



Long Covid Support: Response to the Department for Work and Pensions' Work Capability Assessment (WCA): activities and descriptors consultation October 2023

Long Covid Support

Long Covid Support is a UK based charitable organisation. Long Covid Support (longcovid.org) runs an international peer support and advocacy group for people with Long Covid (pwLC). We provide online support for over 62K members in 100 countries/territories and advocate for pwLC in the UK. Long Covid Support has been proactive in advocating the challenges pwLC face around working since 2020 and to seeking solutions.

For our response we have drawn on our written evidence submitted to the House of Commons Works and Pensions Committee for the Parliamentary inquiries on:

- Employment Support 2021* ¹
- Employment Support and Plan for Jobs 2022* ² 2023*³
- Health Assessment for Benefits 2022 * ⁴

and our written response to the Shaping Future Support: The Health and Disability Green Paper 2021* ⁵

Our response has been agreed and co-signed by the following Long Covid organisations and groups most of which have been campaigning since 2020 [Long Covid Physio](#), [Long Covid Kids](#), [Long Covid SOS](#), [Supporting Health Care Heroes UK](#), Long Covid Nurses and Midwives UK and ME Local Network see page 14.

Given we are ill, our response is limited, and focused on key areas of concern and risks that we foresee will happen if the Department's proposals go ahead. We are open to being contacted about our response.

*Co-authors of these above documents include: Ceolta-Smith, J. and Rayner, C. who are both healthcare professionals with expertise in vocational rehabilitation and occupational health respectively and members of Long Covid Support

Background context

We have provided the Department with an evidenced base section on Long Covid. This detail needs to be considered when reviewing our answers to the consultation questions below.

*“Life is absolutely miserable. Every day is a struggle. I wake up exhausted, the insomnia and night terrors are horrendous as I live through my worst fears every night. Any activity such as eating meals, washing etc will mean I have to go to bed for a few hours. I am unable to look after myself or my child, exercise or maintain social relationships. I have no financial security. Long COVID has totally destroyed my life.” – consultant living with Long Covid (BMA Survey 2023) **

Long Covid is an umbrella term in common usage; adopted initially by patients,⁶ then accepted by the NICE review ⁷ to define persistent symptoms that can affect individuals' organs with multi system involvement that lasts longer than 12 weeks after an acute post COVID-19 infection. The World Health Organisation, while acknowledging the common patient usage of “Long Covid”, agreed its own terminology for the condition, “Post-Covid Condition”, adopted by Delphi consensus in October 2021. ⁸

COVID-19 is caused by the SARS-COV-2 virus which attacks blood vessels and therefore any part of the body, consequently a pwLC may experience a range of problems including heart and heart rate abnormalities, affects to the functioning of the autonomic nervous system, and cognitive impairment. ^{9,10,11} Despite the known probability that SARS 2 would cause a range of health damage because SARS 1 and MERS viruses had done this, and the growing body of research on Long Covid, ¹² many stakeholders including those who work in health provision still have limited understanding of this condition. This lack of knowledge is a significant concern and has caused some patients to be disbelieved and abandoned ¹². Unfortunately, some medical professionals and academics are pursuing and pushing for a psychological cause of Long Covid and ignoring the scientific evidence, which can only be harmful to pwLC. Moreover, we are now fully aware of our former prime minister’s, Boris Johnson’s, damaging personal views on Long Covid from the Covid Inquiry.¹² Thus it is essential that the Department does not accept such unfounded and harmful opinions or allow these to influence its policies, service delivery or frontline staff encounters with claimants.

It has been recognised that 50% of pwLC meet the criteria for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) ¹¹ with some people having a dual diagnosis. So, we believe it is essential to include people with myalgic encephalomyelitis (pwME) in our response. Our response may have transferability for other people with energy limiting conditions, and we signpost the Department to the excellent work of Chronic Illness Inclusion who has been raising awareness of energy impairments for many years. ¹³

*British Medical Association (2023). Over-exposed and under-protected: the long-term impact of COVID-19 on doctors <https://www.bma.org.uk/media/7318/bma-long-covid-report040723.pdf>

