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British Psychological Society response to NICE

Draft Guideline on Management of Long-Term Effects of COVID-19

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Publication and Queries

We are content for our response, as well as our name and address, to be made public. We are also content for the Committee to contact us in the future in relation to this inquiry.

Please direct all queries to:-

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About this Response

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| Recommendation | Comments on this recommendation |
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| Section 1: Identifying people with ongoing symptomatic 1 COVID-19 or post-COVID-19 syndrome | |
| 1.1 Give people...advice and written information... | <p>We welcome the focus on timely provision of clear, evidence-based information regarding recovery as this is fundamental in supporting self-management, particularly when there is ambiguity and a wide range of conflicting and potentially misleading information available from social media.</p> <p>Whilst the effect of information provision has not yet been researched in people recovering from COVID-19, there is good evidence of its effectiveness in recovery from mild head injury/post-concussion syndrome which is similar in that patients often report a constellation of symptoms that are typically self-limiting but can be maintained and exacerbated by a wide range of factors. (Rueben <i>et al</i> 2014)</p> <p>It is obviously helpful to specify what this information would include. In terms of psychological aspects, we would highlight the fact that it is normal to feel more anxious and pay more attention to symptoms, whilst also mentioning the risk of this becoming a maintaining factor. We would also include mention of cognitive problems commonly experienced.</p> <p>Whilst we recognize that this information may be provided outside of a 1-1 consultation, we would highlight that a wealth of research (Ley 1997) has shown that understanding and recall is significantly enhanced by follow-up. We would therefore suggest including a prompt to health professionals to check in a subsequent consultation that patients have a) received this information and b) ask them to explain their understanding of the information they received.</p> <p>Refs: Ley, P., 1997. Communicating with patients: improving communication, satisfaction and compliance. Cheltenham: Thornes. Reuben A, Sampson P, Harris AR, <i>et al</i> (2014) Post-concussion syndrome (PCS) in the emergency department: predicting and pre-empting persistent symptoms following a mild traumatic brain injury. <i>Emergency Medicine Journal</i>, 31, 72-77.</p> |
| 1.2 Provide all information in accessible formats... | <p>We agree that providing information in accessible formats is crucial.</p> <p>The mention of provision in different languages is welcome, it is also important to provide information in formats appropriate for people with low levels of literacy and/or intellectual disabilities.</p> <p>Moreover, since cognitive problems are a common among people experiencing persistent effects of COVID-19 it is crucial that information is provided in highly readable formats, broken into bullet points, using clear language etc and is accessible without the need to negotiate numerous web links.</p> <p>It is also important to remember a significant proportion of the population, does not have regular access to internet or only access via mobile phone limited by screen size and data limits. Thus, printed information must still be available as an alternative to online information.</p> |
| 1.3 Think about the possibility of ongoing symptomatic COVID-19... | <p>Whilst we have included comments on the terminology later, we certainly agree that it is helpful to identify patients with persistent difficulties early as the sooner any factors that may be impeding recovery/exacerbating symptoms can be identified, and support provided the greater the potential for recovery.</p> |

