohnsandcolitis.org.uk\)](#) (last accessed on 27/9/21)

²⁰ [Can't wait card | Crohn's & Colitis UK \(crohnsandcolitis.org.uk\)](#) (last accessed on 27/9/21)

²¹ Immunology_DoF_19MAR2019_MI_SG_001 (unpublished data from Not Every Disability is Visible 2019 Patient Survey, March 2019)

²² <https://www.noteverydisabilityisvisible.org.uk/pledges>

government will increase the number of businesses achieving Leader status, and an increase in the number of large organisations signing up to be Disability Confident.

Access to Work and Disability Confident need to do more to acknowledge and improve work opportunities for people living with invisible disabilities and/or conditions. We believe that both Access to Work and Disability Confident would benefit from using language and descriptions of disability that are more inclusive and that embrace those that are non-visible and fluctuating like IBD.

Given the lack of resources aimed at helping employers/companies to support those living with invisible conditions and/or disabilities, we would welcome the opportunity to work with the DWP and Department of Business Innovation and Skills (DBIS) to produce new or promote existing resources (such as those detailed in the Appendix) to meet this objective. We believe employers would benefit from having practical resources more widely available through Access to Work and Disability Confident programmes.

We would welcome the opportunity to meet with DWP and DBIS officials to discuss the Are You IN? campaign in more detail and potential opportunities to promote or integrate aspects of our campaign nationally.

34. Some early feedback from some employers that have signed up to our Are You IN? campaign is that they would welcome more resources and information on the kinds of reasonable adjustments and steps beyond reasonable adjustments that can be put in place to support people with the full range of disabilities/life limiting conditions. The current Access to Work scheme has a low profile among both employers and employees.
35. Access to Work is currently too focused on aids and equipment in the workplace, reflecting a skewed and outdated idea of disability (as detailed earlier in this submission). Access to Work should extend the approach it takes in mental health, in terms of developing a support plan, to disabilities/long-term health conditions. We believe that this group of workers would also benefit from flexible working patterns, regular catch ups to discuss their concerns, phased work returns and additional time to complete certain tasks.
36. We also believe that support planning would promote a more proactive, preventative approach to managing absence and presenteeism in long-term conditions/disabilities that flare. We believe it would encourage employers and employees to co-produce work strategies to enable employees to work well in the long-term and address periods of ill health, mitigating against avoidable periods of absence or changes to working conditions.
37. A systematic review of research into IBD and employment identified common themes around the importance of reasonable adjustments and accommodations in the workplace for people with IBD, with a significant proportion of respondents reporting that they had some difficulty arranging such accommodations.²³
 - More than two in five people (43%) with Crohn's or Colitis had to make an adjustment to their working life (for example, home working or flexible hours) because of their condition
 - A study reported that 90% of people with IBD who had symptoms at some time during their working life required accommodations. However, many found workplace accommodations difficult to arrange or did not ask for these

²³ [Accommodations and Adaptations to Overcome Workplace Disability in Inflammatory Bowel Disease Patients: A Systematic Review - FullText - Inflammatory Intestinal Diseases 2018, Vol. 3, No. 3 - Karger Publishers](#)

- Two studies reported that only 34% and 40%, respectively, were able to make work adjustments to avoid taking time off due to their IBD

38. Adjustments for consideration included:

- Ensuring storage facilities were available for their own food if necessary to comply with dietary requirements
- Adjusting work patterns for fluctuating health and stamina levels depending on working patterns, for example, shift work or full-time hours
- Redeploying or amending duties to allow employees to continue to work
- Reviewing the risk assessments for the job they undertake - considering what action would be taken if an employee became unwell during their working day and how it would affect them and their colleagues
- Putting contingency plans in place in case an employee becomes unwell and is unable to remain at work
- Having policies for taking off time to attend medical appointments
- Offering later starting times
- Flexibility to support remote/office working
- Arranging for parking nearer to the office entrance
- Adaptions to toilets or bathrooms to accommodate changing a stoma bag