Long Covid and the impact on peoples' everyday lives, workability, and finances

In March 2023 there was an estimated 1.9 million people in the UK self-reporting to be living with Long Covid¹⁴ with the greatest number of people being of working age ranging between 35-69. Difficulties in being able to undertake activities of daily living were self-reported by 1.5 million (79%) pwLC, with 381,000 (20%) reporting their activities had been "limited a lot". Of further concern is that 762,000 (41%) of these pwLC reported their COVID-19 infection was at least two years prior.¹⁴

While pwLC present with their own unique combination and range of symptoms,¹⁵ an unpredictable pattern with relapses and fluctuations that wax, and wane is typical. A common symptom of Long Covid includes debilitating fatigue (energy impairment) which can impact on every aspect of a person's daily life leading to functional impairment.¹⁶ Both Long Covid and ME/CFS related symptoms may be brought on by physical, mental, social, and emotional exertion during or sometime after activities.¹⁷ Further evidence of these impacts on pwLC daily lives are revealed in a recent paper by Owen et al. (2023) and include quality of life and mental health.

Long Covid Support has collaborated with a wide range of stakeholders to support people to return and stay at work. This focus has been necessary because many disabled people in our Long Covid community have not been well enough to work or prepare to return to work since early in 2020. Numerous research studies in the UK and internationally show that many pwLC have had to take extended sick leave, reduce their work hours, change roles, or leave jobs following their illness, for example see Davies et al.¹⁵ Another example is a recent UK evaluation of a sample of 5,318 patients with Long Covid from 14 NHS Long Covid clinics¹⁸. This evaluation revealed that only 21% of pwLC had retained their pre COVID-19 infection work role. Of relevance to the Department is that this evaluation found a high rate of *new-onset disability: as "3,395 patients who completed at least one C19-YRS questionnaire at first assessment showed significant new-onset symptom burden, functional disability, and deterioration of overall health since the COVID-19 infection"*.¹⁸

While we have a good understanding of what might support or hinder a pwLC to return to work,¹⁹ we do not have a strong evidence base on what constitutes 'good work' for pwLC. In addition, there is limited evidence on how work impacts a pwLC's recovery over the long term.¹⁸ Importantly we know that people who have COVID-19 first need adequate treatment, rest, and rehabilitation as appropriate for those who develop Long Covid.¹⁹ We signpost the Department to the guidance on this for example see^{19,20, 21}.

Of concern here is that we know from many grassroots patient groups that pwME have had their condition worsen after having been found 'fit for work' and having tried to stay in work until they were physically broken.

There have been significant negative financial impacts for many pwLC due to the need to have extended periods of sickness absence from working, having to reduce hours of work, change

jobs or leave work. We are aware of pwLC who have had to sell their home and move in with family or friends.

Further examples of the financial hardship experienced are revealed in these quotes from pwLC:

“Maxed out credit cards, overdraft, money from friends, selling possessions, food voucher from council, not buying food, limiting energy use.” Woman, 56–65, other sector. ²² (p,57)

“Renewed my mortgage to pay debt off.” Woman, 46–55, health and social care. ²² (p,57)

Therefore, timely easy access to social security benefits (including contribution-based Employment Support Allowance (ESA)) is vital for pwLC. However, research has shown that delays and denials to benefits, including personal independence payment (PIP), and or the need to undertake lengthily appeals has negatively impacted on pwLC’s physical and mental health, and wellbeing. ^{22,24} For example, as shown in the below two quotes taken from the joint report by TUC and Long Covid Support on: Workers’ experiences of Long Covid ²²

“I was made to feel like a criminal rather than an ill person holding on by their fingernails, they in the process have worsened my condition and I have not yet over a year later regained the already tiny baseline that I lost as a result of this.” Woman, 36–45, other sector. ²² (p, 60)

“What a nightmare system almost ended my life trying to access this for disability is impossible.” Woman, 36–45, education. ²² (p, 60)

We know many people within our Long Covid and ME/CFS communities who have never claimed PIP because of the trauma of having to take their ESA claim to Tribunal. ²²

These barriers to claiming PIP are important to address, because ME Research UK have found that: *“For people with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) 90% of patients will not return to their former levels of function. “Other studies suggest that less than 10% of patients return to premorbid levels of functioning. As the criteria become more stringent the prognosis appears to worsen.” ²⁵*

Challenges in accessing healthcare

Despite some positive developments in relation to the diagnosis, treatment, and management of Long Covid, ^{26,19} many unknowns remain. Many patients have reported to Long Covid Support in our surveys about their ongoing problems receiving a diagnosis; inequitable access to Long Covid clinics and patchy and variable offers of healthcare provision.