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| <p>1.4 Offer a telephone or video consultation...</p> | <p>Proactive screening is generally welcome, particularly when many patients have described feeling actively discouraged from seeking medical help. However, we are mindful that a considerable number of those who have experience COVID-19 are likely to still be experiencing some symptoms at 4 weeks (especially if this is 4 weeks from onset of symptoms, although this is not clearly stated).</p> <p>It was not clear whether the recommendation is to screen all patients with a positive COVID test (which would be necessary in order to achieve the stated aim to “identify people..”) or whether, in fact, the recommendation is to actively encourage those who self-identify as having persisting symptoms to attend a telephone/video consultation. The latter seems more realistic when considering the number of people who have had COVID-19, and the fact that there are already significant numbers of people in the community with long term effects of COVID-19. If the latter is intended, perhaps the recommendation could then be phrased more definitely than the current “Think about the possibility of...”</p> <p>It is likely that at least a proportion of symptoms attributed to COVID-19 may primarily be related to exacerbation of pre-existing underlying conditions.</p> <p>The COVID-19 Yorkshire Rehabilitation Screen (C19-YRS) incorporates an explicit comparison with pre-COVID state, although it is important to note that this measure is designed as a follow up for hospitalized patients.</p> |
| <p>1.5 Do not rely solely on screening questionnaires...</p> | <p>We welcome this recommendation but suggest it would be helpful to specify what should be done in practice. For instance, an explicit recommendation that if primarily using a screening questionnaire, the health professional should always also ask the patient if they have noticed any other significant changes that were not covered within the questionnaire.</p> |
| <p>1.6 Be aware that some people may not have...</p> | <p>Yes and for certain populations including young children, people with cognitive and/ or communication problems, people with intellectual disabilities, health professionals will need to obtain a report from a family member or carer regarding any changes in behaviour from pre-COVID state.</p> |
| <p>1.7 Based on screening, use shared decision making...</p> | <p>We very much welcome the emphasis on shared decision making</p> |
| <p>1.8 Support access to assessment and care after</p> | <p>We very much welcome the recommendation to be proactive in reducing inequalities in access to health care and also the inclusion of examples of ways to achieve this</p> |
| <p>Section 2: Assessing people with new or ongoing symptoms after acute COVID-19</p> | |
| <p>2.1 For people with ongoing symptomatic COVID-19...</p> | <p>We warmly welcomes the emphasis on a holistic, person-centred approach. In our experience, people experiencing persistent effects of COVID-19 frequently talk about the negative effects of feeling that they are not believed, and conversely the immense positive benefit of meeting a health professional who listens and believes their account.</p> <p>We also welcome the recommendation to undertake a broad assessment. It is not entirely clear what the distinction between “Psychological and psychiatric symptoms” is here, we suggest that perhaps “mental health symptoms” might be a simpler description.</p> |

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| <p>2.2 Include in the focused clinical history...</p> | <p>Whilst this guidance is, appropriately, designed to encompass all those who have experienced COVID-19, most of whom did so out of hospital, a proportion of COVID patients will have been hospitalized or attended A+E. They may also have tried to access general practice, and particularly early in the pandemic we know that for some patients the experience of this was distressing.</p> <p>It is therefore crucial to ensure that history of help seeking and health care is included as this is an important factor in shaping patients' illness perceptions and can be a factor in current traumatic symptoms; many people with COVID-19, whether hospitalized or not, believed that they might die, or that they might infect a vulnerable member of their family who might die.</p> <p>In-hospital experiences, particularly delirium but also hypoxia and encephalitis, are also significant risk factors for persistent difficulties.</p> |
| <p>2.3 Discuss how the person's life and activities have been affected...</p> | <p>We strongly welcome the focus on disruption to activities and social role in addition to assessment of symptoms.</p> <p>In addition to disruption on activities, research shows that the development of dysfunctional patterns of activity (particularly an "overactivity-underactivity" or "boom and bust" cycle is a significant predictor of development of chronic problems after mild brain injury or viral illness (Hou <i>et al</i> 2012, Moss-Morris <i>et al</i> 2011). It is therefore critical that clinicians enquire not only about overall disruption, but also specific pattern of activity.</p> <p>We are very surprised that assessment of sleep is not mentioned since sleep disturbance is very common among people with chronic fatigue (e.g. Pedersen <i>et al</i> 2017) and has been identified as being a significant predictor of persistent difficulties following a viral infection.</p> <p>We therefore strongly recommend that a recommendation to assessment sleep pattern and quality is included.</p> <p>In addition to assessment of activities it can also be helpful to enquire about how persistent effects of COVID-19 have affected the individual's sense of identity and also the impact on their relationships with significant others.</p> <p>Refs: Hou R, Moss-Morris R, Peveler R, et al (2012) When a minor head injury results in enduring symptoms: a prospective investigation of risk factors for post-concussional syndrome after mild traumatic brain injury. <i>Journal of Neurology, Neurosurgery & Psychiatry</i>, 83, 217-223.</p> <p>Moss-Morris, R, Spence, M. J & Hou, R (2011) The pathway from glandular fever to chronic fatigue syndrome: can the cognitive behavioural model provide the map? <i>Psychological medicine</i>, 41, 1099–1107</p> <p>Pedersen. M <i>et al</i> (2017) Sleep–wake rhythm disturbances and perceived sleep in chronic fatigue syndrome. <i>Journal of Sleep Research</i>, 26, 595-601</p> |
| <p>2.4 Discuss the person's experience of their symptoms and ask about...</p> | <p>We warmly welcome the recommendation to develop an individualized understanding of the impact of COVID-19 and to normalize the experience of distress.</p> |