39. Recommendation

- **Extend the approach Access to Work is developing in relation to mental health to the application of disabilities/long-term health conditions**
- **Work with the voluntary sector to improve awareness of Access to Work amongst employers and employees**
- **Communicate more clearly how people with IBD and other invisible disabilities could benefit from the Access to Work scheme**
- **Extend an invitation to the stakeholder forum(s) and communications to representatives from Crohn's & Colitis UK**

Research into IBD and employment to inform advice and support

40. There is limited research into IBD and employment. Much of the research that is available is international in origin. Data is also limited on how many people with IBD engage with the Access to Work scheme and consequently how money is spent on supporting this cohort. Data is not broken down for IBD (despite prevalence being higher than for spina bifida or cerebral palsy) or continence. It is unclear where IBD currently fits into the data categories. This means it is difficult to gauge, other than from feedback from people with IBD, how effective this scheme is in reaching this cohort and meeting their needs.

41. Recommendation

The DWP should review the range of data collected on the Access to Work scheme, in consultation with the Stakeholder Forums. Data on the pattern of use of the scheme - for example, demographically (particularly ethnicity), geographically (in line with new Integrated Care Systems (ICS) configurations and Health Boards/Trusts) and across sectors - can help to target promotion. Data collected on the experiences of people with IBD with Access to Work, and the impact of reasonable adjustments on this cohort should be improved.

Support and information for work coaches

42. It is important that Work Coaches have an understanding that IBD is an incurable, fluctuating condition and that employment needs can remain the same or change over time. As previously mentioned, claimants living with Crohn's and Colitis often find it difficult to talk about and articulate their condition within face-to-face assessments. Some may never have talked about their condition before or experience difficulties in talking about their condition. Explaining toilet habits and episodes of incontinence can be embarrassing and lead to lack of disclosure.

43. Recommendation

- The DWP should provide regularly updated information and resources on IBD for work coaches that are co-produced by the voluntary sector, clinicians and people with IBD
- The DWP should develop detailed guidance for staff, with the involvement of disability organisations, on the appropriate use of the Claimant Commitment, specifying the situations in which different levels of conditionality would be applicable, with multiple real examples. This will help to ensure that conditionality is applied appropriately and consistently by Work Coaches.
- The DWP should commit to increasing and protecting the number of Disability Employment Advisers in future and ensuring they receive continuous training in order to help them effectively to support Work Coaches.

Use of case management approaches

44. Case management is critical to delivering success, particularly for people with more challenging and complex needs. Learning from a vocational rehabilitation pilot delivered in Scotland (see Appendix) found clients with IBD responded positively to:

- the professional and knowledgeable approach of the case managers
- the way the service was person-centred and offered continuity of care
- the proactive way the case managers sought help and support for clients

45. The pilot's evaluation found that intensive case management was a critical element and contributed to the achievement of outcomes for clients with complex needs.²⁴

46. This pilot also demonstrated the benefits of case workers working alongside NHS staff and IBD teams. In line with these findings, we would recommend Work Coaches working more closely with local IBD teams to access information, advice and training from IBD specialists.

Making the most of local organisations

47. The Government can make better use of the voluntary sector and peer support. Crohn's & Colitis UK provides over 50 publications including information booklets and factsheets - with information written specifically for employers²⁵ and employees.²⁶ As outlined above, we also run a campaign to encourage companies to learn more about invisible conditions and disabilities by signing up to Are You IN?