Similarly in the BMA survey of doctors with Long Covid more than 65% of doctors who responded “...said their post-acute Covid symptoms had not been investigated thoroughly and effectively by an NHS long Covid clinic or centre. And almost half of doctors reported not even being referred to an NHS Long Covid clinic at all”. ²³

These challenges and delays in diagnostics and treatments may mean that the medical information a pwLC can provide as evidence for a benefit claim may be sparse at best. Thus, questions are raised about how the Department can accurately assess an individual's entitlement to benefits.

Worryingly we have shown that pwLC may have damage to parts of their body which is not known about because they haven't received any medical assessments. Therefore, given there are serious risks with safeguarding claimants' who have Long Covid or ME/CFS physical and mental health, we have focused our response on the Department's proposals on the amendment or removal of the non-functional descriptors. However, we strongly oppose all the proposed changes in the WCA consultation which includes changes to the descriptor for mobility.

The current WCA is unfit for purpose.

Along with many other stakeholders we reported that the WCA is unfit for purpose to the Works and Pensions Committee in 2022. ⁴ The 16 current WCA functional descriptors fail to accurately determine functional disability for a pwLC and whether they are unfit for work, fit for work or able to safely engage in work preparation activities.

Thus, if the proposed changes to the WCA are implemented they will increase the risks of harm to many pwLC and pwME through inaccurate decision outcomes that find people as either fit for work or fit enough to undertake work related activities when this is not the case.

Responses to the Department's questions

We have responded to questions: 5,6,7,8,9,10 which are highlighted in bold below.

Q5 are there any other WCA activities or descriptors that you think we should be considering changes to and why?

We recommend that the Department considers the wealth of evidence that has already been submitted to the Works and Pensions Committee on health assessment for benefits as outlined above.

Research by Chronic illness Inclusion (CII) project highlighted that the Department's "*disability assessments fail to account for energy impairment, especially its key features of payback, reduced capacity and cognitive dysfunction*" p7.²⁷ These findings are of relevance to pwLC and pwME who commonly experience energy impairment, cognitive dysfunction, chronic pain and post exertional malaise (PEM).

We agree with CII that the WCA currently fails to consider a person's function holistically. The 16 functional descriptors do not account for the fluctuating and episodic nature of Long Covid ²⁸ or ME/CFS. For example, In the WCA, Activity 3. is about reaching: Cannot raise either arm as if to put something in the top pocket of a coat or jacket. However, a pwLC or pwME may be able to raise their arm during an assessment and other periods during that day, but then be unable to repeat that activity later that same day or again the following day/s.

The 'reliability' criteria i.e., "meaning the person being assessed should be able to carry out the activity repeatedly, safely and reliably" ²⁹ should be applied to these 16 descriptors. However, it is of concern that the House of Commons Work and Pensions Committee reported that they had "... heard concerns about both how well the activities and descriptors actually reflect living with a disability or condition, and particularly how well the reliability criteria were being applied". ²⁹ Consequently, if the Department removes the LCWRA Substantial Risk regulations the WCA will remain reductionist, i.e., fail to account for how a pwLC or pwME manages their whole day.

Moreover, the proposed changes to the WCA will result in further failings to consider:

- the fluctuating nature of a person's function.
- whether a pwLC or pwME has limited capabilities to engage in a range of activities of daily living repeatedly, reliably, and safely.
- how a pwLC or pwME can plan their whole week and manage activities on consecutive days or not.
- the cumulative impact of a person undertaking different activities of daily living which also includes mobility.

We emphasise to the Department the importance of keeping the current descriptor for mobility and signpost to a study showing that for some pwLC "*walking (...) was consistently linked with an exacerbation of symptoms*" (p4): See Thomas et al. (2023):

*"Try taking my dog for a walk... This was hard as my legs felt heavy and tired to move".
"Walked 50 metres... very tiring and struggled with breathing on return journey".* Thomas et al. (2023, p5).