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| | <p>The recommendation is phrased as discussing the persons “experience” of their symptoms; this is extremely important; however it is also important to understand their <i>beliefs about</i> their symptoms. There is considerable evidence to show the link between illness beliefs and recovery after viral infection (see Hulme <i>et al</i> 2017 for systematic review)</p> <p>Illness beliefs have also been identified by NICE as a predictor of recovery after myocardial infarction, and hence are included in the NICE Guideline on Acute Coronary Syndromes (NG185 – 1.8.6)</p> <p>Ref: Hulme, K., Hudson, J.L., Rojczyk, P., Little, P. & Moss-Morris, R. (2017) Biopsychosocial risk factors of persistent fatigue after acute infection: A systematic review to inform interventions, <i>Journal of Psychosomatic Research</i>, 99,120-129.</p> |
| <p>2.5 If the person agrees, talk to family members or carers...</p> | <p>Involvement of a family member or carer is helpful, not only to provide support with communication, but there is also a wealth of research shows that illness perceptions, and behaviour, of relatives have a significant influence on recovery.</p> <p>Furthermore, research in previous pandemics shows that the prevalence of psychological difficulties including post-traumatic stress disorder can be as high, or even higher, among relatives as the patient themselves and thus clinicians should have a low threshold to offer assessment of psychological wellbeing to family members and carers.</p> <p>Family members and carers also play an important role in supporting rehabilitation and self-management, even more so given the current situation of high demand and limited resources within the NHS, and so should be included in discussion of advice wherever possible and when consistent with patient wishes.</p> |
| <p>2.6 Be aware that people can have wide-ranging and fluctuating symptoms...</p> | <p>Indeed, patients have described experiencing mild or minimal initial symptoms and then subsequently experiencing more debilitating persistent symptoms. It is important that health professionals understand that the uncertainty associated with fluctuating symptoms and unpredictable course is a significant factor impacting on distress associated with managing persisting effects of COVID-19.</p> |
| <p>2.7 Be aware that people who have multiple symptoms...</p> | <p>Agree</p> |
| <p>2.8 Do not rely solely on certain clusters of symptoms...</p> | <p>Agree</p> |
| <p>2.9 Be aware that long-term effects of COVID-19 in older people...</p> | <p>Yes, and, across all groups, it is important to be aware of prior neurological injury or illness (e.g. Traumatic Brain Injury, Stroke, Dementia) which COVID-19 might exacerbate &/or accelerate decline.</p> |
| <p>2.10 If the person reports new cognitive symptoms...</p> | <p>In addition to measurement of cognitive symptoms, we strongly recommend the use of validated measures of other psychological difficulties that are identified in a clinical interview. The BPS guideline on recovery from COVID-19 suggests the GAD-7 for anxiety symptoms, the PHQ-9 for mood symptoms, the Trauma Screening Questionnaire for post-traumatic symptoms and the MOCA for cognitive difficulties.</p> <p>With respect to measurement of cognitive difficulties, it is important to be aware that a brief cognitive screening test may not be sensitive to all cognitive difficulties associated with post-COVID-19 syndrome, since commonly used measures are typically validated for assessment of</p> |