²⁴ [Evaluation of the Vocational Rehabilitation Service Pilot: Final Report, August 2014.](#)

²⁵ [Employment & IBD: a guide for employers | Crohn's & Colitis UK \(crohnsandcolitis.org.uk\)](#)

²⁶ [Employment & IBD: a guide for employees | Crohn's & Colitis UK \(crohnsandcolitis.org.uk\)](#)

48. Recommendation

- IBD services and GPs should provide all newly diagnosed people with IBD with a patient pack with information on IBD and employment
- Staff within the DWP and NHS should be trained to regularly signpost to patient organisations that can support people with IBD with up-to-date information about living with their condition, as well as employment and self-management advice
- DWP should review their resources to make sure that they are signposting both their staff, employers and the public to resources from patient organisations on IBD

Digital Employment Services

49. There are both pros and cons to extending digital employment services. For some people with IBD, the ability to access services from home and proximity of a toilet would be welcome. However, it will be vital not to create a digital divide where quality or access to services is adversely affected by no or limited access to the internet or low digital literacy.
50. Any digital approach should consider:
- The accessibility needs of people with differing needs within the community, ensuring content and design is clear and usable so that most people can use it without needing to adapt it, while supporting those who do need to adapt their digital experience
 - Representative content which reflects lived experiences
 - Co-creation and usability testing that includes people with differing needs within the community

Better support for young disabled people and people with health conditions who are moving out of education to find appropriate work

51. While children and adults living with IBD can be diagnosed at any age, many are diagnosed in their teens and twenties.²⁷ While receiving a diagnosis can be difficult for anyone, for young people it comes at a time when they are completing their education, seeking work for the first time and embarking on a career. Their experience of diagnosis, prognosis and ability to self-manage will shape their ability to gain skills and learn, as well as their aspirations for the future.
52. Young people living with IBD and invisible disabilities must be supported to ensure that they can complete their studies to the best of their ability and are not excluded from the workplace or discouraged from aiming high in their careers.
53. *'Crohn's, Colitis and Employment - from Career Aspirations to Reality'*, found that young people (aged 16-25) with IBD who had not yet entered full-time employment often felt that their condition had compromised their education and significantly limited their career aspirations. Those surveyed also reported that when they reached the workplace, they often felt under-supported by their employers. A follow up report *'Inflammatory Bowel Disease in Young People: the impact on education and employment'* found that more than two thirds (67%) felt that their IBD had delayed or was delaying their education/training and most stated that their IBD had prevented them from reaching their full educational potential.

²⁷ IBD UK. IBD UK Patient Survey 2019 (unpublished data). (2019).

54. Having a diagnosis of IBD has been found to affect young people's career confidence and self-esteem. More than half of respondents suggested that, due to their IBD, they have ruled out some career options that they may otherwise have considered. Nearly 49% of respondents revealed that their IBD had delayed them starting work or looking for employment.
55. 16-25-year-olds who had not yet entered full-time work said that being able to take time off work for medical appointments, flexible working, toilet facilities and frequent toilet breaks were important characteristics of future employment.

56. Recommendation

To prepare and support disabled young people moving into employment, the Department for Education and DWP should work together to ensure disabled young people are aware of the full range of support options available to them, including Access to Work.

57. Recommendation

Clearer and more tailored information for disabled people and people with long-term conditions is needed on the [National Careers Advice](#) website.

Advice is currently somewhat hidden within the website.²⁸ The service is also described in terms of being available to those who are 'experiencing problems' and/or discrimination. We would invite the National Careers Service to review the way in which the service is described, with a view to making the offer more open, aspirational, welcoming and accessible. The addition of some case studies and role models that young people can relate to and be inspired by would be small improvements that could reap benefits. The resources offered are also limited - we would be happy to share a link to resources that we have produced on this topic - and more generally they could benefit from being updated and made available in different accessibility formats.

58. Recommendation

Clinicians and healthcare providers should be incentivised to talk to patients about working life, and to young people about their aspirations, as part of personalised care and support planning.

Measures to increase this activity could include employment modules in self-management education programmes and incentives could include use of the Quality and Outcomes Framework, local Commissioning for Quality and Innovation Schemes and/or, potentially, a Best Practice Tariff. The creation and transition to Integrated Care Systems is an opportunity to bridge traditional policy gaps between health, education, work and business through close working with the DWP and the DBIS.