Therefore, if the proposals are agreed, there will be significant safeguarding risks and especially in relation to when a pwLC or pwME experiences PEM/ post exertional symptom exacerbation (PESE). ²¹

Of further concern is that we hear that the majority of pwME have had to attend a Tribunal (or at least a Mandatory Reconsideration) as their inability to undertake activities safely, reliably, repeatedly, to a certain standard and within a reasonable timeframe has not been recognised by the healthcare or one of the Department's decision makers. Whatever evidence has been supplied is also often completely overlooked.

Q6. What are your views on how the LCWRA Substantial Risk regulations could be amended with the emphasis on what work preparation activity an individual is able to safely undertake?

We first would like to point out to the Department that the original policy intent for substantial risk predates COVID-19 and the new disease named Long Covid. Therefore, the

Department's claim that too many people are currently being assessed as having LCWRA conflicts with the original policy intention, is invalid with reference to pwLC.

In our view it is essential that the non-functional descriptors **are not** amended or removed as they are the only safeguard in which pwLC or pwME can be safely assessed as having limited capability for work related activities.

There is consensus amongst healthcare professionals^{30, 20} focused on return to work that pwLC need to have consistency in their ability to undertake day-to-day activities such as getting washed and dressed before they can consider returning to work. When weighing up the Department's proposals for change in relation to conditionality and work preparation activities it is equally important to consider this same level of consistency with carrying out essential daily activities of living. Indeed, the Department's own assessment criteria is focused on a person being able to perform activities safely, reliably, and repeatedly and within a reasonable timeframe.

Given the current functional descriptors are unfit for purpose, there are serious physical and mental health and wellbeing risks for pwLC if the Department's medical assessors do not have the availability of the non-functional descriptors to make safe, fair, informed, and accurate clinically reasoned decisions and identify people who have LCWRA.

We agree with CII who stated that *"The relationship between overexertion and increased disability means that in many cases, work is not good for health"*.³¹ There is a need to apply a cautionary principle here when thinking about a pwLC's or pwME 's engagement in work preparation activities. For example, an individual may be unable to prepare a meal after being required to attend an online work course or make a telephone call to find out about a wellbeing service that a work coach signposted them to. Hence the cumulative impact of being required to undertake both essential daily activities of living and work preparation activities may compromise or inhibit an individual's ability to manage their essential daily activities of living.

We refer the Department to the WHO guidance on Post Covid Condition guidelines where it is explicitly stated that an individual should not return to work if they cannot manage day to day activities.²⁰

Relevant examples of the pwLC's lived experiences further support our views:

"My ability to tolerate any kind of exertion is significantly affected – I get postural and inappropriate tachycardia/shortness of breath symptoms with simple activities like dressing, rolling over in bed, doing my hair etc. I have become very weak compared to previous and struggle with many household activities (doing bins, laundry etc). Due to cognitive symptoms I often struggle with following many step recipes/instructions."
Junior doctor BMA survey²³ (p4)

"I am unable to carry out most activities of daily living and my children are having to help me around the house. I am almost housebound, and have had to buy a mobility scooter for the

few occasions that I am well enough to get out. For the last 6 weeks I have been relying on family members to help me look after my children.” Consultant BMA survey ²³ (p4)

Given the individual nature of Long Covid, it is feasible that someone may be assessed as having LCW and be required to undertake work related activities. In such circumstances we strongly advise there is scope for consideration of further assessments to explore whether any reasonable adjustments are required. We advise a cautious approach in such circumstances (see below for specific reference to pwME*.) with close monitoring for any relapses of their condition being essential too. Being able to take adequate rest is also essential for pwLC and pwME. This need for rest may be misunderstood, minimised, or disbelieved by the Department’s stakeholders.

Q7. What do you think would be the impact of these changes?