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| | <p>people with dementia, stroke and traumatic brain injury. Passing a cognitive screening test should not prevent referral for investigation of cognitive difficulties if the clinical history and the person's account of their symptoms suggests the presence of cognitive difficulties.</p> <p>Ref: British Psychological Society (2020) Meeting the psychological needs of people recovering from severe coronavirus (Covid-19) https://www.bps.org.uk/coronavirus-resources/professional/psychological-needs-recovering-severe-coronavirus</p> |
| Section 3: Further investigations and referral | |
| 3.1 Refer people...to the relevant acute services... | n/a |
| 3.2 Refer people...urgently for psychiatric assessment... | Yes agreed |
| 3.3 Carry out appropriate tests, depending on setting... | We would suggest rewording the phrase “depending on setting” – as it seems to imply that the tests undertaken would be determined by the setting rather than the individual's clinical presentation. |
| 3.4 Offer an exercise tolerance test suited to the person's ability... | n/a |
| 3.5 For people with postural symptoms, for example palpitations... | n/a |
| 3.6 Offer chest X-ray by 12 weeks after acute COVID-19 illness... | n/a |
| 3.7 Follow relevant national or local guidelines on referral for people... | <p>We believe that the first bullet point “common mental health symptoms” should read “symptoms of common mental health conditions”. It is important that this is specified since a) common psychological symptoms, such as anxiety, are entirely normal in the context of COVID-19 and it is important not to inadvertently pathologize this.</p> <p>Moreover, psychological therapy services, such as IAPT in England, are designed to provide evidence-based psychological therapies for specific mental health <u>conditions</u>.</p> <p>In contrast, Clinical Health Psychology services are not focussed on specific mental health conditions and work in an integrated way with complex physical /psychological presentations where multi-morbidity is common (such as persistent pain, diabetes, renal, cardiology).</p> <p>Clinical health psychology input is often integrated within a multidisciplinary team; access is variable but is available in many acute and many community settings and should be considered where appropriate within a stepped care pathway (as outlined in the BPS Guidance on psychological needs of people recovering from severe coronavirus).</p> <p>Health professionals should also be aware of specific risk factors that are associated with high risk of psychological difficulties such as, Post Traumatic Stress Disorder; these risk factors include delirium (predominantly in hospitalized patients but also experience by non-hospitalized patients), hallucinations and delusions, sedation, prolonged ventilation, fear of dying or others dying (See BPS guideline for more detail).</p> |

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| | <p>Ref: British Psychological Society (2020) <i>Meeting the psychological needs of people recovering from severe coronavirus (Covid-19)</i> https://www.bps.org.uk/coronavirus-resources/professional/psychological-needs-recovering-severe-coronavirus</p> |
| 3.8 Do not discount the possibility of another diagnosis unrelated... | <p>Agree, and for many patients, post-COVID-19 symptoms will be present alongside symptoms of pre-existing health conditions that may have been exacerbated by COVID-19.</p> |
| 3.9 Refer people who would benefit from specialist or rehabilitation... | <p>Agree</p> <p>Section 3 would benefit from additional specific recommendations with regard to referral pathways when persistent cognitive difficulties are identified. Recommendation 3.9 is not sufficiently specific in relation to what to do when cognitive difficulties (one of the major classes of long-COVID-19 symptoms recognised in Section 2.1, 2.10)</p> <p>We suggest the recommendation should be:</p> <p>“Follow relevant national or local guidelines on referral for people who have cognitive symptoms. Consider referral to clinical neuropsychology or specialist neurorehabilitation services.”</p> |
| Section 4: Planning care for people with ongoing symptomatic COVID-19 or suspected post-COVID-19 syndrome | |
| 4.1 After the holistic assessment, use shared decision making... | <p>We welcome this recommendation, particularly the emphasis on shared decision making and making clear that self-management must be supported by integrated and coordinated health services.</p> <p>However, we suggest some it would be helpful to define what supported self-management might entail, and who will be providing support.</p> |
| 4.2 When discussing with the person the appropriate level of support... | <p>Agree</p> |
| 4.3 If the need for support from multidisciplinary rehabilitation services... | <p>Agree</p> |
| Section 5: Management | |
| 5.1 Give advice and information on self-management to people... | <p>Overall, we agree with the recommendation for supported self-management.</p> <p>We suggest broadening the first bullet point “ways to self-manage their symptoms” to “ways to self-manage their symptoms and recovery” which encompasses managing significant activities rather than purely symptoms.</p> <p>In keeping with other NICE guidelines, it would be appropriate to list the key components of self-management advice, in order that health professionals provide comprehensive self-management advice rather than focussing on one aspect.</p> <p>Psychological components of self-management would include</p> <ul style="list-style-type: none"> • Managing anxiety • Managing traumatic stress symptoms • Managing mood and frustration |