59. Recommendation

Increase the number and quality of work experience traineeships, work trials, supported internships and graduate programme opportunities for young people with disabilities, especially in the NHS, civil service and armed forces.

60. Recommendation

Increase opportunities for young people with IBD to learn entrepreneurship skills, so that they can start and run their own businesses.

²⁸ [Career and job support for people with a disability | National Careers Service](#)

61. Recommendation

Increase the numbers of employers using Access to Work to support work experience and apprenticeship opportunities.

62. Recommendation

Strengthen rights in the workplace and to flexible working and improve access to advice on employment rights for disabled young people, their families and employers.

63. Recommendation

Work with patient organisations like Crohn's & Colitis UK to increase awareness and uptake of Intensive Personalised Employment Support for people with IBD, especially amongst those of school leaving age.

64. Recommendation

Ensure that young people with IBD, fluctuating and invisible conditions transitioning from education to work, are part of DWP pilot testing the Access to Work adjustment passport.

65. Recommendation

Increase access to online learning and education for those who are unable to attend face-to-face classes.

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

Appendix

About the Are You IN? campaign

Crohn's & Colitis UK Are YOU IN? campaign invites employers and companies to sign-up to pledges, showing their commitment to making the workplace more inclusive for people living with invisible conditions and disabilities. Crohn's & Colitis UK have created a range of free tools and resources to help companies do this.

Employers/companies can sign up to either Silver or Gold pledges. Crohn's & Colitis UK do not expect companies to implement all of the pledges straight away but implement what they can and have a clear plan for considering the rest of the pledges.

About the Silver pledge

The Silver pledges are all about Appointing, Empowering and Informing - so that the right structures and support are in place to make the workplace more inclusive, with staff feeling more informed and empowered to approach conversations around invisible disability.

APPOINT

- Appoint an Invisible Condition Rep as a point of contact to signpost colleagues towards the campaign resources and relevant company policies or employee assistance programmes. Please note, a training guide covers the specific remit of this role, which is not an advice-giving role.
- Install *Not Every Disability is Visible* [accessible toilet signs](#) in company accessible toilets. Crohn's & Colitis UK template signage can be used or adapted into your own company branding if preferred.

EMPOWER

- Empower managers, HR and people living with invisible conditions to talk with confidence about invisible conditions by promoting our conversation guides. They give tips, practical examples, and support on how to approach conversations about invisible conditions.
- Train and educate all staff on invisible conditions and, specifically, Crohn's and Colitis. There is a range of training options from apps to videos and infographics to choose from.
- Comply with current government recommendations for a COVID-19 safe workplace, including conducting a risk assessment where an employee at moderate or high risk of complications from coronavirus is asked to come back to the company workspace.
- Consider, both currently and as part of a post-COVID climate, offering remote and flexible working hours as a means of not only improving employee wellbeing but also productivity and job satisfaction.

INFORM

- Roll out a selection of campaign assets to promote staff engagement with the campaign, choosing from email signatures, Outlook profile pictures, screensavers, stickers and posters.
- Announce support of the campaign internally and externally. Crohn's & Colitis UK provide template internal comms, a press release and social media posts to make this easy.
- Report bi-annually in the first year and annually thereafter on pledge implementation and impact on staff. Crohn's & Colitis UK provide a short survey and the questions can be incorporated into any existing staff surveys you might have.

Gold Pledges

The Gold pledges are all about taking your commitment one step further. To gain Gold status your company must fulfil all Silver pledges and pledge to implement at least three additional pledges from the list below. By becoming a Gold employer, your company can offer your employees with invisible conditions the highest level of support. You can help us to spread the word about the campaign by promoting your commitment externally and encourage other companies to get involved, increasing support for people with invisible conditions across on a much wider scale.