- Given the complexity of Long Covid and ME/CFS, it is not safe or appropriate for Jobcentre work coaches (or other frontline staff in the Department’s contracted provision) to make discretionary recommendations about tailored work preparation activities. Work coaches and disability employment advisors are unqualified, and untrained for such tasks and may cause pwLC or pwME unintentional harm.
- There has been widespread and ongoing disbelief and disregard about the lived experiences of many pwLC as revealed in the current COVID-19 Inquiry with evidence submitted by four Long Covid Groups.¹² Consequently pwLC have experienced gaslighting and stigma by a range of stakeholders including healthcare professionals and people connected to the workplace. CII has been instrumental in bringing people with energy limiting conditions lived experiences of disbelief and disregard to the foreground ³² and we urge the Department to consider their research and recommendations concerning benefits and working.
- If work related activities were found to be appropriate for a pwLC, we would expect in most circumstance that these would be best advised by a healthcare professional working in vocational rehabilitation who has competent skills and relevant knowledge for example, as part of a Long Covid clinic vocational rehabilitation provision rather than a work coach. The NHIR LOCOMOTION study in Leeds is developing a vocational rehabilitation road map which aims to offer guidance to allied healthcare professionals and other clinicals about this.³³ A cautious slowly monitored approach with ongoing evaluation would be essential and there must be scope for someone to be reassessed as having LCWRA where appropriate. In our view ongoing funding for Long Covid clinics and related vocational rehabilitation services is vital. This view is supported in the recent evaluation cited above too.¹⁸

- Furthermore, the Department states in its consultation paper that “*working from home brings new opportunities for disabled people to manage their conditions in a more familiar and accessible environment*, (p3). But the Department needs to consider how it will ensure pwLC and pwME can be safely supported to undertake work related activities at home. For example, by assessing whether an ergonomic workstation and any modifications are needed. These considerations are essential if the Department wants to prevent peoples’ existing musculoskeletal conditions worsening or prevent new ones developing. At present Access to Work is accessible when a person has a job, but not when engaging in work preparation activities. The Department is also making assumptions about disabled people having an accessible environment that can be readily transformed into an effective and suitable home office.
- We must make clear the paramount importance of the Department adhering to the current best practice of the NICE Guidelines (NG206) and particularly with reference to dealing with peoples’ “flare-ups and relapses” and the need to do no harm by following best practice.³⁴
- Similarly, the Department must adhere to the importance of the responses to: “My Full Reality: Interim Delivery Plan on ME/CFS”³⁵ as there has been a call for national auditing to include: flare-ups and relapses – when they occur in relation to interaction which includes welfare services.

Some NHS healthcare professionals have limited disease knowledge and preparedness to support pwLC safely and effectively and pwME, therefore, we foresee that the Department’s existing programmes such as the Work and Health programme are unlikely to be prepared and staffed with competent healthcare professionals who can support pwLC and pwME.³⁶ So, these types of contracted provision and any emerging new health related employment support pilots (e.g., the 12 pilots that were announced by the Department on 26th October 2023), need to be carefully considered by the Department if safeguarding claimants with Long Covid or ME/CFS physical and mental health is to be ensured.

We urge the Department to consider the future needs of children and young people who are living with Long Covid and how these proposals may impact their lives. We recommend that the Department consults with Long Covid Kids about this:

Q8. What could constitute tailored or a minimum level of work preparation activity?

If deemed safe as outlined above, tailored work preparation activity would need to be carefully considered for a pwLC. A claimant may have lost their previous job and career due to their illness/disability and may benefit from career guidance. Again, a competent healthcare professional may be best placed to provide advice and work alongside a work coach to support the identification of suitable forms of work (e.g., job matching) if needed.

However, a healthcare professional has ethical and professional codes of conduct that they must adhere to. Therefore, they would not be able to work with a claimant unless they had given their informed consent, and the intervention was a voluntary provision³⁶. i.e., not mandated and not subject to benefit sanctions. Of course, there are serious concerns raised about coercion here too, and whether a claimant would comply with seeing a healthcare professional following a discussion with a work coach e.g., for fear of losing their benefits. This type of experience has been evident in past DWP programmes of employment support. e.g., in the Pathways to Work policy.

In the consultation paper, the Department has listed example work related activities offered by a work coach as: *“activities to build confidence or wellbeing, learn skills, or gain a greater understanding of different sectors, local provision, or support.”* p13

It is paramount that the Department follows the NICE Guidelines³³ to safeguard pwME from harm and of equal importance for pwLC, it would be wrong and potentially harmful if the Department’s work coaches tried to ‘sell’ courses on being physically active to pwLC and pwME for example. We refer the Department to the NICE Guidance on ME as this is explicit in being against “any programme based on fixed incremental increases in physical exercise for example graded exercise therapy (GET).”³⁴.

Many pwLC in our community have waited significant periods of time i.e., longer than a year for NHS and other health related services from third or private sectors. Therefore, it is highly questionable as to which wellbeing services a work coach would be able to sign-post a pwLC to. Questions are also raised as to whether any local provision would be safe, suitable and, importantly, effective for pwLC.