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| | <ul style="list-style-type: none"> • Managing cognitive problems • Managing sleep disturbance (nb tailored sleep management advice for patients presenting with chronic fatigue is provided in NICE CG53 - 1.4.2.1) <p>Each of these areas is explained in detail on the open access Your COVID Recovery website (which several of the authors of this response contributed to). We believe that it would be appropriate to advise clinicians to familiarize themselves with the content of the self-management advice on the Your COVID Recovery website, or alternative, in order that they can advise patients appropriately, direct them to relevant sections and also check understanding in subsequent consultations.</p> |
| 5.2 Explain to people that it is not known if over-the-counter vitamins... | n/a |
| 5.3 Support people in discussions with their employers... | <p>We agree that this is an important recommendation. Our clinical experience is that return to work is a significant source of stress, and indeed often relapse, for people experiencing persistent effects of COVID-19. We suggest that the guideline could be specific about the national guidance on advice on returning to work, and where it can be found.</p> <p>It may also be helpful to state that the NHS Your COVID Recovery website includes a page with advice on return to work.</p> |
| 5.4 Assess people referred to integrated multidisciplinary rehabilitation... | <p>Comprehensive assessment is, of course, fundamental to effective multidisciplinary rehabilitation.</p> <p>The first line should include the word “cognitive” to highlight that cognitive aspects are distinct from psychological and psychiatric aspects and to be consistent with the previous sections of the guideline.</p> <p>We are disappointed that the guidance does not contain any information on the recommended content, or form, of multidisciplinary rehabilitation for people with long term effects of COVID-19 we have made some further comments on this in the general comments section.</p> |
| 5.5 Work with the person to develop a personalised rehabilitation... | <p>We agree that developing a personalised rehabilitation and management plan is crucial.</p> <p>We would welcome the inclusion of a reference to shared decision making here in the same way as it is referred to earlier, it is at least as relevant to planning rehabilitation, if not more so, as it is to decision of self-management.</p> <p>Although the term “rehabilitation prescription” was used in relation to rehabilitation from traumatic injury within the Major Trauma pathway, we caution against the use of the term “prescription” in this context. The term could be appropriate in the context of transfer of a patient from a major trauma centre to home or to a less specialist service but is not appropriate in the context of working collaboratively with a patient referred from primary care to a rehabilitation team. We believe the term “personalised rehabilitation and management plan” is adequate, although we certainly agree that this should be documented & communicated appropriately.</p> |
| 5.6 Encourage people to keep a record of, or use a tracking app to monitor... | We agree with this recommendation with respect to goal monitoring which is central to effective rehabilitation. |

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| | Symptom monitoring can be helpful if there are clear aims; for instance, identifying triggers. However, it is important to note the risk that excessive symptom monitoring can inadvertently become a factor maintaining in anxiety. A blanket endorsement of symptom monitoring, (or indeed physiological monitoring which is obviously distinct from symptom) could actually be harmful in some patients. (See further comments in 6.4) |
| 5.7 Consider additional support for older people with... | Agree |
| 5.8 Consider early referral between 4 and 12 weeks for specialist advice... | Agree |
| Section 6: Follow-up and monitoring of people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome | |
| 6.1 Agree with the person how often follow-up and monitoring... | Agree |
| 6.2 Using shared decision making, offer people the option... | Agree |
| 6.3 Tailor monitoring to people's symptoms and discuss any changes... | Agree. It is also important to tailor monitoring, and support for monitoring to people's abilities – for instance someone with impaired, or fluctuating, level of cognitive functioning may require additional support. |
| 6.4 Consider self-monitoring at home, for example heart rate... | As mentioned earlier, self-monitoring of symptoms, and in some cases physiological monitoring (which is obviously distinct from symptom monitoring), can be extremely valuable. However, the caveat is rather contradictory as currently worded (i.e. to “consider” - “if this is agreed”). We suggest that, in order to be helpful to clinicians, it would be appropriate to highlight the factors that determine whether self-monitoring is likely to be helpful or may actually be serving to exacerbate anxiety. For instance, “Consider self-monitoring, for example heart rate, blood pressure and/or pulse oximetry if there is a clear clinical rationale to do so; for instance to better understand triggers, to evaluate response to intervention or to guide help seeking. Patients should be advised as to how frequently to undertake routine monitoring, be provided with specific, personalized guidance on thresholds for seeking help (e.g. oxygen saturation level) and also provided with information about normal variation in physiological functions.” |
| 6.5 Be alert to symptoms developing that could mean referral... | Agree – this could include physical or psychological symptoms. |
| Section 7: Sharing information and continuity of care | |
| 7.1 Share information, including discharge letters, clinical records... | Agree |
| 7.2 Include baseline measures in information shared between services... | Agree |
| 7.3 Think about ways to improve information sharing and integrated... | Agree |
| 7.4 Provide continuity of care with the same healthcare professional... | Agree |