- Offer remote working and flexible working hours to staff.
- Promote your campaign pledge badge externally on some aspects of your company literature such as email signatures / recruitment packs / website etc.
- Illustrate, through a case study, the work that you are doing within the invisible condition space. Crohn's & Colitis UK will promote the content across our social channels and Not Every Disability is Visible website.
- Host a *Not Every Disability is Visible* virtual launch event for employees.
- Facilitate the sign up of any sister companies and / or suppliers to the campaign.
- Talk to us about other ways you may be able to support our work.
- Fundraise for Crohn's & Colitis UK. Crohn's & Colitis UK can provide a variety of fundraising options to suit.

Are YOU IN campaign resources: [Not Every Disability is Visible | Campaign resources](#)

Case Study: Vocational Rehabilitation Service (VR Service)

The following case study illustrates effective joined up join up employment support in health settings

The Vocational Rehabilitation Service (VR Service) was a pilot service which provided VR support for people with cancer, Multiple Sclerosis (MS) and inflammatory bowel disease (IBD). It was delivered between June 2011 to July 2014 by NHSGG&C and external partner agencies including Macmillan Cancer Support, Glasgow City Council, NHS Healthy Working Lives Greater Glasgow and Clyde and the Scottish Government.

The Service had a target of engaging 160 clients by the end of July, 2013. At the end of the pilot data collection period (June, 2011 to 19 May 2014):

- 303 people had used the VR service;
- 260 had been discharged;
- 43 clients were still receiving support.

This is almost double the numbers of clients which had been expected. The main referral sources were the NHS and self-referrals. Self-referrals were signposted from a range of sources including health professionals. The case managers were successful in raising awareness of the service and encouraging health professionals to refer and signpost.

The service model offered:

- A tiered case management process with 3 Tiers:
 - Tier 1 can be described as self help and was offered to all acute patients of working age with cancer, MS or IBD.
 - Tier 2 offered moderate support which could involve giving information about how to manage health conditions at work, providing a positive message about work and signposting/referrals to other services if additional support was needed.
 - Tier 3 offered specialist and intensive support using a bio-psychosocial model.
- Specialist support with a strong focus on clients' work needs delivered by case managers who are vocational rehabilitation specialists;
- Client led support;
- Open access with referrals accepted from a wide range of sources;
- Links to other services to facilitate referral and signposting.

Case Management Interventions The specialist support offered to clients involved:

- Detailed assessment of work skills and capacity, job requirements and demands, work environment and social support systems.
- Prioritising key issues and setting short term and long-term goals.
- Problem solving.
- Supporting work preparedness and work readiness activities - building confidence.
- Strategies for managing particular health problems in the workplace.
- Negotiating a phased return to work, not just in hours but also tasks and responsibilities.
- Psychological interventions including coaching and other interventions underpinned by a range of CBT principled activities.
- Information and advice on disclosing diagnosis to managers and colleagues - legal rights and responsibilities.

- Referral or signposting to support services including careers advice and guidance.
- Liaison with employers including visiting work sites.
- Modifications to the work environment.
- Supporting withdrawal from work

Outcomes

The evaluation showed that the Service was associated with a range of outcomes including improvements in health. The EQOL5D was used to measure this. There were improvements across all domains with the biggest increases in the numbers with 'no problems' in the domains of self-care, ability to take part in usual activities, pain and discomfort and depression and anxiety. It should be remembered that these clients have severe and enduring health conditions, and any positive shift is important. The Hospital Anxiety and Depression Scale (HADS) was used to measure two aspects of psychological health relevant to patients, anxiety and depression. There were declines in anxiety and depression between joining and discharge.

The Service was also associated with an increase in the numbers of people in work and reduction in the numbers off sick. These work outcomes were sustained as a follow up survey of 6 months after clients were discharged showed 92% of people who were in work when discharged were still in work. Some clients who were not at work when they were discharged had also returned to work so that the overall proportion of those in work at discharge has increased from 66% to 90%.