Setting minimum requirements for work related activity is inappropriate and unsafe for pwLC or pwME due to the individualised fluctuating nature of these long-term conditions. It would be highly risky to suggest, for example, a set amount of time or type of work-related activity such as attendance at a group online for one hour a week for the reasons explained above. Importantly, if such activities are attempted too soon by a pwLC this can jeopardise their recovery.

Subjecting people who are required to undertake work related activities to conditionality and potential sanctions is known to exacerbate peoples’ health condition and can lead to mental ill-health.³⁷ Such consequences can only be harmful to pwLC and pwME health and wellbeing and threatens their recovery and quality of life.

To self-manage symptoms pwLC and pwME need to take quality rest periods, which requires daily planning, prioritisation and pacing of activities. Rest would need to be well understood by all staff within the Jobcentre and the Department’s contractors of employment support.

The Department must consider the associated tasks (e.g., involving physical, cognitive, mental, emotional demands) that a pwLC would need to do when being required to carry out work-related activities i.e., to factor in the planning, preparation, rest, and recovery times this

entails. It is vital that a pwLC or pwME can stop, rest and pace their own activities. Further details are available to the Department about this need via [MEACTION](#). A detailed activity analysis from an occupational therapist could provide further details.

It is evident that many pwLC in our community who have been assessed to have LCWRA are unlikely to be moved closer to work without effective treatment, as self-management strategies such as pacing while crucial are not a cure for pwLC. Thus, the Department's proposals to change the WCA are likely to cause unnecessary anxiety and stress, which may exacerbate symptoms for pwLC and pwME who are currently receiving benefits or will in the future need to make a claim.

Q9. What are your views on whether we should remove the LCWRA risk group and instead place this group in LCW risk?

The Department has acknowledged that there are risks in placing people in the LCW by attaching Risk to this revised definition, i.e., LCW Risk. Therefore, we are confused and concerned by the notion of a new group called LCW Risk. We are concerned that the primary aim of LCW Risk is to reduce the amount of benefit awarded overall. If someone is at risk if they undertake work related activities, then why would they be placed in LCW Risk and expected to do so? Surely LCW Risk is akin to LCWRA but with less benefit awarded and the added element of conditionality and risk of sanctions for non-compliance, with the discretionary powers given to work coaches to enforce work related activities?

We believe it is vital to signpost the Department to The Decode ME Study which has shown that ME/CFS (a long-term chronic disease) is now proven to worsen as it progresses.³⁸

Therefore, we propose an alternative for the Department to consider to LCW Risk for pwLC and pwME which would permit people to remain in the LCWRA but safely allow people to opt into employment support opportunities when they are able to do so. So rather than implementing changes to the WCA at haste and risk peoples' physical and mental health, we propose that the LCWRA group is kept as this is vital for pwLC and pwME.

Alternative measures can be implemented by the Department to ensure that employment support is available. We recommend that the Department place greater reliance on the disclaimer that all claimants must sign on the ESA50 and declaration of change in circumstances. For example, if a claimant has made sufficient recovery, they can opt in to engage in work related activities or make good use of the existing use of the permitted work rules i.e., for people in receipt of employment support allowance.

Furthermore, the Department could provide an opt-in light touch form of communication such as a telephone call by a work coach at a set time such as 6 months, 9 months, or 12 months and, or provide a named contact of a work coach or disability employment advisor. A pack of information could be given to a claimant following their medical assessment outcome listing the available options for support should their circumstances change. Such measures would put the claimant in control and if things have improved sufficiently with their

ill-health, they could access support via the Jobcentre without fearing conditionality pressures.

We feel the need to emphasise that the majority of pwLC and pwME **want to** work and therefore there is no value in the Department implementing harmful measures i.e., *carrot and stick*, as in our view this would be counterproductive. In addition, we can only foresee an increase in demand for NHS services, GPs and third sector if the Department's proposals are implemented and pwLC or pwME are inaccurately assessed as LCW.

We are alarmed that the Department has failed to highlight the risks of pwLC or pwME being inaccurately assessed to be found fit for work if the proposed changes go ahead.

Q10. How can this group be safely supported within the LCW risk group?