| Section 8: Service organisation | |
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| 8.1 Consider providing one-stop multidisciplinary clinics for assessment... | <p>We agree that provision of “one-stop” multidisciplinary clinics is helpful.</p> <p>Cognitive symptoms may be the predominant, or only symptom, for some patients.</p> <p>We therefore believe it is important to specify that these should provide assessment of “physical, cognitive, and mental health symptoms”.</p> |
| 8.2 Provide integrated, multidisciplinary rehabilitation services... | <p>“Including treating fatigue...” is more appropriately worded “experience in the management of fatigue...”</p> <p>We recommend also including expertise in management of psychological aspects of chronic health problems, cognitive problems, and sleep management, in the list of specialist skills.</p> |
| 8.3 Share knowledge, skills and training between services to help... | <p>We agree that sharing knowledge, skills and training is important. We suggest that in addition to helping community practitioner to provide “assessments and interventions” it will also enable them to provide advice on supported self-management more effectively.</p> <p>In addition to physical assessments and techniques, this can also include psychological approaches, for instance identifying unhelpful thinking in relation to physical symptoms and generate alternative ways of thinking (as outlined on the Your COVID Recovery website).</p> <p>We believe that, for the recommended sharing of knowledge, skills, and training to happen, it will be necessary to establish facilitating structures – for instance local hubs, either linked to the post COVID-19 assessment clinics or standalone. These hubs would map and engage services and practitioners across the formal and/or informal COVID-19 rehab pathway in their local system in order to create cohesive and collaborative learning networks to inform and advance clinical practice and improve the patient experience.</p> |
| 8.4 Agree local referral pathways between primary and community care... | Agree |
| Key recommendations for research | |
| 1. Risk factors for post COVID-19 syndrome | We agree. Such research will clearly need to encompass both physical and psychological factors and proximal and distal influences. |
| 2. Interventions for post COVID-19 syndrome | <p>We agree that it will be important to undertake research to identify effectiveness and efficacy of interventions, and indeed approaches to self-management, for managing persistent effects of COVID-19.</p> <p>We would also stress the need to look beyond symptoms, or clusters of symptoms, for predictors of outcomes. The link between nature and severity of symptoms and outcomes has been found to be low in other health conditions, including recovery from sporadic and epidemic viral infections. In contrast psychosocial factors, such as illness beliefs and social support have consistently been found to be significant predictors (Moss-Morris <i>et al</i> 2011) and should be included as a priority area in Post COVID-19 research.</p> |

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| | <p>An important aspect of intervention evaluation will be assessing the effect of early intervention, including provision of information and self-management advice, on recovery.</p> <p>Intervention trials will also need to carefully consider the effects of co-morbidity of other physical and mental health conditions.</p> <p>Ref: Moss-Morris, R, Spence, M. J & Hou, R, 2011. The pathway from glandular fever to chronic fatigue syndrome: can the cognitive behavioural model provide the map? <i>Psychological medicine</i>, 41(5), pp.1099–1107</p> |
| 3. Post COVID-19 syndrome in black, Asian and ethnic communities | <p>We agree and suggest that it will also be important to identify if there are differences within the presentation of Post COVID-19 syndrome in different populations in addition to simply prevalence and incidence.</p> <p>We also believe that it will be important that research is undertaken to identify the effectiveness of specific adaptations of intervention and self-management advice for different communities.</p> |
| Other recommendations for research | |
| 1. Prognostic markers of developing post-COVID-19 syndrome | Agree |
| 2. Presentation of post-COVID-19 syndrome in children, young people and older people | Agree |
| 3. Natural history of post-COVID-19 syndrome | Agree |
| 4. Validated tools for screening for post-COVID-19 syndrome | We agree and would stress the need for comprehensive screening tools that include physical and psychological aspects of Post COVID-19 Syndrome. We recommend that such measures are developed on the basis of the range of actual patient experience rather than clinical assumptions based on experience of specific groups of patients (such as hospitalized patients) as was understandably necessary early in the pandemic. |
| Rationales | |
| Would you like to provide comments in relation to the rationales? | No |
| Equality Impact Assessment | |
| Would you like to provide comments in relation to the equality impact assessment? | No |
| Case definition | |
| <p>The guideline uses the following names and definitions to separate the effects of COVID-19 into three phases:</p> <p>Acute COVID-19 infection: Signs and symptoms of COVID-19 for up to 4 weeks.</p> <p>Ongoing symptomatic COVID-19 (long COVID 4 to 12 weeks): Signs and symptoms of COVID-19 from 4 weeks up to 12 weeks.</p> <p>Post-COVID-19 syndrome (long COVID 12 weeks or more): Signs and symptoms that develop during or following an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis. It usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time</p> | |