- The consultation document reveals that the Department appears to have defined a new group **LCW Risk** to replace LCW. Of significant concern is that while LCW Risk has provisos outlined in the consultation document as to whether and how a claimant would be required to undertake work preparation. I.e., at the discretion of a work coach. Such discretion is inappropriate and unsafe for pwLC or pwME as already outlined above. Therefore, there would be serious safeguarding risks. Given the Departments' history of failing to ensure it has a duty of care ³⁹ alongside the current lengthy demands for NHS services and waiting times for provision, these proposals if implemented would place many pwLC and pwME in extremely vulnerable positions.
- People who would previously be deemed as having LCWRA would not be subjected to conditionality, have a higher payment award and still be able to engage in activities such as volunteering or permitted work if and when they were able to do so. So essentially the Department's proposals appear to be based on the premise that most people should be in paid work, and that if they are not, then they need to be preparing for working at all costs. We know that some pwLC and pwME have been in the LCW for over a year. Unfortunately, there appears to be little room in the Department's policies for people who are never going to be able to undertake paid work.
- Questions are raised about the Department's duty of care and as to who would monitor any deterioration in peoples' physical and mental health if they are required to undertake work related activities that are unsafe or lead to significant harm including self-harm.
- Similarly, people who are assessed as having limited capability for work with requirements to engage in work preparation activities may need reasonable adjustments to mitigate any risks of harm to their health and wellbeing and

sustainable recovery. Thus, the quality and accuracy of the WCA will be crucial if pwLC are to be assessed fairly, effectively, and safely.

- Though a sensitive subject, we have also had reported cases of suicide and suicidal ideation within the Long Covid community.⁴⁰ Therefore, the Department must ensure that it reviews its safeguarding measures, to meet its duty of care and does not cause harm to pwLC's mental health by inaccurately deciding someone has LCW when they do not.
- Importantly there is no indication that the Department plans to use a test and learn approach for the proposed changes if these go ahead. In addition, we have concerns that the Department has failed in such approaches, for example, when advised by the Work and Pensions Committee.⁴¹

Summary

We remain disappointed and concerned that the Department has not listened or acted upon the wealth of written and oral evidence provided by disabled led organisations and people who are in receipt of benefits to date on how and why the current WCA is unfit for purpose. Therefore, we urge the Department to refrain from implementing the proposed changes which we consider are in haste and potentially harmful to many claimants' health. Given there are already proposals to end the WCA in favour of the PIP assessment, we strongly advise further consultation on the fitness for work assessments for pwLC and safe engagement in work preparation activities. These assessments are complex and require a detailed understanding of the impact of any medical conditions and of the range of activities required by an individual. The individual nature, complexity, variability, and the impact on function of Long Covid is not understood by many, and perhaps only by those with specific expertise in occupational medicine and vocational rehabilitation.

Long Covid Support continues to collaborate with stakeholders on supporting pwLC to return safely and sustainably to work. But we seek assurance from the Department that our community can have trust in being able to access the benefits they need and will be believed when they report on the impact of their symptoms to the Department's assessors and front-line staff. Finally, we restate the call for urgent Government investment in biomedical research, treatments, and timely effective NHS provision for pwLC and pwME. We hope our response will be well considered. We are happy for the Department to contact us about our response.

The following groups and organisations agree with our response and have co-signed this:

Louise Beaton and Linda Hending on behalf of ME Local Network: melocalnetwork@gmail.com

Prof Todd Davenport Chair and Dr Mark Faghy Vice Chair on behalf of Long Covid Physio: (<https://longcovid.physio>)

Dr Alison Twycross on behalf of Supporting Health Care Heroes UK: (<https://shh-uk.org/>)

Ondine Sherwood on behalf of Long Covid SOS: (<https://www.longcovidosos.org/>)

Sammie McFarland on behalf of Long Covid Kids: (<https://www.longcovidkids.org/>)

Long Covid Nurses and Midwives UK (LCNMW-): @LCNMUK

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The Long Covid organisations and groups co-signers' time and helpful responses.

To all the people living with Long Covid and ME/CFS who have co-authored papers cited in our response.

Authors: Dr Jenny Ceolta-Smith (Long Covid Support Advisor, occupational therapist living with Long Covid) and Dr Clare Rayner (Long Covid Support Advisor, occupational health physician living with Long Covid).

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