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| <p>and can affect any system in the body. Post-COVID-19 syndrome may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed.</p> | |
| <p>Having now read through the guideline and reviewed the draft recommendations, do you think these names and definitions are an accurate way to define the long-term effects of COVID-19 for the purposes of this guideline?</p> | <p>Yes</p> |
| <p>Why do you think this?</p> | <p>Overall, we agree with the distinctions made between Acute, Ongoing and Post COVID-19 Syndrome and duration cut offs specified for each, which were felt to be helpful and in keeping with clinical experience. We believe it is important to emphasise both the diversity of presentations and also the often-fluctuating nature as well as intensity of symptoms</p> <p>We agree that it is appropriate not to use the term “Chronic” in relation to Post COVID-19 Syndrome.</p> <p>There are pros and cons of the use of the word “syndrome”. On the one hand, it is consistent with that used for other conditions that share some features with Post COVID-19 Syndrome (such as Post-Concussion Syndrome and Chronic Fatigue Syndrome). However, there is a potential risk for patients to perceive the label “post-COVID-19 syndrome” as a distinct new condition and its use at 12 weeks, or even before, could conflict with the expectation of natural recovery.</p> |
| <p>Would you like to provide general comments in relation to the guidance?</p> | <p>Overall, The British Psychological Society welcomes this NICE guideline and feel it would be very helpful.</p> <p>We particularly value the emphasis on proactive engagement with people experiencing persisting effects of COVID-19, holistic assessment, shared decision making, emphasis on supported self-management and integrated multidisciplinary rehabilitation.</p> <p>We recognize that the evidence base regarding persisting effects of COVID-19 is currently very limited, and that that NICE guideline will be updated as this develops. However when we developed the BPS guidance in early April, there was virtually no research evidence to draw upon but we were able to produce detailed guidance based on extensive bodies of knowledge in relation to similar conditions (including recovery from other viral illness including SARS/MERS and other chronic conditions). We are certainly mindful of the risk of overreliance on commonalities with other conditions, for instance we agree that whilst there are similarities with chronic fatigue syndrome there are also important differences. However, we are pleased that, eight months later, the BPS guidance has generally stood up well with increased understanding. We would, therefore, encourage NICE to consider some of the recommendations we have included from that guidance that are based on strong evidence from related conditions.</p> <p>Finally, we were disappointed by the lack of specific guidance in relation to the content of self-management advice or rehabilitation. The guidance is focussed on management of long-term effects of COVID-19, but the vast majority of the content relates to assessment and onward referral. We would suggest that it is particularly these aspects that health professionals will be looking to the NICE guidance for and, whilst there is currently virtually no research evidence in relation to long term outcomes of interventions for persisting effects of COVID-19, we do believe that the</p> |

broader literature does provide clear pointers for this. As mentioned, this informed the development of the BPS guidance, and we have also contributed to the development of the Your COVID Recovery programme over the past several months, for which we combined the existing research evidence from related conditions and clinical experience of people recovering from COVID-19. We strongly believe that this approach is appropriate for consideration of the psychological aspects since existing research clearly shows commonalities across psychological aspects of recovery and self-management in other health conditions. We therefore very much hope NICE will consider the suggestions we have made on this basis in this response.

Ref: British Psychological Society (2020) Meeting the psychological needs of people recovering from severe coronavirus (Covid-19)

<https://www.bps.org.uk/coronavirus-resources/professional/psychological-needs-recovering-severe-coronavirus>

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